

**A SOCIOLOGICAL STUDY ON THE CHALLENGES TO TREATMENT ADHERENCE IN
ANTIRETROVIRAL THERAPY IN THE MOPANI DISTRICT OF THE LIMPOPO PROVINCE**

THESIS

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“Halting the spread of HIV is not only an MDG in itself, it is a pre-requisite for reaching most of the others”

- Kofi Annan

DEDICATION

This thesis is dedicated to my beloved late maternal grandparents: Reverend Edmund Shimange and *Juffrou* Rebecca Mabyalane and paternal grandparents: Mbhehlane Jutas and Julia Zinto Mona. The love, care, guidance, good morals and values that you expressed and instilled in me keep me focused and enable me to always maintain a positive attitude in spite of adversities that confront me. Indeed we serve an awesome God! My life is a Miracle.

DECLARATION

I hereby declare that this thesis is a presentation of my own original work and effort. Wherever contributions of other researchers are made, an endeavour is made to state this evidently with due reference to the literature and acknowledgement of research and discussions. This work has not been submitted anywhere for any other degree at any other institution.

Declaration by: Tiny Petunia Mona

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ABSTRACT

This study investigated the challenges to antiretroviral therapy adherence. Qualitative and quantitative research methodologies were applied in the study. Purposive sampling was used to select clients on antiretroviral therapy, convenience sampling was applied to select clients who participated in the focus group discussions and health care workers and lay counsellors were selected through the simple random sampling method. In-depth interviews were conducted with 31 clients on antiretroviral therapy at 8 health facilities, 2 focus group discussions comprising of 7 members each were conducted at two health facilities, medical records of all respondents on antiretroviral therapy were reviewed and a stigma scale was administered. A questionnaire was distributed amongst 17 health care workers and lay counsellors.

Most of the respondents who participated in this study were females. Data gathered in this study confirmed that women are more vulnerable to HIV than men. The majority of the respondents were poor African people. The predominant language amongst the respondents was the Xitsonga language; hence the world-view of the Va-Tsonga people was assessed. HIV and AIDS cause many social problems in communities.

Some of the major findings are that:

Literacy levels were found to be very low as most of the respondents pointed out that they had only obtained grade 7 or below. However, this did not have an impact on treatment adherence. Some respondents indicated that they were unemployed; the majority said they were employed.

Even though the stigma and discrimination experienced by the respondents was very low, the few who experienced it had very traumatic and cruel experiences perpetrated by their own family members and people in the community. In terms of disclosure, data indicates that most people prefer disclosing to their mothers as they feel that they will get support. The majority of the respondents disclosed to female family members and they were supported by the people they disclosed to.

Social support is very crucial for people who are on antiretroviral therapy (ART), most of the respondents indicated that they had treatment supporters. Institutional support was very minimal in that most pointed out that they did not belong to any support groups. There were some who did not even know about the existence of any support groups at the health facilities where they were receiving their treatment.

Most of the respondents indicated that they disclosed to their colleagues and others had not as they feared that they would lose their jobs. Those who had disclosed indicated that they needed support from their colleagues and employers with regard to compliance with their clinic appointments. Most of the respondents had sexual partners, and had also disclosed to their sexual partners, and disclosure was almost immediately after being diagnosed HIV-positive. There are those who had not disclosed to their sexual partners as they feared rejection or violent reaction. There were sero-discordant couples amongst the respondents who supported each other regarding adherence. Most of the respondents indicated that they had taken care of a family member living with HIV.

HIV prevalence also varies amongst health facilities. Strategies employed by health facilities to monitor and evaluate HIV and AIDS programmes differ. Health Care Workers and lay counsellors provided contrasting information. Primary Health Care facilities have been accredited to provide ART, however the down-referral system seems to be failing as some clinics now have more clients on ART than hospitals. Health Care Workers and counsellors also need to be familiarized with the World Health Organization (WHO) standards. The level of adherence acceptable for an individual on ART is 95%; there is however health facilities that indicated the adherence level far below the required level.

LIST OF ABBREVIATIONS AND ACRONYMS

ABC	Abstain, Be faithful, Condomise
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community Based Organization
CCMT	Comprehensive Care Management and Treatment
CDC	Centre for Disease Control and Prevention
CEO	Chief Executive Officer
CET	Cognitive Evaluation Theory
CICT	Client-initiated Counselling and Testing
CRP	Community Responsiveness Programmes
DHIS	District Health Information System
DOH	Department of Health
DOT	Directly Observed Treatment
DOTS	Directly Observed Treatment Short-Course
FBO	Faith Based Organization
FGD	Focus Group Discussion
GIPA	Greater Involvement of People Living with HIV & AIDS
HAART	Highly Active Antiretroviral Therapy
HCBC	Home Community Based Care
HCT	HIV Counselling and Testing
HIV	Human Immune Deficiency Virus
HSRC	Human Sciences Research Council
MDGs	Millennium Development Goals
MRC	Medical Research Council
NDOH	National Department of Health
NGOs	Non-governmental Organizations
NHI	National Health Insurance
NSP	National Strategic Plan
OIs	Opportunistic Infections

OPD	Outpatients' Department
PFMA	Public Finance Management Act
PICT	Provider Initiated Counselling and Testing
PLWHA	People Living with HIV and AIDS
PMTCT	Prevention of Mother - to - Child Transmission
RT	Routine HIV Counselling and Testing
SADC	Southern Africa Development Community
SAHRC	South African Human Rights Commission
SDGs	Sustainable Development Goals
SDT	Self-Determination Theory
SANAC	South African National AIDS Council
SPSS	Statistical Package of Social Sciences
STIs	Sexually Transmitted Infections
STIs	Structured Treatment Interruptions
TB	Tuberculosis
TAC	Treatment Action Campaign
TS	Treatment Supporter
UNAIDS	United Nations Program on HIV and AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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DELINEATION OF THESIS

The study is presented in 11 chapters. At the end of each chapter a summary is articulated.

Chapter 1 Introduces the study. It clearly articulates the research problem, research questions, the purpose of the study, the aim of the study, objectives of the study and rationale and motivation of the study.

Chapter 2 Presents the epidemiology of HIV and AIDS globally, regionally, nationally and locally.

Chapter 3 Outlines policy responses of the South African government to the HIV and AIDS epidemic.

Chapter 4 Deals with antiretroviral therapy adherence and social aspects.

Chapter 5 Focuses on the theoretical perspectives and framework

Chapter 6 Outlines the research design and methodology

The findings of the study are discussed in chapters 7, 8 and 9. The analysis addresses the objectives of the study. The literature review and theoretical frameworks have been integrated into the discussion of the findings

Chapter 7 Critically analyses data from in-depth interviews with clients on ART.

Chapter 8 Is a critical analysis of data from focus group discussions.

Chapter 9 Analyses data from the health care providers and lay counsellors.

Chapter 10 Consists of the presentation of the proposed adherence model.

Chapter 11 Outlines the conclusion, general recommendations and recommendations for further research.

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CHAPTER 1

GENERAL ORIENTATION OF THE STUDY

1.1 Introduction

The HIV and AIDS epidemic is not only a health challenge, but also a developmental issue. The first cases of HIV infection were reported in 1981, and astonishingly there are now 34 million people living with the disease worldwide (U.S Global Health Policy, 2012). The Sub-Saharan African region has been hardest hit and South Africa has the highest number of people living with HIV and AIDS in the world.

The South African Government was very reluctant in responding to the epidemic. The apartheid government and the democratically elected government under former President Thabo Mbeki made very little effort to curb the spread of the disease. When the democratically elected government finally made the decision to roll-out antiretroviral therapy (ART) in public health facilities in August 2003 many people were already infected and some had lost their lives to the epidemic.

The Operational Plan on Comprehensive HIV and AIDS Care, Management and Treatment was launched in November 2003. There has been much progress since then. There have however been challenges such as delays in accrediting ART public health facilities, providing adequately trained health personnel and registering ART (Department of Health, 2003a).

In the Limpopo Province, regional hospitals were the first ones to be accredited to roll out ART in 2004. Thereafter, district hospitals were accredited in 2005 and these were followed by NGOs and primary health facilities. HIV treatment includes the use of combination ART and other prophylaxis to prevent and treat opportunistic infections.

The Health Ministry in South Africa has launched the triple fixed-dose combination (FDC) tablet. This implies that people on ART will now only have to take one tablet once a day instead of six tablets or more a day. Reducing the pill burden of the first-line regimen to one

pill once daily may improve adherence levels. The provision of comprehensive adherence counselling remains essential (Southern African HIV Clinicians Society, 2013).

Other challenges associated with the provision of ART and adherence include; stigma and discrimination, disclosure, poverty, unemployment and illiteracy. Initially when ART was first rolled-out one of the criteria for a health facility to qualify included that they should have an active support group of people living with HIV and AIDS. Support structures are crucial in ensuring that people on ART are adherent. Self-efficacy is also very important.

1.2 Research Problem

According to UNAIDS (2012), during the year 2012 an estimated 6.1 million people were living with HIV in South Africa. Antiretroviral therapy (ART) is now widely available to people living with HIV and AIDS. However, in order for antiretroviral therapy to be effective the client needs to maintain high levels of treatment adherence, as non-adherence may result in resistance (Steel, Joshi & Paige, 2005). Complete adherence implies that a client is able to take 100% of the prescribed amount of medication. The client is therefore, required to maintain very high levels of adherence so as to ensure that the viral load is kept at undetectable levels, which means that the test reveals that the viral load is below 40 and that the CD4 cell count improves dramatically. There are political, economic and environmental factors that diminish the probability of access to health care and that adversely impact on adherence (Kagee, Nothling & Coetzee, 2012). These factors need to be given solemn attention. Structural barriers consist of the following, poverty-related barriers, institution-related barriers as well as political and cultural barriers (Kagee *et al*, 2012). Patient-related factors also play a major role in positively influencing adherence, these include; social, demographic, economic and behavioural factors (Chesney, 2000, Ferguson, Stewart, Funkhouser, Tolson, Westfall & Saag 2002). People on antiretroviral therapy also need to overcome challenges such as interference of daily routine (Johnson, Charlebois, Morin, Remien & Chesney 2007).

As indicated, this study sought to identify social support structures available to people on antiretroviral therapy; challenges to treatment adherence such as the effects of stigma and discrimination on treatment adherence, examine the role of self-efficacy in promoting

treatment adherence, determine the consequences of disclosing one's HIV status and to gather information on antiretroviral therapy adherence from clients and support groups and ultimately to identify strategies to improve adherence so as to develop an intervention plan in a form of a treatment adherence model.

“Social support is the perception or experience that one is loved and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations” (Taylor, 2007: 145). Social support can influence how people on antiretroviral therapy cope with stressful situations, as well as the worth of their lives (Helgeson, 2003). Support from people who are close to the person living with HIV, such as close family members and friends can greatly enhance treatment adherence as it inspires them to have a positive outlook on life (Shumake & Hill, 1991). Clients who enjoyed family support were more likely to adhere compared to those who did not enjoy such support (Harris, Pillinger, Fromstein, Gomez, Garris, Kanetsky & Gross, 2011).

A critical challenge regarding treatment adherence in South Africa is stigma associated with HIV and AIDS. Most clients indicated that they did not feel comfortable with disclosing their HIV status to their family members as they did not trust them to maintain confidentiality, some went further to point out that some of their family members consumed alcohol and may publicly announce their positive HIV status. In South Africa people living with HIV who were stigmatized or discriminated against were found to be reluctant to disclose their HIV status to their sexual partners (Mahajan, Saytes, Patel, Remien, Ortiz, Szekeres & Coates, 2008).

In order for Highly Active Antiretroviral Therapy (HAART) adherence to succeed there has to be community support. Being fearful of stigma may lead clients to take their medication secretly and could also miss their doses when others are nearby (Nachega, Knowlton, Deluca, Schoeman, Watkinson, Efron, Chaisson & Maartens, 2006).

Self-efficacy also influenced adherence in that those who had social support had better chances of having stronger self-efficacy (Luszczynska, Sarkar & Knoll, 2007). Information and emotional support from peers also enhanced adherence (Simoni, Huh, Frick, Pearson, Andrasik, Dunbar & Hooton, 2010).

HIV and AIDS related stigma is defined as unfavourable attitudes, beliefs and policies directed toward people perceived to have HIV and AIDS, as well as toward their significant others, loved ones, close associates, social groups and communities (Monger, 2011). Those who are infected with HIV are often blamed for their condition as some people feel that they could have easily avoided it Stigma affects the capability and inclination to access treatment and some medical doctors refuse to treat clients who have HIV (Monger, 2011).

Discrimination is the result of stigma, it is defined as when in the absence of objective justification, a distinction is made against a person that results in that person being treated differently as a result of them belonging to a certain group (Mahajan, Sayles, Patel, Remien, Ortiz, Szekeres & Coates, 2008).

In a study conducted by Wills and Vaughan (1989) it was found that it was not all social relationships that were good for people on ART, behaviours that promoted substance abuse were more harmful. People who lived in urban areas were three times more likely to be adherent than those who lived in rural areas (Peltzer, Friend-du Preez, Ramlagan & Anderson, 2010).

Whether treatment will succeed or fail is entirely dependent on the level of adherence. If the client is adherent their health is likely to improve tremendously (National Collaborating Centre for Infectious Diseases, 2010). Strategies that improve adherence are identified as Directly Observed Treatment for antiretroviral therapy, provision of basic adherence tools, continuous education and counselling, multidisciplinary and peer support, home visits conducted by health care workers, couple counselling, the use of mobile phones (Amico & Orrell, 2013). Reduction of the number of pills in the form of fixed-dose combinations was also found to greatly improve adherence, interventions that involved spouses were found to improve adherence (National Collaborating Centre for Infectious Diseases, 2010). The use of computer-based technology to educate and support HIV-positive individuals in adhering to specific ART regimens was also regarded as a viable strategy (Simoni, Amico, Pearson & Malow, 2008).

South Africa is unique compared to other African countries, in that the country experienced apartheid. Segregations introduced by this system were deeply entrenched. The democratically elected government is faced with the task of bridging the gap between the rich and the poor. The success of the antiretroviral programme is therefore highly dependent on the political will of the government. South Africa has the highest number of people living with HIV in the world; the government's response to the epidemic has however been very slow as the roll-out was mired by controversial debates (Ojikutu, Jack & Ramjee, 2007).

The provinces within the country also pose a challenge in that there are inequities amongst them as some are well-resourced, whereas some are severely under-resourced. The Western Cape and the Limpopo provinces are extremes in this regard, with the Western Cape being well-off than the Limpopo province (Ojikutu *et al*, 2007).

The South African health care system is inefficient in that it is a two-tier system made up of public and private health care facilities. There are also disparities regarding public health care facilities. Public sector ART roll-out was initiated at government hospitals as human resources and laboratory facilities were considered much superior compared to clinics (Ojikutu *et al*, 2007). Long queues were a challenge at these facilities, until recently when the roll-out has moved to primary health care facilities as well. Non-governmental organizations have also been accredited to provide antiretroviral therapy.

There is a shortage of staff at public health facilities, with many health care workers preferring to work at private health facilities. Provision of care is largely doctor dependent, which is problematic as there is a shortage of medical doctors, more especially in rural areas. Generally, those who make use of services in the public health care sector often do not have any other option as private health care is too expensive (Kagee, Le Roux & Dick, 2007). It is therefore envisaged that the much anticipated National Health Insurance (NHI) initiative will bring relief to poor communities.

Most ART roll-out initiatives in South Africa, are not integrated into the mainstream of primary health care. Integration is crucial, more especially in a country where the co-infection rate is very high. Transportation costs may be the most significant challenge to accessing treatment amongst clients who are unemployed as well as having to deal with the negative attitudes of

health care workers (Kagee, Nothling & Coetzee, 2012). It is thus envisaged that the down-referral system will enable clients on antiretroviral therapy to access treatment much easier at their local clinics.

People who are employed also experience challenges as they have to visit clinics more often for treatment and monitoring. The cost of absconding from work may be too high for some (Ojikutu *et al*, 2007). On the other hand, there are those people who prefer receiving medication from health facilities that are very far from their homes as they do not want to be recognized by those who know them (Kagee *et al*, 2012). Stigma and discrimination also affect treatment adherence. Those whose family members are not aware of their HIV status, often have to hide their treatment and conceal that they are on treatment as they fear being discriminated (Kagee *et al*, 2012).

In a study conducted in South Africa at Dr George Mukhari Hospital in Pretoria with 289 clients, it was determined that only 57.2% of the clients reported taking more than 95% of their prescribed doses. This low level of self-reported adherence could lead to the danger of antiretroviral drug resistance (Malangu, 2008).

There are many factors that contribute towards HIV treatment adherence. However, this study focused on social support, self-efficacy, treatment knowledge, disclosure and stigma and discrimination. Social support, self-efficacy and treatment knowledge influences many other factors such as patients' personal and belief systems as well as the ability to access health facilities.

Behavioural scientists have a crucial role to play in the context of medical advances in the treatment of HIV infection. Sociologists can also contribute in conducting research into the determinants of adherence in people who are HIV-infected and on antiretroviral therapy. The information gained from this study, will be used to develop innovative and sustainable interventions to increase treatment adherence of clients on antiretroviral therapy.

1.3 Research Questions

The study intends to answer the following research questions:

- What kind of support structures is available for people on antiretroviral therapy (ART)?
- How does stigma impact on treatment adherence?
- How does discrimination impact on treatment adherence?
- What is the role of self-efficacy in promoting treatment adherence?
- What are the consequences of disclosing one's HIV status?
- What strategies could be identified that could be used to improve adherence, which can be useful for planning an intervention?

1.4 Purpose of the Study

The aim of the study is to investigate challenges to antiretroviral therapy (ART) adherence.

1.5 Objectives of the Study

The following are the objectives of the study:

- To identify support structures available to people on antiretroviral therapy;
- To investigate the effect that stigma has on treatment adherence;
- To investigate the effect that discrimination has on treatment adherence;
- To examine the role of self-efficacy in promoting treatment adherence;
- To determine the consequences of disclosing one's HIV status and
- To gather information from clients on antiretroviral therapy and support groups as well as to identify strategies to improve adherence, and to plan an intervention in the form of a model.

1.6 Rationale and Motivation

The HIV and AIDS epidemic is one of the most devastating challenges that the world has ever faced. Antiretroviral therapy enables those who are infected to lead normal and healthy lives. Understandably the topic on the challenges associated with antiretroviral therapy has been approached from many different angles. Due to the fact that there is not yet a cure for HIV, antiretroviral therapy remains one of the most viable options for those who are infected with HIV.

The study has explored support networks that are available to people who are on antiretroviral therapy, the effects of stigma and discrimination on ART adherence, the role of self-efficacy, consequences of disclosure of HIV status, planning an intervention strategy through engaging with people who are on treatment and support group members as well as developing a family-centred ART model on adherence.

The family is a primary institution of socialization. The role played by the family in upholding certain values and norms and providing support for family members cannot be over-emphasized. Previous research has focused on the negative aspects of HIV status disclosure and antiretroviral therapy. In a study conducted by Kagee, Nothling and Coetzee, (2012), participants indicated that stigma was a major challenge in their families, to the extent that they were reluctant to disclose their HIV status to their family members. This particular study focused on the positive role that can be played by family members.

The researcher has worked in the HIV and AIDS field for the past 13 years and with great concern has noticed that some clients face several challenges that make it difficult for them to adhere to their medication. Some of these challenges include unreliable transport, unemployment, illiteracy, substance abuse, failure to disclose, stigma and discrimination, insufficient support networks, as well as side effects.

Recent HIV and AIDS data indicates that there are no reductions in terms of HIV infections in South Africa (The National HIV and Syphilis Prevalence Survey South Africa, 2009). Therefore, for clients who become infected with HIV, ART remains the effective alternative when their immune systems become compromised.

The Comprehensive Plan for Management, Care and Treatment of HIV and AIDS was initiated by the National Department of Health (NDOH) and approved by cabinet in 2003. In the Limpopo Province the programme started in 2004, with only regional hospitals being allowed to render the service.

The success of the ARV programme will depend on a number of factors, including the readiness of the individual to embark on treatment, adjustment to being on treatment, an ability to adhere to medications and the capacity to deal with treatment change or failure, or side-effects. The study seeks to ultimately plan and develop an intervention strategy in a form of a model that could be useful for the government.

With regard to the clients on antiretroviral therapy (ART), adhering to treatment is crucial in order for the medication to succeed. Near-perfect pill-taking is required to achieve viral suppression and to avoid the occurrence of viral resistance. When clients omit the prescribed amount and do not take their ARV medications regularly, viral resistance develops and this may impede the medication from working. The study uncovered various factors that affect ART adherence.

1.7 Trustworthiness

The researcher has worked at the Community Responsiveness Programmes (CRP), a non-governmental organization funded by the Department of Health as the co-ordinator of the Lay Counsellor Programme. During the period that the researcher was employed at this organization, she was responsible for training, placing trained lay counsellors at health facilities, mentoring them and assisting them to establish support groups of people living with HIV. The researcher was also employed by the Department of Health and she was mainly responsible for implementing the Flemish Government's HIV Counselling and Testing Project. During this period, the researcher was able to provide financial support to nine (9) lay counsellor organizations through the Flemish Government funding.

1.8 Summary

In South Africa HIV prevalence was 29.5% in 2011. The prevalence differs according to the various provinces, KwaZulu-Natal has been the hardest hit province. The Limpopo province continues to have the third lowest HIV prevalence, the province with the lowest prevalence being the Northern Cape followed by the Western Cape. The Mopani district has the third highest HIV prevalence, the Vhembe and the Waterberg districts are extremes in that the Vhembe district has the lowest prevalence and the Waterberg district has the highest prevalence.

Antiretroviral therapy (ART) is now widely available in South Africa and in the various provinces and respective districts. The triple fixed dose combination has now been introduced in South Africa. The researcher has identified and outlined specific questions and objectives to be addressed by the study. In order for the Comprehensive Care Management and Treatment of HIV programmes to succeed it is essential to ensure that the programme is inclusive. There is a need to have on-going education in the community and various structures within the community need to be involved in the implementation of the programme. Continuous training of health care workers and counsellors is also important. The study employed three theoretical frameworks.

CHAPTER 2

EPIDEMIOLOGY OF HIV AND AIDS GLOBALLY, REGIONALLY, NATIONALLY AND LOCALLY

2.1 Introduction

The HIV and AIDS epidemic has negatively impacted the whole world. The impact of this epidemic varies from continent to continent, country to country, province to province, district to district and sub-district to sub-district and of course health facility to health facility. The African continent has been severely affected by the epidemic. Global, regional, national and local HIV and AIDS prevalence will be outlined in detail in this chapter.

2.2 The State of HIV and AIDS Prevalence

According to the 2013 UNAIDS report on the global AIDS epidemic an estimated 35.3 million people were living with HIV globally in 2012. It is astonishing to realize that there are still new HIV infections. There were 2.3 million new infections globally (UNAIDS, Global Report, 2013). Sub-Saharan Africa remains the region most severely affected by HIV. Of the estimated 35.3 million people worldwide living with HIV, 71 percent were in sub-Saharan Africa (UNAIDS, Global Report, 2013).

The first case of HIV in South Africa was identified in 1982. The first annual national survey was conducted in 1990 and it was found that the estimated HIV prevalence was 0.8% among pregnant women. The following year, the HIV prevalence was 1.5%, an indication that the country was facing an AIDS epidemic (Fletcher, 2009).

South Africa is one of the countries that have been hardest hit by HIV and AIDS. The estimated total number of people living with HIV in 2012 was 6.1 million. The prime mode of HIV transmission is heterosexual sex and this is followed by mother-to-child transmission (UNGASS, Country Progress Report, 2012).

The Antenatal HIV Sero-prevalence survey is conducted annually among pregnant women aged 15-49 years. It provides an estimate of the point of prevalence for that particular year in the antenatal population of South Africa, and the results are then used to estimate prevalence in the general population (Country Progress Report, 2010).

The control of HIV in South Africa involves multi-sectoral approaches involving government, research and academic institutions, civil society, non-governmental organizations, community based organizations and the private sector. In 2011, the overall HIV prevalence amongst antenatal women was 29.5%, a decrease of 0.7% from 30.2% in 2010 (The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

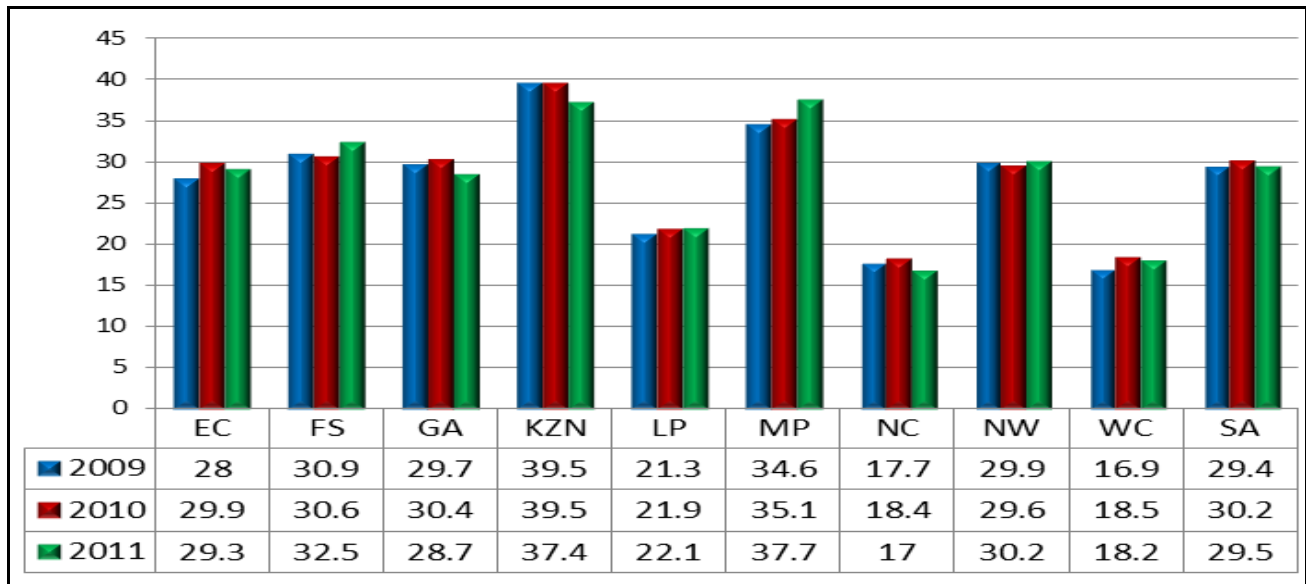
According to the 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey, the national HIV prevalence was 29.5% in 2011. KwaZulu-Natal continues to be the hardest hit province, boasting a prevalence of 37.4%. The Mpumalanga Province's HIV prevalence has demonstrated a steady increase, as in 2009 they were at 34.6%, 35.1% in 2010 and 36.7% in 2011. The Free State Province has also recorded an increase from 30.6% in 2010 to 32.5% in 2011, and in 2009 the Province was at 30.9% (The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

The North-West Province has also recorded an increase, in 2009 they were at 29.9%, 29.6% in 2010 and 30.2% in 2011. The Eastern Cape Province has shown a slight decrease, from 28.0% in 2009, 29.9% in 2010 to 29.3% in 2011 (The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

The Gauteng Province is also making some positive strides in that it recorded a prevalence of 29.7% in 2009, 30.4% in 2010 and 28.7% in 2011. The Limpopo Province has however, indicated a gradual increase as it was at 21.3% in 2009, 21.9% in 2010 and 22.1% in 2011 (The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

The Western Cape Province has the second lowest HIV prevalence in the country, having recorded a prevalence of 16.9% in 2009, 18.5% in 2010 and 18.2% in 2011. The Northern Cape Province remains the province with the lowest HIV prevalence, at 17.7% in 2009, 18.4% in 2010 and 17.0% in 2011 (The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

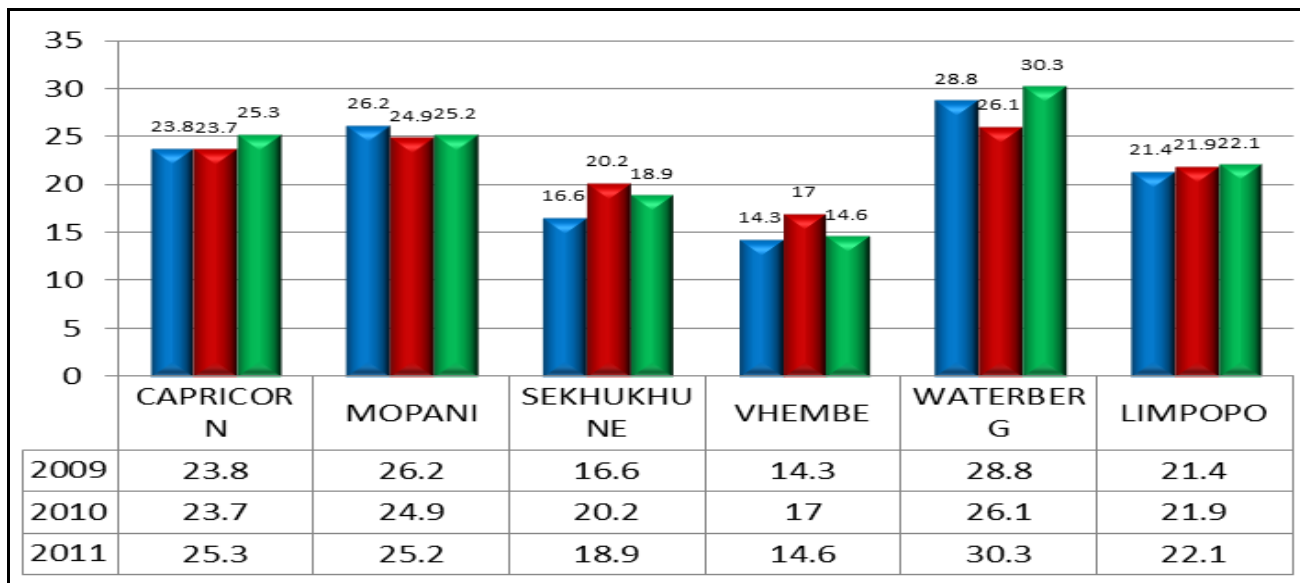
2.3 National and Provincial HIV Prevalence from 2009 to 2011



Bar Graph 1: The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa

South Africa is very unique compared to other African countries in that the country experienced apartheid. The policies of the apartheid era contributed to fuelling the spread of the HIV epidemic. People were displaced as they were forced to move from rural areas to urban areas. The negative effects of apartheid were reinforced by the effects of a migratory work system that was created to support the mining industry. There was very limited work for women, and those who found jobs in the homes of white people, substituted their salaries by becoming commercial sex workers in the mine compounds. The migrant patterns encouraged men to have many sexual partners as they were very far from their wives. There was a rapid spread of sexually transmitted infections. The social and political atmosphere of South Africa was very unhealthy and led to the outbreak of the HIV and AIDS epidemic in that it was characterised by destitution, marginalization, rapid urbanization, the anonymity of urban life, labour migration, widespread population movements, social disruption, displacement and wars (Fletcher, 2009).

2.4 Limpopo Provincial HIV Prevalence

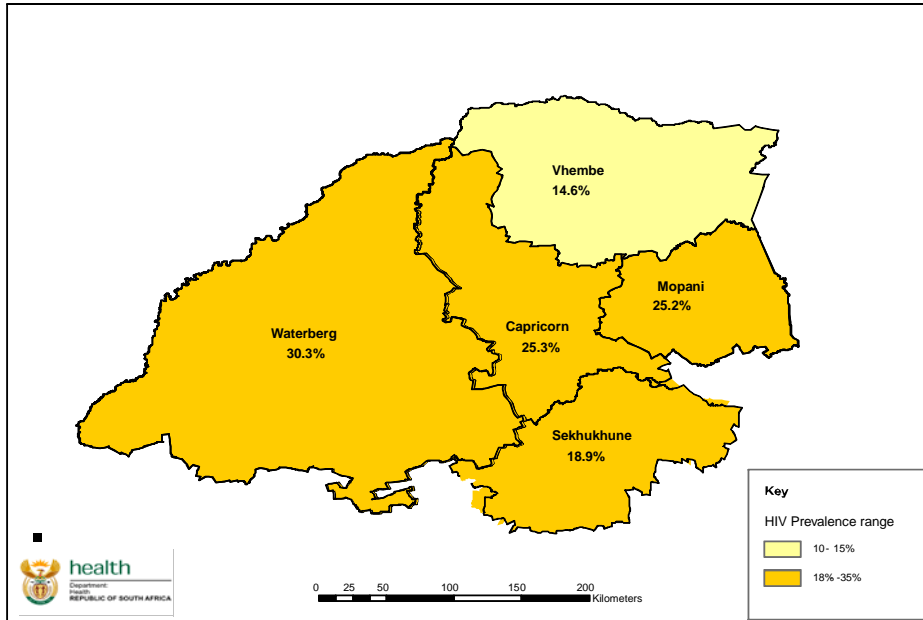


Bar Graph 2: The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa

With regard to the Limpopo province the provincial HIV prevalence was at 22.1%, the Waterberg District remains the hardest hit having recorded a prevalence of 30.3% in 2011, demonstrating a slight increase from 26.1% in 2010 and 28.8% in 2009. The Capricorn District has also shown an increase from 23.7% in 2010 to 25.3% in 2011 and in 2009 the province was at 23.8%. The Mopani District has also indicated an increase from 24.9% in 2010 to 25.2% in 2011. The district was at 26.2% in 2009. The Sekhukhune District has demonstrated a decrease, from 20.2% in 2010 to 18.9% in 2011, the district has recorded a prevalence of 16.6% in 2009. The Vhembe district remains astonishingly the least affected district, even though the district is next to the Beit Bridge border. The HIV prevalence in the district was at 14.3% in 2009, 17.0% in 2010 and 14.6% in 2011 (The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

Social factors that fuel the spread of HIV are abuse of alcohol, unemployment, financial dependence on male partners, domestic violence, sexual abuse, multiple sexual partners, commercial sex work, migration and women's inability to negotiate for safer sex practices.

2.5 Map of the Mopani District



Map 1: The Mopani District

(The 2011 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa).

2.6 Summary

The global state of the HIV and AIDS epidemic was presented. There are still new HIV infections world-wide. The Sub-Saharan Africa is the most severely affected by the epidemic. South Africa has many people living with HIV and AIDS and the apartheid system has had a very negative effect on the country. The country has the largest ARV programme in the world. HIV prevalence varies according to provinces, with KwaZulu-Natal remaining one with the highest prevalence. With regard to the districts, there are extreme cases in that some have recorded a very high prevalence rate whilst others have recorded a very low prevalence.

CHAPTER 3

POLICY RESPONSES OF THE SOUTH AFRICAN GOVERNMENT TO THE HIV AND AIDS EPIDEMIC AND CONFLICTING IDEAS

3.1 Introduction

This chapter outlines the national and international obligations with regard to the HIV and AIDS epidemic. Guidelines on Antiretroviral therapy will also be articulated. New developments regarding the provision of ART will be discussed. National strategies such as the National Strategic Plan on HIV and AIDS, STIs and TB will be clearly delineated. The responses of various government administrations will also be described.

3.2 The Constitution of South Africa

The Constitution of South Africa, Act 108 of 1996 is the supreme law of the country. All new laws developed have to be in line with the Constitution. The South African Constitution is the preliminary point to regulate the role of international law domestically. Section 39 of the Constitution states that the courts, and other legal bodies, when interpreting the Bill of Rights:

- Must consider international law.
- May consider foreign law.

South Africa is signatory to a number of international treaties. Section 231 of the Constitution says that a treaty binds South Africa after approval by the National Assembly and the National Council of Provinces (Constitution, Act 108 of 1996).

South Africa is a rights based society, to that end; chapter 2 of the Constitution contains the Bill of rights, which is comprised of the rights that each South African citizen has to enjoy. “Human rights are a set of universal entitlements that individuals enjoy irrespective of their sex, nationality, religion, culture or other status, that are inherent to human beings and that are proclaimed and protected by international law” (Patterson & London, 2002). Human rights guide governments on how to respond appropriately to the pandemic. They also provide a

coherent system for the public health sector to address health issues, in particular HIV and AIDS issues.

3.3 International Obligations

The UNAIDS and the World Health Organization (WHO), launched the Treatment 2.0 Framework of Action in 2010. The initiative was aimed at ensuring universal access to treatment and to increase the benefits of ART as a preventive strategy (WHO, 2011). The treatment 2.0 builds on the 3 by 5 strategy as well as the experience over the last 10 years to expand access to HIV diagnosis, treatment and care through a series of innovations in five priority work areas. The treatment 2.0 priority work areas are as follows:

- Optimize drug regimens
- Provide access to point-of-care diagnostics
- Reduce costs
- Adapt delivery systems
- Mobilize communities

Despite the enormous gains in reducing transmission and HIV-related illness and death over the past decade. The goal of achieving universal access to all faces financial and technical challenges (WHO, 2011). Many low and middle-income countries (LMIC's) are under resourced, and HIV and AIDS services are not easily accessible. There are also challenges associated with the provision of ART, such as human rights violations and gender inequality (WHO, 2011).

3.4 National Antiretroviral Treatment Guidelines

The main aim of the guidelines is to help the HIV and AIDS management team in effectively managing clients who are on antiretroviral therapy. The approach that is adopted is the one that consists of the continuum of care, with an all-inclusive client focus in an integrated health system. This system is integrated from primary to tertiary levels, as well as from the clinic to the community, as many people are found in various communities and from pre-diagnosis to palliation whichever is appropriate. The focus is at the primary level with the District Health

System being implemented throughout the country so as to ensure uniformity (The South African Antiretroviral Treatment Guidelines, 2004). Decentralization of the health care system is crucial, so as to enable clients on ART to access their medication easily.

3.5 Goals of Antiretroviral Treatment

3.5.1 The Primary goal of ART is to decrease HIV-related illnesses and death

Antiretroviral therapy ensures that:

- The client should experience fewer HIV-related illnesses;
- The client's CD4 cell count should increase and remain above the baseline count and
- The client's viral load should become undetectable and remain undetectable on ART (The South African Antiretroviral Treatment Guidelines, 2004).

HIV compromises the immune system of the infected individual. It is therefore, imperative that HAART should be initiated when the CD4 cell count is at 350 according to the WHO guidelines, so as to prevent opportunistic infections. Usually, after a few months of initiating therapy the CD 4 cell count improves and the viral load decreases up to undetectable levels. Improvement on the client's health can only be attained if they are adherent. Treatment adherence counselling is of critical importance.

3.6 Patient Selection Criteria

Patients' selection criteria include the following:

- CD 4 cell count of less than 350/mm³ regardless of the WHO stage.
- WHO stage IV regardless of CD 4 cell count.

Due to financial constraints facing the country, the South African government has opted for delayed therapy. The implication is that people infected with HIV may only initiate therapy when their CD4 cell count has decreased to 350/mm³ or when they have reached WHO stage IV, which is usually accompanied by many opportunistic infections (The South African

Antiretroviral Treatment Guidelines, 2013). Initially, those who are infected would only qualify for ART with a CD4 cell count of 200. The new policy affords many people who are infected an opportunity to survive

3.7 The Psycho-Social Aspects to be taken into Consideration

The following psychosocial aspects need to be taken into account:

- The client demonstrates commitment. They have attended three or more scheduled visits to an ART clinic.
- Should not be consuming alcohol or abusing drugs or other substances.
- Should not be depressed.
- Should have disclosed their HIV status.
- It is further recommended that the client should be in a support group of people living with HIV.
- The client should have accepted their HIV-positive status.
- The client needs to be empowered about HIV information and how anti-retroviral therapy can reduce some of the adverse effects of HIV.
- The clients should be in a position to attend the antiretroviral centre on a regular basis.
- The client also needs to have reliable transport (The South African Antiretroviral Treatment Guidelines, 2004).

The considerations indicated point to the fact that the client has to be self-reliant, exercise self-care and have self-efficacy. The health care providers can only help the client to adhere and comply. If they demonstrate commitment it becomes easier for health care providers to assist them.

3.8 Fixed-Dose Combination

During the year 2012, the Minister of Health in South Africa, Dr Aaron Motsoaledi made an announcement on the award of a new antiretroviral (ART) tender worth R 5.9 billion that also includes a triple fixed-dose combination (FDC) tablet. This approach will enhance cost-effectiveness and simplifies the first-line regimen (Southern African HIV Clinicians Society, 2013). Dosing for clients on antiretroviral therapy will be made easier.

The logistics involved in prescribing, dispensing and stock management is simplified because the first-line regimen is reduced from 3 separate drugs to 1 combined drug. The fixed-dose combination therapy was launched at Garankuwa in Pretoria South Africa, by the Minister of Health Dr Aaron Motsoaledi on the 8th of April 2013. The fixed-dose combination is easier and more effective to administer (Southern African HIV Clinicians Society, 2013). Health facilities will no longer have to handle large amounts of medication.

All pregnant and breastfeeding women will be initiated onto FDC, and if they are already on ART they will be changed over to FDC ART. All expectant women regardless of their CD4 cell count, will start FDC from 14 weeks of pregnancy and continue throughout the breastfeeding period, until one week after breastfeeding stops. After the breastfeeding period, women with CD4 cell counts of less than 350 will continue on FDC for life (National Department of Health, 2013). Promotion of prevention of Mother-to-Child Transmission of HIV is critical and research has demonstrated that many women who comply and adhere to the treatment give birth to HIV negative babies, thus contributing to the goal of attaining an HIV free generation.

Women will only have to take one pill once a day instead of three or more a day and will have to undergo fewer laboratory tests once they are on treatment. It is therefore envisaged that adherence will significantly improve and maternal mortality will be reduced (National Department of Health, 2013). Adherence fatigue is a challenge for many people on antiretroviral therapy, as they also have to battle coping with competing priorities.

3.9 Tuberculosis (TB) and HIV and AIDS

Tuberculosis (TB) is a bacterial disease frequently caused by mycobacterium tuberculosis. TB is not a new disease, it has affected human beings for many years. Many people who are infected with TB are not aware that they are suffering from TB, because an immune system which is functioning well is able to overpower the illness thus preventing the bacteria from multiplying. When the immune system is weak due to HIV, the bacteria begins to multiply and this often leads to active TB (Achmat & Roberts, 2005). Hence, it is crucial for health care providers to screen all clients to come forward for HIV counselling and testing for TB as well and provide HIV counselling and testing to all clients who present with TB symptoms.

Tuberculosis (TB) has a very strong relationship with HIV and AIDS. Many people who are infected with HIV are also infected with TB. The disease is the leading cause of death among people living with HIV. The co-infection rate in South Africa is more than 50%. Tuberculosis (TB) can occur at any time, but occurs early in the course of HIV disease. Tuberculosis (TB) accelerates HIV disease. It is however encouraging to learn that TB can be prevented even in people living with HIV and AIDS using isoniazid prophylaxis.

The Directly Observed Treatment, Short-Course (DOTS), is an effective strategy to treat TB (The Department of Health, 2000). According to the WHO Global TB control Report of 2008, the DOTS strategy has been successful in reducing TB deaths and prevalence rates. The strategy has not made any major impact regarding the prevention of transmission and trends in new cases.

In a study conducted by Matebesi, Meulemans and Tommerman (2005) on Health-care seeking behaviour among clinic-based tuberculosis patients, they found that the majority of the clients in the study did not have any information about TB prior to their diagnosis. Community outreach programmes also need to focus on TB awareness. The co-infection rate in South Africa is very high and health care workers need to address the twin-epidemic (HIV/TB) as a collective.

The Directly Observed Treatment, Short-course (DOTS) is an internationally recommended strategy to deal effectively with TB. South Africa has been implementing DOTS since 1996 (The Department of Health, 2000). The DOTS strategy needs to be widely applied within the ART programme as well so as to promote treatment adherence.

The migrant labour system in South Africa played a critical role in the spread of TB. The leading cause of death in people who are infected with HIV is TB. Treatment collaboration between these twin epidemics need to be strengthened. In a study that was conducted in Khayelitsha, Cape Town, it was found that health care providers miss opportunities to detect and treat TB clients (Matjila, Hoosen, Stoltz & Cameron, 2008). However, in their attempt to collaborate it is important for the health care providers not to duplicate services.

3.10 The National Strategic Plan for HIV and AIDS and STIs, and TB 2012 – 2016

The National Strategic Plan (NSP) on HIV, Sexually Transmitted Infections (STIs) and TB 2012-2016 provides a guideline for the government and other non-governmental structures in responding to the “twin epidemic” that is HIV and TB for the next five years (National Strategic Plan on HIV, STIs and TB: 2012-2016). Tuberculosis is the leading cause of mortality among HIV positive individuals. The global HIV/TB co-infection rate was as 13% in 2012 and the co-infection rate in South Africa is at 65% (WHO Global TB Report, 2012). It is therefore crucial for the two epidemics to be managed and treated together because TB can be cured even if a person is infected with HIV. The plan addresses the drivers of HIV and TB epidemics and also builds on the achievements of the previous NSPs to achieve its goals. Interventions that have been successful in the past are intensified.

The NSP is also aligned with regional and international obligations and commitments related to HIV, TB and STI's (National Strategic Plan on HIV, STIs and TB: 2012-2016). One of the aims of the NSP is:

- Ensure that at least 80% of people who are eligible for treatment of HIV are receiving it.

(National Strategic Plan on HIV, STIs and TB: 2012-2016).

The NSP has identified four strategic objectives to reach its five-year goals: These are:

- Address social and structural factors that influence HIV, STIs and TB. The primary objective being to address societal norms and behaviours that fuel the twin epidemics of HIV and TB.
- Prevent new HIV, STIs and TB infections. The primary objective being to use a combination of biomedical, behavioural, social and structural interventions.
- Sustain health and wellness. The primary objective is to ensure access to quality treatment, care and support services for those with HIV, STIs and TB.
- Protect human rights of people living with HIV. The primary objective is to end stigma, discrimination, human rights violations and gender inequality.

(National Strategic Plan on HIV, STIs and TB: 2012-2016).

3.10.1 The NSP and International Obligations

The NSP aims to align with relevant international and regional obligations, commitments and targets. The Millennium Development Goals (MDGs) present specific development and health targets for 2015 towards which South Africa and other countries are striving.

3.11 HIV and the Millennium Development Goals in South Africa

South Africa is committed to fulfilling its constitutional obligations to deliver socio-economic rights hence these rights are enshrined in the Constitution of the country Act No 108 of 1996 (UNDP South Africa, 2013).

There are eight Millennium Development goals that the country needs to respond to, this particular study addressed goal number 6, which is to: Combat HIV and AIDS, Malaria and other diseases.

Target 7: To have halted by 2015 and begun to reverse the spread of HIV and AIDS.

Target 8: To have halted by 2015 and begun to reverse the incidence of malaria and other major diseases.

3.11.1 Progress in South Africa regarding the Millennium Development Goals (MDGs)

The government has intensified the implementation of policies, strategies and programmes aimed at combating HIV and AIDS. In order to combat the spread of HIV and AIDS and other diseases such as TB, the government needs the commitment of all sectors of South Africa. HIV prevalence rates are still very high in South Africa compared to some countries in Africa. On the positive side, it would appear that the HIV epidemic has stabilized. Gender inequality is still a major challenge, more especially in rural communities. Young girls are also engaging in sexual relationships with older men, which further fuel the spread of the epidemic (UNDP, South Africa, 2013). Programmes aimed at empowering young women need to be developed and implemented to prevent them from being exposed to HIV.

3.12 The Thabo Mbeki Administration

In 1999 Thabo Mbeki was elected as president and Manto Tshabalala-Msimang as his Minister of Health. The South African government initially cited affordability as a reason for non-availability of ARVs. The Thabo Mbeki administration then raised different concerns about the efficacy of ARVs, drug resistance and the toxicity of their side effects on the human body. Eventually, the government and the Health Ministry were compelled by the court to introduce nevirapine to prevent Mother-to-Child transmission of HIV (Nattrass, 2007). Valuable time had already been lost and innocent life was being lost. Many HIV infected mothers were giving birth to babies infected with HIV.

Mbeki's position on PMTCT was not clear but he was very silent and as a result the country did not act early with regard to PMTCT (Nattrass, 2007). His doubts on the effectiveness and toxicity of AZT also compromised the efforts within the health department of fighting against HIV and AIDS.

Mbeki argued that poverty was the cause of the AIDS epidemic and the reason why babies were not being vaccinated (Van Rijn, 2006). Mbeki and his government were very slow to respond to the challenges caused by the HIV and AIDS epidemic.

Former Health Minister Manto Tshabalala-Msimang aligned with Mbeki politically as she also was in opposition to using AZT for preventing MTCT. Her position on the provision of nevirapine was that more research was needed to prove that it was not toxic to pregnant women and children. She raised concerns about the toxicity of nevirapine during a speech made to Parliament in April 2000 (Heywood, 2009).

The Treatment Action Campaign (TAC) and its most recognized leader, Zackie Achmat, were responsible for challenging the government in their claims about the toxicity of ARVs for HIV infected mothers. The TAC demanded essential documents specifying the reasons for the delay in rolling out the pilot programme. It was evident that the late and former Health Minister Dr Manto Tshabalala-Msimang was instrumental in the political stalling.

3.12.1 Resisting and undermining the HAART roll- out

AIDS dissidents resisted the epidemiological models of AIDS deaths and also resisted the use of antiretroviral therapy. The Health Minister lost the court case against the TAC and complained bitterly thereafter that she was being forced to give people poison (Van der Vliet, 2004). Ultimately, many lives were saved by providing free ART in the public health facilities.

The Health Minister also resisted the national roll-out of ARVs citing its side-effects and the complicated nature of the administration of the drugs, but also lost the court case again. The government was faced with a civil disobedience campaign which was led by the TAC and eventually gave in and in 2003 the cabinet announced that the government would roll-out HAART in the public sector (Butler, 2005). The Health Minister distanced herself from the decision indicating that she was not responsible for the drastic step, but as the Health Minister had no choice but to ensure that the decision was implemented (Mail and Guardian, 15-20/8/03). The outcome of the court case was a victory for South African citizens.

One month after the Cabinet decision on antiretroviral therapy, the government released its operational plan to have 54, 004 people on treatment by March 2004 (Department of Health, 2003). The Health Minister did not support the roll-out of ARVs, but continued to emphasize the side effects of the drugs and praised the benefits of nutrition. The Health Minister singled out garlic, lemon, olive oil and beetroot as alternatives to ARVs. This resulted in infected

people refusing to take ARVs as they feared to be poisoned (Cullinan, 2005). The Health Minister continued to show support for alternative remedies (McGregor, 2005). She supported the activities of Matthias Rath, a wealthy German entrepreneur who has a foundation called Rath Health Foundation. The foundation sells multivitamins which cost more than antiretroviral drugs. They claim that these micronutrients treat, or cure, a range of illnesses including cancer, asthma and AIDS (Geffen, 2005). As part of its marketing strategy the Rath Health Foundation criticized ARVs by saying that they were severely toxic.

3.12.2 The Case for Antiretroviral Access (TAC)

There was a delay in the implementation of the pilot programme in the provision of nevirapine to HIV-positive pregnant women which prompted the court case against that government which started in 2001. Former Minister Tshabalala-Msimang stated concern for the provision of the medicine but ultimately listing barriers such as the inadequate health infrastructure that legitimizes the delay of the roll-out (Heywood, 2009).

The TAC took the matter to court and the case was decided in favour of TAC after two days in December 14, 2001 by Judge Chris Botha. He ordered the government to develop a fully capable and effective national programme to reduce Mother-to-Child Transmission of HIV (MTCT) by the following year. Tshabalala-Msimang decided to appeal the decision, arguing that the decision by the judiciary traversed constitutional boundaries and interfered with the executive branch's role in deciding matters for the country. The appeal was withdrawn in 2002 (Heywood, 2009).

3.12.3 The Jacob Zuma Administration: The Turning Point

In 2009 Jacob Zuma was elected as president and Dr Aaron Motsoaledi as his Health Minister. Zuma's presidency having noticed mistakes committed by former President Mbeki showed commitment to managing and treating HIV in that towards the end of the year in 2009 his cabinet conveyed its commitment to test all children exposed to HIV and provide all HIV-positive children with ART. Coverage of HIV-positive mothers with AZT treatment was estimated at over 95% by 2010. Mother-to-Child transmission was reduced by 3.5% (South Africa History on line, 2013).

In April 2010 the HIV Counselling and Testing (HCT) campaign was launched by President Jacob Zuma to ensure that people have access to their right of knowing their HIV status. The president was publicly counselled and tested for HIV as a symbol of commitment to combating the disease. The HCT campaign was rolled out nationally. However, with regard to ART the government was lagging behind in that by the end of 2010 only 55% of people who needed ART were on treatment. The government's goal was 80%. The government has introduced a wide spread ART programme through public health facilities including primary health care facilities (South Africa History on line, 2013). The Health Minister also demonstrated commitment by making bold and strategic decisions in the management of the epidemic.

3.13 Summary

People living with HIV and AIDS are often stigmatized and discriminated therefore, it is imperative to put measures in place so as to protect them. The Constitution of South Africa is the Supreme law of the country and clearly outlines the rights to health care services that each South African citizen should enjoy. It also recognizes international laws. The South African government has ratified several international laws so as to strengthen the protection of the rights of people living with HIV and AIDS. Antiretroviral therapy guidelines at international and national levels have been developed to ensure the continuity of care and effective roll-out of the programme. The HIV/TB co-infection rate is very high in South Africa therefore, the two programmes have been integrated. The South African government will be able to meet some of the Millennium Development Goals (MDGs). Various administrations responded differently to the epidemic, from being passive, reluctant and denying the reality to being positive, proactive and accepting the challenge.

Thabo Mbeki's administration failed to acknowledge the enormous challenge that was confronting the country regarding this epidemic. Thabo Mbeki applied the denialist approach and had conflicts with the Treatment Action Campaign because of his views regarding HIV and AIDS. The Health Minister under his administration was also very controversial as she would promote fruits and vegetables in managing HIV. It was during president Zuma's reign that people witnessed the president taking the lead with regard to HIV and AIDS management

by openly being counseled and tested for HIV. President Jacob Zuma also launched a massive campaign on HIV Counselling and Testing. The Minister in his administration, Dr Aaron Motsoaledi also came up with important strategies and policies such as the Fixed-dose combination therapy (FDC), which will greatly improve adherence and lessen side effects.

CHAPTER 4

ANTIRETROVIRAL THERAPY ADHERENCE AND SOCIAL ASPECTS

4.1 Introduction

This chapter seeks to articulate factors associated with antiretroviral therapy adherence. The concepts adherence and compliance will be defined, the ART programme within the public sector will be described. Factors that contribute to adherence and non-adherence will be outlined. Predictors of good and poor adherence will be deliberated as well as the strategies that could be employed to deal with the challenges. Other social factors related to ART adherence will be discussed at length.

4.2 Adherence

Adherence implies taking one's drugs exactly as they are prescribed. It further means taking them at the right time. Adherence also includes following a particular nutritional pattern (Kagee, 2004). Adherence does not only involve taking one's medication correctly and consistently, but furthermore involves having a balanced diet. Adherence may be operationalized in different ways. "Dose adherence implies the amount of doses taken, whereas schedule adherence is adherence to drugs taken on specified time, and dietary adherence refers to the amount of medication taken appropriately with proper nutrition (Schonnesson, Diamond, Ross, Williams & Bratt, 2006). Non-adherence to antiretroviral therapy may also occur and this is the situation whereby the client on ART does not take their medication completely, not following the correct schedule, taking the wrong dosage or even abruptly halting the therapy on their own before discussing the matter with their health care provider (Miller, 1997). In order for the client to benefit from the therapy, there has to be a good relationship between them and the health care provider. The client needs to feel comfortable to discuss challenges that they might experience whilst taking the medication. Poor adherence to antiretroviral therapy can be costly to the government and the Department of Health. Failed treatment has to be replaced by another regimen and at times clients have to be hospitalized (USAID, 2010). Adherence is crucial as it is not a guarantee that the second regimen will be successful.

Antiretroviral therapy (ART) is now widely available to people living with HIV and AIDS. However, in order for antiretroviral therapy (ART) to be effective the client needs to maintain high levels of treatment adherence, as non-adherence may result in resistance (Steel *et al*, 2005). Clients on antiretroviral therapy need to demonstrate a high level of commitment, this is shown through the behaviour.

The client is therefore, required to maintain very high levels of adherence so as to ensure that the viral load is kept at undetectable levels, which means that the test reveals that the viral load is below 40 and that the CD4 cell count improves dramatically (Sahay, Reddy & Dhayarkar, 2011). In a study conducted in South Africa at Dr George Mukhari Hospital in Pretoria with 289 clients, it was found that only 57.2% of the clients reported taking more than 95% of their prescribed doses (Malangu, 2008). The low level of self-reported adherence amongst the other clients could lead to the danger of antiretroviral drug resistance.

There are many factors that contribute towards HIV treatment adherence, however, this study seeks to focus on social support, disclosure, self-efficacy and stigma and discrimination. Social support, self-efficacy and treatment knowledge influence many other factors such as patients' personal and belief systems as well as the ability to access health facilities.

Behavioural scientists have a crucial role to play in the context of medical advances in the treatment of HIV infection. Sociologists may also contribute in unearthing social factors associated with antiretroviral therapy adherence. The findings from this study, will be used to develop innovative and sustainable interventions to increase treatment adherence of clients on antiretroviral therapy.

The success of the ARV programme will depend on a number of factors, including the readiness of the individual to embark on treatment, adjustment to being on treatment, an ability to adhere to medications and the capacity to deal with treatment change or failure, or side-effects. The study sought to ultimately plan and develop an intervention strategy in a form of a model that could be useful for the government.

With regard to the clients on antiretroviral therapy (ART), adhering to treatment is crucial in order for the medication to succeed. Near-perfect pill-taking is required to achieve viral suppression and to avoid the occurrence of viral resistance. When clients omit the prescribed

amount and do not take their ARV medications regularly, viral resistance develops and this may impede the medication from working.

In 2003 a World Health Organization (WHO) working group adopted and developed a new definition of adherence as the ability of the person on ART to be able to fit-in the medication in their lifestyle, adopting responsible behaviour-taking medication, corresponds with agreed recommendations from a health care provider (Fomundam, 2005). This means that there should be a working relationship between the client and the health care provider.

A review conducted by the Treatment Action Campaign (TAC) on the roll-out of ARV's pointed out at the significance of managing imbalances between provinces, the lack of additional capital or human resources promised by the roll-out plan and problems with drugs supplies (Brouard, 2005). These factors need to be addressed to ensure adherence to antiretroviral therapy. It should also be taken into consideration that provinces are unique and policy developers need to take this into account.

4.3 Compliance

Compliance refers to the extent to which the client follows the recommendations of the health care provider (Hugtenburg, Timmers, Elders, Vervloet & Dijk, 2013). Medication compliance is defined as the extent of conformity to the recommendations about daily treatment by the health care provider it involves the timing, dosage and frequency (Cramer, Roy, Burrell, Fairchild, Fuldeore, Ollendorf & Wong, 2008). The term could also mean the degree to which the client's behaviour matches the prescriber's recommendations (Cribb & Kellar, 2005). Even though the concept compliance is commonly used in medical literature, it has been criticized as it has negative connotations with regard to doctor-client relationship (Stimson, 1974).

4.4 Public ARV Provision in South Africa

The Cabinet of South Africa approved an Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment on the 17th of November 2003. The provision of antiretroviral therapy in the public sector started with few selected hospitals in all the nine

provinces (Treatment Action Campaign, 2006). This commitment meant that many lives were going to be spared.

In the Limpopo Province the programme started in 2004, with only regional hospitals being allowed to render the service (Senior Manager HIV and AIDS, STIs: 2010). It was the Provincial government's responsibility to ensure that all accredited sites were well-resourced.

Prior to 2004, antiretroviral therapy was available in only a limited number of health centres in few provinces. The only people who could afford ARVs were only people who could buy them. It is however envisaged that if the CCMT programme is implemented correctly, it will help to save many lives. It will assist in increasing awareness and encourage prevention. It is estimated that currently there are a thousand new infections on a daily basis in South Africa (Senior Manager HIV and AIDS, STIs: 2010). This is an indication that unremitting education is vital.

4.5 Factors Contributing to Adherence

In a study conducted by Coetzee, Boulle, Hildebrand, Asselman, Van Cutsem and Goemaere (2004) it was discovered that following strict time restrictions contributed to adherence. Strict adherence counselling sessions also contributed to adherence. Clients with average family income of middle and highest were more likely to adhere than those with lower average family income (Coetzee *et al*, 2004). Other factors that contributed to adherence were support from the family and being reminded to take their medication (Coetzee *et al*, 2004). Disclosure, more especially to close family members is critical as they are able to provide vital support to those on antiretroviral therapy. Cellular phones may also be used to enhance ART adherence as they could be used to communicate with those on treatment (Tam, Pharris, Thorson, Alfven and Larsson, 2011). Being reminded or asked about their condition by health care providers who send text messages enable clients to realize that someone cares about them.

4.6 Factors Contributing to Non-Adherence

Running out of medication has been found to contribute to non-adherence (Coetzee, 2004). Being preoccupied with other duties, forgetting, poverty, fear of side-effects may contribute to non-adherence (Coetzee, 2004). Depression could also lead to non-adherence. Living as a couple could improve adherence as it increases the routinization of daily chores (Coetzee *et al*, 2004). Provision of practical support had significantly greater influence on adherence than emotional support (Coetzee *et al*, 2004). Having attained secondary school education was found to impact negatively on adherence. The use of illegal drugs also contributed to non-adherence (Hansana, Sanchaisuriya, Sychareun, Chaleunvong, Boonyaleepun and Schelp, 2013). Other factors associated with non-adherence were the distance to the clinic, having to take many drugs, difficulty in maintaining the medication regimen and self-stigma (Hansana *et al*, 2013).

Self-stigma may prevent those who are on ART from taking their medication for the fear of being noticed by other people. Being on antiretroviral for more than 2 years was also associated with non-adherence and it was found that the reason could be that the longer people stay on treatment the more they became complacent (Hansana *et al*, 2013). Antiretroviral therapy is a life-long treatment, hence adherence fatigue is likely to occur at some point. In a study conducted in Vietnam it was discovered that family members who were supportive at the beginning of the therapy and would constantly remind the client on ART to take their medication assume that the person is being adherent and stop reminding the person to take medication (Tam, Pharris, Thorson, Alfvén and Larsson, 2011).

Challenges associated with poor access to public transport lead to non-adherence. Many of those who rely on public health care cannot afford private transport and public transport is expensive for those who are unemployed and usually unsafe (Kagee *et al*, 2007). In South Africa, people living with HIV and AIDS qualify for a disability grant. However, as soon as the CD 4 cell count improves and the viral load becomes undetectable, the social security grant is cut off. Therefore, non-adherence may result so as to remain on the state grant (Nattrass, 2006). Long waiting periods, poor infrastructure and the shortage of health care workers contribute towards non-adherence (Medicines Sans Frontiers, 2007).

The lay counsellor programme in South Africa seeks to ensure that quality counselling services are provided to clients on antiretroviral therapy. However, due to the lack of confidence in their abilities, they are relegated to disseminating information other than providing pre and post HIV counselling and treatment adherence counselling. The training package offered to lay counsellors in certain instances is inadequate to enable them to perform their tasks optimally (Rohleder & Swartz, 2005). Thus a comprehensive training package should be offered to each lay counsellor and complemented by refresher courses.

People living with HIV and AIDS often have to deal with stigma and discrimination, and in order for them to feel accepted they may skip their doses and fail to even disclose their HIV status (Klitzman, Kirshenbaum, Dodge, Remine, Ehrhardt, Johnson, Kittel, Daya, Morin, Kelly & Lightfoot, 2004).

4.6.1 Predictors of poor and good adherence

Studies have revealed that the following individual factors are predictors of poor adherence; a high amount of psychological stress, poor coping skills, poorly developed social support networks and low belief in the efficacy of treatment (Moatti, Souteyrand, Sandfort & Aggleton, 2000). It was however, found that the following factors were predictors of good adherence, positive attitudes towards Highly Active Anti-Retroviral Therapy, time on HAART, experiences of HAART side effects, level of knowledge about HAART and length of time known to be HIV-positive (Moatti *et al*, 2000).

According to the study conducted by the Western Cape Department of Health (2006) the main factors identified as contributing to poor adherence amongst adults were, alcohol consumption, (more especially amongst male clients), non-disclosure of HIV status and competing priorities.

The study also found that clients who perceived themselves to be very ill prior to commencement of treatment were more likely to be adherent than those who did not perceive themselves to be very ill. Health care services are also supportive of client adherence. Clients also concurred that taking self-responsibility was crucial for lasting adherence. Certain clients reported modern techniques to remind themselves to take medication, such as

cell-phone alarms, the timing of soap operas and depending on their children to remind them (Western Cape Department of Health, 2006). The study also showed that clients who have been on ART for a longer period of time have different adherence support needs compared to those commencing treatment.

4.6.2 Other Predictors of Poor Adherence

Prior the initiation of antiretroviral therapy (ART), the Department of Health in South Africa relied on particular factors to determine whether a client will be able to adhere or not. The following are predictors of poor adherence.

- Lack of trust between patient and provider;
- Active drug/alcohol use;
- Active mental illness;
- Lack of patient education;
- Inability of patient to identify medication;
- Lack of reliable health care access and
- Domestic violence

(McNicholl: 2008).

Other predictors of poor adherence were found to be being female, not knowing anyone on ART, having been tested for HIV without one's knowledge, initiating ART at very low levels of less than 200 cells/mm³, lack of knowledge regarding the positive outcomes of ART, non-disclosure of HIV status as well as sharing medication with family members and friends (Dahab, Charalambous, Karstaedt, Fielding, Hamilton, La Grange, Churchyard and Grant, 2010).

Being on traditional medicine was a predictor of poor adherence as those who consult traditional healers are likely to mix traditional and modern medication. Having been on chronic medication before could also be a predictor of poor adherence (Dahab *et al*, 2010).

Lower literacy levels are linked to poor adherence (Kalichman, Cherry & Cain, 2000). In South Africa, there are very high rates of migration which bring about instability within the family. Families are often forced to live in overcrowded conditions, levels of family violence are also very high and these factors contribute to poor adherence (Wood, Tobias & McCree, 2004).

4.7 Difficulties with Highly Active Antiretroviral Therapy (HAART)

In high-income countries, where combination ART became widely available from 1996 onwards, AIDS related mortality declined markedly in the following two to three years, and has since increased. However, provision of ART in developing countries has been limited due to a number of factors, most importantly the high costs of ARVs. For example, in Uganda in December 2002 the end-user price for one month's treatment using a Providing Antiretroviral Treatment in Southern Africa generic three-drug combination of stavudine, lamivudine and nevirapine (Triomune) was 56 520 Ugandan shillings (US\$31), whilst a combination of zidovudine and efavirenz, cost 115 200 Ugandan shillings per month (about US\$63) (International HIV/AIDS Alliance 2002a). Since per capita income in Uganda was less than US\$ 250 per annum and an estimated 35% of Ugandans lived below the poverty line of less than US\$1 per day, these treatment costs remained beyond the reach of most people (CIDA, 2004). South Africans are fortunate in that many people with HIV can afford to buy the drugs privately either through medical aids or cash.

The provision of ART has also been limited by the poorly developed health care infrastructure in many developing countries (UNAIDS, 2002). Concerns have also been raised about viral resistance developing if ARVs were to be improperly used on a wide-scale in African countries. Even where ARV services are available, fear and stigma associated with HIV and AIDS and human rights abuses of people living with HIV and AIDS have contributed to the ongoing reluctance among many people to come forward for testing and treatment (Parker & Aggleton, 2001).

As a result of these constraints, some government leaders and a variety of other AIDS and public health commentators have argued that ART could not be introduced in developing countries, and have motivated that money could be better spent on preventing new infections

(Hills-Jones and Kanabus, 2003). Until recently dominant thought held that ART would, at least for the near future, remain financially and logistically beyond the reach of most HIV-positive people living in low- and middle-income countries. An International Monetary Fund policy discussion paper evaluating the impact of HIV and AIDS on health care services in Southern Africa for example, held that “with the possible exception of Botswana and South Africa none of the countries in the region will be able to offer general access to highly active antiretroviral therapies through the public sector service.” (Haacker, 2001). The paper further argues that “the scope for alleviating the impact of HIV and AIDS on the health sector through financial aid is limited”. There are NGOs in South Africa that are funded by donors privately to provide ART, but this funding is not sustainable.

In contrast, other individuals and groups have demonstrated the potential benefits of providing ART and have argued for its provision on moral, ethical and economic grounds. The Joint Health and Treasury Task Team (2003) set up in South Africa to investigate the feasibility of providing ART through the public sector demonstrated the likely effect of provision of ARVs on AIDS-related mortality and morbidity. The Team estimated that between 2003 and 2010, assuming a 20% ARV coverage scenario, an estimated 293,000 deaths would be averted until after 2010 (Stewart, 2004). Many people on ART are able to lead normal healthy and productive lives.

4.8 Strategies to Improve Adherence

Adherence is critical in the management of HIV and AIDS. A multifaceted approach to improve adherence is the most likely to be favourable, the active participation of clients in their own treatment is also very crucial. Support groups of people living with HIV and AIDS are important, educational programmes that focus on behaviour change also play a vital role. An individualistic approach is also critical in the success of HAART (WHO, 2003a). The individual on ART is the one who will have to ultimately decide whether they are going to remain on treatment or not. Support groups can help to enhance one’s confidence and self-esteem, but the individual has to show dedication in order for ART to succeed.

Treatment Adherence is a huge responsibility for the client on ART therefore, Health Care providers need to assist clients on ART. The client's willingness to adhere is key to the success. They should also inform the clients about the possible side-effects that they may experience. It is also crucial that clients fully understand the benefits of adherence and the dangers of non-adherence. Delayed therapy could also assist in preparing clients thoroughly. Identification of potential barriers to adherence could also assist the client. A trial run of the regimen could also be done with the client. Such a trial could give clients an idea on how dosing schedules and other complexities, such as food restrictions or requirements will fit into their daily routine (WHO, 2003a).

It is also important for the Health Care Provider to work with the client to assist them to select a regimen that would be suitable for their lifestyle. The Health Care provider should also ensure that the client understands the dosing schedules and instructions. Fitting the regimen to the client's lifestyle requires working with the client to associate medication doses with routine activities performed at the times that the medication should be taken. For instance, morning activities such as brushing teeth could be associated with medication dosing (WHO, 2003). The onus rests with the individual to identify the strategy that works best for them.

It is impossible for Health Care Professionals to determine whether a client will be adherent or not. They can however assist clients to improve it. Strategies to improve patient adherence can be grouped into two categories and should be consistent with the client's lifestyle. Developing a relationship with a client as well as asking open-ended questions is critical (McNicholl, 2008). A non-judgmental attitude amongst Health care providers is critical.

4.8.1 Patient-Related Strategies to improve adherence

Clients on antiretroviral therapy need to take an active role in their own health care, by developing a healthy working relationship with Health Care Providers. They can achieve this by observing the following:

- Establish readiness to start therapy
- Provide education on medication dosing
- Review potential side effects

- Anticipate and treat side effects
- Utilize educational aids
- Engage family, friends
- Simplify regimens, dosing, and food requirements
- Utilize team approach with pharmacists, nurses, etc.
- Provide accessible, trusting health care team
- Assess literacy level
- Involve patient in regimen selection

(McNicholl, 2008).

4.8.2 The Health Care Provider strategies to improve adherence

Health Care Providers working with clients on ART can be able to assist them to adhere by observing the following:

- They establish a trusting relationship with the client.
- They need to ensure that there is on-going communication between clinic visits.
- There has to be on-going adherence monitoring.
- Respond promptly to uncomfortable or short-term illness.
- Establish street drop-in centres for homeless people.
- There should be training programmes especially designed for the youth.
- Treatment Adherence Counselling is critical and should be done before the initiation of ART.
- The Directly Observed Therapy Short-Course should be adopted.

(McNicholl, 2008).

Directly Observed Therapy Short-Course (DOTS), is a process whereby trained Home Based Carers observe TB clients taking their medication in the comfort of their homes. The same approach could be applied in ART adherence with the aid of family members, who can literally observe family members on ART taking their medication.

4.9 Side Effects

If clients experience side-effects that they view as being problematic, they may discontinue the treatment. It is important for Health Care Providers to be proactive and develop strategies to assist clients to cope with potential side-effects. Close contact should be maintained between the Health Care Provider and the client to assist them to cope with side effects, this can also assist them to identify toxicities. Giving clients positive feedback also enhances adherence. Conducting CD4 cell count and viral load tests could also help to motivate clients to adhere if their immune system improves (WHO, 2003a). It is the responsibility of Health care workers to convey such results to clients in a way that they will easily understand the implications. An undetectable viral load could be misunderstood by some as implying that they are cured.

In South African public health facilities, clients are thoroughly counselled prior to initiating antiretroviral therapy. One of the reasons for providing treatment adherence counselling is to prepare them for the side effects that they might encounter. Antiretroviral therapy is associated with a number of undesirable side effects which include the following; nausea, vomiting, diarrhoea and fatigue. Longer term side-effects are also experienced in the form of peripheral neuropathy oral numbness and lipodystrophy or fat redistribution (Chesney, Morin & Sherr, 2000). All possible side effects need to be openly discussed with a client on ART so that they do not become discouraged by prolonged or severe side effects. At one public hospital, most women on ART complained about fat redistribution and the fact that their body shapes had changed as a result of being on ART.

If clients are given an opportunity to plan and play an active role in their health care and also see themselves as partners of their medical doctors by being involved in critical decisions about their health, adherence to antiretroviral therapy (ART) is high (Sikkema & Kelly, 1996). It is expected that attitudes would improve if the individual feels that they are at liberty to decide to participate in drug therapy at their own free will and if they believe it is important to them. Health care workers need to have a positive attitude when confronted by clients regarding side effects as negative reaction could further diminish their already low-esteem.

4.10 Gender Related Issues

Research has proven that the levels of risk differ considerably between males and females, the roles and the manner in which men and women relate also play a role on whether one becomes infected or not. In certain instances, gender is also a factor in determining the level and quality of care, treatment and support that HIV-positive men and women receive. The burden of caring for the ill is taken on largely by women and so are the negative economic and social consequences of AIDS (WHO, 2003b). More efforts to empower women need to be made. Gender norms and unequal power dynamics between men and women are largely influenced by institutions of socialization such as schools, workplaces, families, and health systems.

Masculinity has an influence in how men behave and the choices that they make. In some societies in order for a man to prove that he is indeed a man, he has to engage in demeaning and abusive behaviour towards women in his life. Men who do not comply are considered feminine (VSO, 2012). The values and norms shared by a society thus have a critical role in influencing the behaviour of the members of that society.

Culture also has an influence on how people relate to men and women. Gender plays a key role in one's ability to access services, information as well as how one behaves sexually. How one copes with a positive HIV status is also influenced by gender. Most societies regard women as weaker, inferior, needy and submissive. Many societies still consider women as subordinate, dependent and passive. Their role is seen as being able to nurture, possessing high moral standards, and being able to conform and these are regarded as key qualities of perfect womanhood (WHO, 2003b). It is therefore, not a surprise that many people diagnosed HIV positive choose female family members to disclose to.

In many societies in Africa, women's primary role is still seen as that of giving birth to children and raising them. Men's role, on the other hand, is perceived to be that of earning a living and dealing with the broader and more serious issues of society on behalf of the family (UNFPA, 2000). Hence, caring for family members infected with HIV is also seen as women's responsibility. Women do not only care for sick family members, but also accompany those

who are ill to health care facilities as their treatment supporters and to collect antiretroviral therapy on their behalf.

Gender inequality within families also prevents women from accessing health facilities and treatment. Many women depend on their male partners financially and have to seek their permission before they can go to health facilities for treatment (ICW, 2004). The gender imbalance places women at a disadvantage as they cannot freely exercise their rights. Many of these women have to come up with excuses for the reason to be away from their homes, in order for them to consult at health facilities. There are those who even start treatment without informing their spouses and have to continuously hide their medication from them (Human Rights Watch, 2007). Competing priorities make it difficult for women to adhere and comply with their treatment.

Gender based violence equally poses a challenge for women with regard to ART adherence, because due to the abuse many often missed their doses (Human Rights Watch, 2007). These women feel that they would rather be non-adherent than risk their husbands finding out that they are HIV-positive. In certain instances, some men force their wives to share their antiretroviral therapy with them (Rwechungura & Kayitare, 2006). In most instances these men did not even know their HIV status. In a study by (Watt, Maman, Earp, Eng, Setel, Golin & Jacobson, 2009) it was found that once men initiated therapy they were motivated to adhere as they were bread-winners. The responsibility of caring for the family usually rests with the man within the family.

Women who are married or in stable relationships find it difficult to adhere to their treatment, as they have to cope with multiple roles (Bonolo, Ceccato, Rocha *et al*, 2013). Gender stereotypes within households exacerbate women's position in the society, because they are forced to be dependent to their male partners.

In South Africa however, women seem to be the dominant sex at public health facilities. The challenge may be that many of these women wait until it is too late before they seek medical assistance. In HIV infection this may be dangerous as controlling a very high viral load and attempting to improve a low CD 4 cell count may be a challenge and sometimes the client may not even respond well to treatment due to the severely compromised immune system.

Some women only learn about their HIV status during pregnancy as they are encouraged to enroll for the Prevention of Mother-to-Child Transmission of HIV. Research has demonstrated that women who are HIV-positive usually experience challenges that are related to gender with regard to them having access to treatment (Eckman, Huntley & Bhuyan, 2004).

The study demonstrates how social support or the lack thereof impact on treatment adherence amongst people who are on antiretroviral therapy in the Limpopo Province. Limpopo is a rural province, and women are often financially dependent on their partners. The burden of caring for the ill is also largely women's responsibility. For instance, the Home/Community Based Care programme in the Limpopo province is largely implemented by women. The study could shed some light on how these competing priorities impact on treatment adherence amongst women who are on antiretroviral therapy.

Studies that have been conducted on alcohol and ART adherence have indicated that the effects of alcohol differ between males and females. In a study conducted by Berg, Demas, Howard, Schoenbaum, Gourevitch and Amsten (2004) it was found that alcohol consumption negatively influences antiretroviral adherence in women. The negative effects of alcohol abuse are more evident in women than men, because there tends to be stigma attached to women who drink alcohol compared to men. It is therefore, important for these women to hide the fact that they drink alcohol (Berg, Demas, Howard, Schoenbaum, Gourevitch & Arnsten, 2004). Alcohol consumption may lead to forgetfulness and as a result the person who drinks whilst on ART may miss their doses.

There was poor ART adherence amongst male clients who used cocaine actively and it was found that adherence was much better amongst men and women who had decent and long-term housing. There were negative consequences regarding ART adherence amongst those who had temporary housing and homeless (Berg *et al*, 2004). There are many poor people who live in informal settlements in South Africa, and do not have access to basic services. Being in a support group of people living with HIV was found to promote adherence and those who experienced side effects were likely to be non-adherent (Berg *et al*, 2004). HIV and AIDS services need to be extended to accommodate vulnerable groups and health care providers also need to be empowered to care for these groups (Tapp, Milloy, Kerr, Zhang,

Guillemi, Hogg, Montaner & Wood, 2011). Support groups of people living with HIV need to be prioritised as they provide people on ART with the support they need and encourage adherence.

4.11 Social and Provider Support

Researchers have constantly revealed the fact that in order for clients to adhere there has to be social support (Simoni, Frick & Huang, 2006). Social support for adherence is the moral support and continuous encouragement of a client on ART, by family members and friends. The relationship between the health care professional and the client has also been associated with adherence (Johnson *et al*, 2007).

As Comprehensive Care, Management and Treatment of HIV (CCMT) programmes are expanded; investments must be made to simultaneously expand intensive and interactive counselling models that address risks, such as the heightened exposure to partner violence, related to disclosure of HIV status. Effective counselling is also critical to help maintain adherence, face stigma, identify and link people to referral and support services as well as to build overall community support. Recent studies show that uptake and adherence levels are lower in communities where these issues were not proactively addressed. Treatment uptake and adherence are higher in those settings, such as in Brazil and Khayelitsha, South Africa, where intensive counselling and the involvement of people living with HIV and AIDS in community mobilization have helped overcome barriers to uptake and adherence to treatment (WHO, 2004b). In South Africa, the role played by people living with HIV and AIDS is noticeable. Organizations of people living with HIV and AIDS, such as the Treatment Action Campaign (TAC) and the National Association of People living with HIV and AIDS (NAPWA) are constantly interacting with the government in ensuring that the rights of people living with HIV and AIDS are respected and protected.

With regard to the cultural and physical constraints that are imposed on women and men, women are more affected than men. Prevention strategies such as counselling as well as treatment, care and support need to be incorporated. Health systems also need to be capacitated to deal with the high demand of ART (WHO, 2004b). Couple counselling needs to be encouraged amongst married people and those who have sexual partners.

Antiretroviral therapy (ART) provision in Khayelitsha started in 2001, and the Western Cape Province has adopted the patient-centred adherence support model. This model encourages individual patient's comprehension and accountability for their therapy (Western Cape Department of Health, 2006). The role played by the individual regarding their own health care is of paramount importance.

Many people living with HIV are concerned about the well-being of their loved ones, being concerned about family members led to stress. Others were worried about how community members would treat their children once they realized that they were HIV positive (Adedimeji, Alawode & Odutolu, 2010).

In a study that was conducted in Tanzania, it was found that respondents who felt that they were not receiving the necessary support from their family members stopped taking their treatment even in situations where their health was improving (USAID, 2010).

4.11.1 Individual Support

The Western Cape Department of Health has identified several strategies to enhance individual support. Individual counselling visits for treatment preparedness have been structured and standardized. All clients undergo a minimum of three counselling sessions so as to prepare them, before the initiation of therapy. Clients are also required to identify a treatment supporter (Western Cape Department of Health, 2006). This approach was not found to be useful at some health facilities in the Mopani District as clients would at times bring in strangers claiming that they were related to them. As a result having a treatment supporter prior to initiating ART is no longer a prerequisite.

In Khayelitsha, South Africa everyone who enrolls for antiretroviral therapy is required to identify a treatment supporter. Lay counsellors trained and placed at public health facilities assist clients on ART with developing individual treatment plans (University of Cape Town and Western Cape Provincial government, 2003). People on antiretroviral therapy have social and spiritual needs as well as biomedical needs. Comprehensive counselling and support groups are essential in this regard. In some instances, some need spiritual support from a pastor of a particular church (Hope & Israel, 2007).

4.11.2 Peer Support

Owing to the fact that the number of clients on ART is increasing, ensuring that there is regular attendance at support groups has become challenging. Clients on ART have different needs and aspirations depending on the duration on treatment. Support groups of people on ART were also divided accordingly. Clients are divided according to the number of months that they have been on ART. In certain instances, support groups of caregivers of children on ART are provided (Western Cape Department of Health, 2006). Dividing support group members according to their age groups could also be ideal, at the Letaba Regional Hospital there was a 66 year old woman who alleged that she was not welcome into the support group as the members felt that she was too old. People are similarly more comfortable with interacting with people of their own age groups or those that they feel share similar characteristics and values.

In the Umzimkhulu area, support was sought from family, friends and neighbours. It was found that the same sources were also crucial in Paarl, however, female clients at this site pointed out at institutional support in the form of NGOs, hospitals and government grants as other sources of support. Support groups of people living with HIV and AIDS are easily accessible and were important in providing both social and psychological support. It was however discouraging to find that these kind of support groups were almost non-existent in the Umzimkhulu area. Other social support interventions that existed in Paarl included the Mothers-to-Mothers programme, church support groups and the Treatment Action Campaign, and these do not exist in the Umzimkhulu site (Norman, Chopra & Kadiyala, 2005). Lack of standardization in delivering HIV and AIDS service is a common and widespread challenge in South Africa. Uniformity and consistence would help to ensure that all people in communities receive similar and equal care and support.

4.11.3 Material Support

Many clients on ART consider pill boxes to be effective. The Western Cape Provincial government has taken over the provision of pill-boxes in 2005. Treatment identification charts have been updated as regimens and formulations have changed (Western Cape Department of Health, 2006). Antiretroviral therapy is a life-long commitment, the use of devices to remind

clients to take their medication is now very common. It is the responsibility of each client on ART to use whatever device or strategy works for them so as to prevent resistance.

HIV and AIDS has become a social calamity for Africa, especially in Sub-Saharan Africa. HIV and AIDS turn children into orphans, women to widows and weaken the breadwinner. In addition to its appalling human consequences, it weakens societies, destroys productive forces, reduces life expectancy, and demolishes social structures (UNAIDS, 2002; Oluwagbemiga, 2007). South Africa has been hardest hit by the epidemic, and as a result many South African families have family members who are infected with HIV. Most of the respondents in this particular study indicated that they had the experience of caring for an HIV infected relative and some had more than one HIV positive family member.

More research needs to be done on the socio-economics consequences of HIV and AIDS. It has however, been revealed that the pandemic places a heavy burden on women and children as well as family members who have to care for orphaned children. By killing productive adults who are the key family providers, HIV and AIDS shatters social networks that provide households with community help and support. Survivors are left with few relatives upon whom to depend. The consequences of modernization and present day economic realities have eroded this traditional safety net for many Africans. The support of the extended family kinships no longer exists in many countries, as more families have become individualistic (Oluwagbemiga, 2007). The Comprehensive Care Management and Treatment of HIV (CCMT) programme in South Africa, relies heavily on the support of family members. Family members act as treatment supporters of those who are on antiretroviral therapy within the family. This approach works out well as there is trust amongst family members.

A body of social science literature has indicated that non-compliance to medical care is not an irrational behaviour, and is not solely related to the client's individual responsibilities, but that their interactions with the health care professionals and the social environment also play a vital role (Moatti, Souteyrand, Sandfort & Aggleton, 2000). Hence, this study identified and assessed the effectiveness of support structures available to people on anti-retroviral therapy.

Formally integrating support partners into the intervention helps to address many other common adherence barriers. It has been proven that family and friends can play a pivotal role in ART adherence. Enlisting the assistance of support partners is a practical and economical approach to adherence counselling (Davies, Koenig, Stratford, Palmore, Bush, Golde, Malatino & Todd-Turner, 2006). The Comprehensive Care, Management and Treatment of HIV (CCMT) programme in South Africa recommends that the client should have disclosed their HIV status to at least a friend, family member or a member of the support group.

4.12 The Importance of Disclosure

An unpublished study in Soweto found that the relationship between disclosure and adherence were not so clear, it was however demonstrated that a positive attitude and socializing had an influence on adherence. Higher treatment literacy was considered a good predictor of higher adherence, that perception of treatment efficacy was important, that side-effects were generally well managed and did not impact on adherence and that improved quality of health led to improved quality of life. The conclusion drawn was that clients needed to play an active role in their own treatment and communicate with health care professionals. It was therefore, crucial to ensure that the treatment was built-into one's lifestyle and that working together with community organizations was of vital importance (Brouard, 2005). Antiretroviral therapy comes with many challenges that may be difficult for a client to deal with on their own. Informing other people that the client trusts is important so that they offer their support.

The magnitude of the HIV and AIDS epidemic in the Sub-Saharan Africa region has forced various governments to respond to the challenge. Even though the response was delayed, South Africa has developed effective prevention and treatment strategies, as the country has more than 6 million people who are estimated to be living with HIV (UNAIDS, 2012a). It is the responsibility of Health care workers and lay counsellors to empower those who are diagnosed HIV positive with skills to be able to disclose their HIV conditions.

Behaviour change is very crucial when dealing with HIV and AIDS. As one of the prevention programmes the Voluntary Counselling and Testing Programme, has proven to be effective in encouraging people to change their behaviour (Norman *et al*, 2005). During counselling clients are asked questions about their sexual history and counsellors help them to develop risk reduction plans and encouraged to refrain from engaging in risky sexual behaviours. Those that test HIV negative are encouraged to stay negative and those that test HIV positive are provided with the support they need through continuous counselling and treatment to ensure that they live longer and healthier lives.

Disclosure of one's HIV status is also critical in ensuring that one obtains the necessary treatment, care and support that they need. In order for ART to be effective it is very crucial that people on treatment should get support to enable them to adhere to the medication. Due to the fear of being identified as people who are HIV positive some clients have reported that they had rather skip their doses than risk being seen taking ART (Chesney & Smith, 1999). In order to access various programmes and services that are offered it is critical for HIV positive clients to disclose their HIV status (Norman *et al*, 2005). Assertive clients on antiretroviral therapy seem to cope much better with taking their medication, than those who have a very low self-esteem.

Disclosure of HIV status is very challenging as it exposes one to stigma and discrimination (Praxton, 2002). The aim of disclosure should be to get support, therefore clients need to disclose to people who will support them to ensure continuity of care (Norman *et al*, 2005). The environment in which one chooses to disclose needs to be conducive to enable them to obtain the desired outcome.

In a study that was conducted in Paarl in the Western Cape and Umzimkhulu in the Eastern Cape it was found that, the source of support for most of the participants were family members. Disclosing to their family members enabled clients to lead normal and productive and less disrupted lives. Female family members were found to be very supportive (Norman *et al*, 2005).

HIV Counselling and Testing (HCT) emphasize the fact that clients need to disclose to their sexual partners. Disclosure has a number of benefits which include, provision of support from family members, easy access to services and medication, improved opportunities to discuss and implement a risk-reduction plan with partners. There are, however, also possible risk factors in disclosing one's HIV status. These may include, loss of financial support, blame, rejection, physical and emotional abuse, discrimination and the family setting may also be disrupted (WHO, 2004b). It is therefore essential not to lose sight of the benefits and positive reaction that one may obtain by disclosing their HIV status.

Studies done in both developed and developing countries found that the rates of disclosure differ, in that people in developed countries were more likely to disclose to their sexual partners than people in developing countries. It is however encouraging to learn that in both settings the rates of disclosure increased with time (WHO, 2004b). Disclosure therefore, encourages people on antiretroviral therapy (ART) to adhere to treatment.

Currently, many people who are HIV positive are not aware of the kind of services that they need and are available to them. Prevention of new HIV infections is critical and therefore important that people living with HIV disclose their HIV status to their partners so as to prevent new HIV infections. The World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) also emphasize the importance of disclosure to sexual partners in their protocols for HIV testing and counselling (Meddley, Garcia-Moreno, McGill & Maman, 2004). Disclosure of one's HIV status to a sexual partner or partners will prevent infection or re-infection. This is dependent on a multiplicity of factors such as partners' knowledge and understanding of HIV and AIDS provision of support and knowledge of one's HIV and AIDS status.

There are many benefits in disclosing one's HIV status, not only for the individual but for the community as well. The community will be encouraged to be supportive of those who are infected and stigma and discrimination will be eliminated. Many women believe that disclosure of HIV status to sexual partners reduces anxiety and encourages social support (Meddley *et al*, 2004). Open and honest communication between the couple is very important.

Studies conducted in Kenya and Zambia indicates that many women's relationships with their male partners improved after disclosure (USAID/Synergy, 2003). It would therefore be advisable for people to disclose to their sexual partners as evidence indicates that there are benefits in doing so.

It is believed that disclosing one's HIV status improves access to HIV prevention and treatment programmes, it also enables people living with HIV to reduce the risk and to plan appropriately for the future. Disclosure of HIV status also increases the awareness of HIV risk to sexual partners who have not yet been tested for HIV and thus has the potential to increase the counselling and testing uptake and can also lead to behavior change (Meddley *et al*, 2004).

Disclosure of HIV status to sexual partners depends on the type of relationship one has. Disclosure patterns would differ amongst sero-discordant, sero-concordant and couples whose HIV status was not known (Mlambo & Peltzer, 2011). Many people who are on antiretroviral therapy and choose to disclose their HIV status, do so as a result of feeling responsible for the health and well-being of their sexual partners (Klitzman & Bayer, 2003). Thus, empowerment of people on antiretroviral therapy is critical as it enables them to act responsibly. Mlambo and Peltzer (2011) in a study that was conducted in Mpumalanga found that a major challenge with regard to disclosure amongst sero-discordant and sero-concordant couples was that some would decide to end the relationship after disclosure or support each other with adhering and complying with treatment.

Research indicates that risky behaviours change radically when both partners are aware of their HIV status. Disclosure also helps in preventing unwanted or unplanned pregnancies amongst women who are HIV positive. There are however, disadvantages in disclosing one's HIV status more especially for women in that this may lead to the loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships (Issiaka, Cartoux , Ky-Zerbo, Tiendrebeogo, Meda & Dabis, 2001).

These risks may lead women to choose not to share their HIV test results with their friends, family and sexual partners. This, in turn, leads to lost opportunities for the prevention of new infections and for the ability of these women to access appropriate treatment, care and

support services where they are available (Meddley *et al*, 2004). It is vital to indicate that women are not the ones who are reluctant to disclose their HIV status. This study revealed that there are incidents of men who even after their partners had offered their support, would choose to go for counselling and testing alone and if diagnosed HIV positive would take antiretroviral therapy secretly.

Many people are uncomfortable and unwilling to disclose their HIV status as they are afraid of being abandoned, rejected, stigmatized and discriminated. They may face violent reaction, hurting family members and allegations of unfaithfulness (Simoni, Mason, Marks, Ruiz, Reed & Richardson, 1995). With regard to males the disinclination of disclosure to sexual partners may be due to guilt and fear of being blamed for infecting them with HIV.

A study conducted by Antelman, Smith, Kaaya, Mbwambo, Msamanga and Hunter (2001) amongst HIV positive women who were pregnant found that women were not likely to disclose their HIV status to their sexual partners if they were not married, were financially dependent on their partners, were on a contraceptive and receiving support from a family member. Non-disclosure is a challenge as it prevents one from adopting safer sex practices and if one partner is on antiretroviral therapy, this may lead to resistance to their partner. This may limit the partner's options in future regarding antiretroviral therapy.

4.13 Traditional Medicine and the Effect on ART

According to the World Health Organization (WHO) traditional medicines include various health practices, approaches, knowledge and beliefs incorporating plant, animal and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness (Ritcher, 2003). Traditional medicine is thus practiced all over the world to treat various ailments.

There are two groups of traditional healers, those that are considered diviners and those that are seen as healers. The diviner employs divine means to make a diagnosis. The herbalist selects and implements relevant medicines. The continent and indeed the universe are changing rapidly due to modernization. The AIDS epidemic forms part of the modernization

powers as it continuously defies and transforms traditional healers' roles and practices (Ritcher, 2003). Traditional healers have been known to have the experience of treating and healing certain diseases, but with regard to HIV there is not yet a cure and thus some encourage their clients to adhere to antiretroviral therapy (Mall, 2008). Fostering good working relations between traditional healers and western doctors is of utmost importance as dispelling myths and preventing confusion is important.

However, lay counsellors in some health facilities were found to be totally against traditional medicine regarding HIV and AIDS care. They openly support the roll out of ART that is monitored by health care professionals and do not see the role of traditional healers in this regard (Mall, 2008). The government' stance in the role of traditional healers regarding HIV and AIDS need to be properly communicated to all stakeholders to ensure coherence.

The majority of South Africans consult traditional health practitioners on a regular basis for health problems and diseases. These practitioners utilise traditional methodologies that stretch back thousands of years. Often the traditional health practitioner is the first port of call for someone sick with HIV or AIDS (Department of Health, 2003). Many people infected with HIV are pressurised by family members to consult traditional healers (Mall, 2008). Illness can be interpreted to be a result of the anger of the ancestors (Abdool Karim, 1994). Therefore, in order to appease the ancestors, families feel obliged to consult traditional healers so that they can receive advice on the necessary steps to take. The person who is ill usually does not have a choice, as rebelling may lead to isolation by family members.

According to the National Department of Health (NDOH) an operational plan for comprehensive HIV and AIDS care and treatment in South Africa must acknowledge traditional medicine as an important modality of treatment for HIV and AIDS a modality that patients are free to choose, and to discuss with biomedical health practitioners without fear of stigma and being ostracised (Department of Health, 2003). People on antiretroviral therapy need to be empowered with information on both traditional and modern medicine to enable them to make informed choices regarding their treatment.

The Traditional Healers Organisation (THO) is the largest traditional healer umbrella organisation in South Africa and was established in 1970. It has 69 000 traditional healers in Southern Africa as members, with 25 000 of those living in South Africa. Traditional healers who intend to join the THO have to attend a one-day workshop, which introduces them to THO activities and a five-day workshop on traditional primary health care. Members also have to produce a good character reference. At the moment the THO has provincial branches in Mpumalanga, Limpopo, KwaZulu-Natal and the North West province, while the head office is located in Johannesburg. The South African Traditional Healers Health Care Group is another example of an umbrella body of traditional healers. It has a number of branches over South Africa, and focus specifically on home-based care, Direct Observation Treatment (DOT) support for people with TB, HIV Counselling and Testing, education on HIV and AIDS and 'street counselling' (Ritcher, 2003). The traditional view of the causes of TB is different from HIV and AIDS, TB is an older illness than HIV and people suffering from TB tend to seek traditional advice as they believe that the disease is caused by poison and yet they also receive TB medication from the health facility. Client advocates indicated that there were no drug interactions between traditional medicine and western medicine and as a result when the clients' health started improving they would believe that it was due to the traditional medicine (Mall, 2008). Collaboration between traditional and western medicine needs to be widely encouraged.

Traditional health practitioners can enhance the implementation of the ART component of this plan by mobilising communities, drawing patients into testing programmes, promoting adherence to drug regimens, monitoring side effects, establishing good working relationships with modern doctors, and continuing their acknowledged mission in improving patient well-being and quality of life (Department of Health, 2003). In a study conducted by Amzat and Abdullahi (2008) it was found that in many developing countries around the world, traditional medicine is widely used due to its accessibility, acceptability and affordability. There are also more traditional healers than modern or western doctors. In South Africa, the CCMT programme relies heavily on the support of medical doctors and this poses challenges since there is a shortage of medical doctors at public health facilities.

People living with HIV in Senegal use herbal medicine in treating their condition, they also have regular meetings with other people who are also infected to care and share experiences. This practice has proven to have positive effects on them psychologically (Amzat & Abdullahi, 2008). Positive living is a concept that is widely practiced in South Africa. People living with HIV are encouraged to care for themselves holistically by adhering to their medication, exercising, attending counselling sessions, attending support group meeting, adopting a healthy diet and avoid alcohol and smoking cigarettes or drugs.

Contrary to the findings of the above-mentioned study regarding the use of traditional medicine amongst people living with HIV, in another study conducted by (Mall, 2008) in the KwaZulu-Natal province of South Africa, it was found that most respondents indicated that they did not believe in traditional healing. Respondents pointed to the value and norms that have been instilled in them during their up-bringing and for some it was discouraged by their churches and yet some felt traditional healers could not be trusted as they were only interested in making money.

Traditional medicine is very popular amongst African people, thus when the ubhejane was introduced in KwaZulu-Natal, the then Minister of Health Dr Manto Tshabalala Msimang and the Health MEC in KwaZulu-Natal did not hesitate to support and encourage its use amongst people infected with HIV. The efficacy of the medication has however not been proven. AIDS activists were also concerned that the government's support for ubhejane could hinder the smooth roll-out of ARVs. Both the former president, Mr Thabo Mbeki and the former Health Minister Dr Manto Tshabalala Msimang were widely criticized for their reluctance and denialist approach when dealing with HIV and AIDS. Some clients on ART have been reported saying that they would prefer taking traditional medicine as ARV's are a life-long commitment, and that ubhejane would be more tolerable as it stems from their culture. The Deputy Dean of the University of KwaZulu-Natal's School of Medicine, Professor Nceba Gqaleni indicated that there is still not enough information on the effects of traditional medicine on ARVs, some studies however indicate that there are interactions in some instances (Reuters Foundation, 2006). The involvement of traditional healers in health issues and the treatment of HIV in particular remain crucial.

There is a stigma and shame associated with consulting traditional healers, more especially amongst more affluent people as a result many professionals who consult diviners choose to do so at night when they may not be recognized by other people. Amongst the less affluent communities, this practice is accepted and encouraged. Seeking services at health facilities was believed to result in disclosure of HIV status and that led to stigmatization (Mall, 2008).

Complementary and alternative therapy is very popular amongst people infected with HIV and is believed to offer a more holistic approach to their health (Campbell & Robertson, 2013). Some NGOs and institutions have realized that traditional healers can play a critical role in the provision of counselling services as well as support, and have initiated counselling training programmes for traditional healers. One such NGO in the Limpopo province is Takalani Nana Home Care Centre, an organization for people living with HIV and AIDS.

The WHO estimates that up to 80% of the population in Africa access traditional medicine. The Department of Health estimates that there are 200 000 traditional healers active in South Africa and that 97% of people living with HIV and AIDS (PLHAs) first sought out traditional or complementary medicine and only then seek the help of a biomedical doctor if the ailment persists. It is evident that traditional healers and traditional medicine play an influential role in the lives of African people and have the potential to serve as crucial components of a comprehensive health care strategy (Ritcher, 2003). Traditional healers may not however claim that they have a cure for HIV and need to be open and honest to their clients about this. One client indicated that he used traditional medicine successfully to treat asthma symptoms and had not mixed traditional medicine with ART since he initiated the therapy and another client who had experienced infertility problems was assisted by traditional medicine, but had also not used it since she started taking ART (Mall, 2008).

4.14 The World View within the Shangaan Culture

Ethnic people's languages, philosophies and world views should be taken into consideration when conducting a sociological study, as it is through these constructs that people make sense of themselves and their world (Mkhize, 2004). The Shangaan people originate from the Southern Mozambique, but there is also a large group of Shangaan speaking people in

the Mopani District of the Limpopo province. Most of the Shangaan people consider themselves Christians, either being Catholic or Protestant (Joubert-Wallis, 2008).

According to Niehaus and Johnson (2005), the HIV and AIDS prevalence is very high within the lowveld area where the Shangaans reside. There is also a lot of secrecy, denial and suspicion around the disease (Sanders & West, 2003). This view is confirmed by the latest HIV sero-prevalence survey statistics.

Identity is the established social and cultural rules through which we derive knowledge and experience about ourselves (Hook, 2007). The Shangaan people have faith in their ancestors. This faith has an effect on how people respond to illness and other social ills. Many of them consult traditional healers and sangomas when the need arises and it is believed that Shangaan healers are empowered by alien spirits (Niehaus, 2002). However, as more people become educated there is also a realization that some diseases can only be effectively treated with western medicine.

4.15 Self-Efficacy

Self-efficacy is our conviction in our ability to succeed in particular circumstances. Our sense of self-efficacy can play a major role in how we approach goals, tasks and challenges. The concept of self-efficacy lies at the center of Bandura's social cognitive theory which emphasizes the role of observational learning and social experience in the development of personality. According to Bandura's theory, people who have high self-efficacy are more likely to look at difficult tasks as something to be mastered rather than something to be circumvented (Bandura, 1994). Adherence self-efficacy is considered to be one of the key factors that are linked to ART adherence. Self-efficacy is an important component in many theoretical models of health behavior (Johnson *et al*, 2007). The significance of the role played by the individual in their own health care can never be overemphasized.

Self-efficacy has also been associated with improved levels of adherence. Instructions for clients, such as the presentation of oral and printed material such as visual aids may assist in clarifying the information to clients. Greater involvement of clients in their care is very crucial. Encouraging clients to use reminders in the form of special pill packaging, medication charts

and appointment reminders are some of the aids that can be utilized in enhancing adherence. Providing clients with incentives such as rewards could also encourage them to adhere. The number of visits to health care facilities could be reduced. Clients who have a greater level of confidence in being able to carry out the health professional's instructions are more likely to succeed in antiretroviral therapy than those who are not (Kagee, 2006). Self-awareness is very essential in this regard.

4.16 People Living with HIV and AIDS (PLHA) Self-Empowerment

Studies on HIV and AIDS have shown that people living with HIV are actively involved in the comprehensive response to the epidemic. People living with HIV are taking the lead in prevention, treatment, care and support, advocacy, programme management, addressing stigma and discrimination and policy-making (Kober & Van Damme, 2006).

This present state is the result of a self-empowerment process that began with the establishment of the first association of PLHA. Globally, an international network of people living with HIV was initially formed in 1986, and later became the Global Network of People Living with HIV and AIDS (GNP+). On the African continent the first PLHA association, The AIDS Support Organisation (TASO) was established in Uganda in 1987. Today most countries have at least one PLHA association, and the majority of HIV and AIDS programmes in low-income countries are run with some kind of involvement of PLHA (Kober & Van Damme, 2006). People living with HIV and AIDS are experts when it comes to dealing with the disease and living positively with HIV and have become “responsibilised” in playing an active role in their own health care (Robins, 2005).

The principle of the ‘Greater Involvement of People Living with HIV and AIDS’ (GIPA) was formally acknowledged at the 1994 Paris AIDS Summit, and in 2001, the United Nations Declaration of Commitment on HIV and AIDS endorsed the GIPA principle. The WHO, in the guiding principles of their ‘3 by 5’ initiative, advances the critical role that People Living with HIV and AIDS have to play. The Initiative clearly places the needs and involvement of people living with HIV and AIDS at the centre of all of its programming (Kober & Van Damme, 2006). In South Africa organizations such as the Treatment Action Campaign (TAC), have treatment

literacy programmes whereby people on antiretroviral therapy are trained to enable them to take their medication properly.

The majority of programmes providing care and treatment of HIV and AIDS, including ARVs, involve PLHA in some way or another. Habitually PLHA are directly linked to the treatment site as some of them are on ARVs, which means they belong to its HIV-positive patient pool and have volunteered to become actively involved in the continuum of HIV care which is often referred to as 'peer support'. The most common tasks of PLHA have to do with treatment adherence support. The MSF project in Khayelitsha, for example, has several peer support groups differentiated according to the duration of treatment of its members. The TAC is also very active in the promotion of treatment literacy (Kober & Van Damme, 2006).

4.17 Socio-Economic Factors

Literature constantly shows that demographic characteristics are not strong predictors of adherence. Age may influence adherence. Studies have found that apart from the most elderly adherence increases with age. In two studies associated with HAART, adherence showed a positive correlation with younger age (Nakiyemba *et al*, 2004). This study aims to confirm or dispute this claim. Peer pressure faced by adolescents poses a challenge, as they do not want to be different from their peers and will often reject medication such as antiretroviral therapy (ART), for the fear of being ridiculed and stigmatized (Heyer & Ogunbanjo, 2006).

Illiteracy has a negative effect on treatment adherence, whereas being knowledgeable and literate has been found to have a positive effect on adherence. Literature reveals that clients earning higher salaries have less difficulty with adherence. However, poverty is an increasing feature of the face of HIV especially in the Third World where many people are living below the poverty line (Nakiyemba, Kwasa & Akurut, 2004). This study found that the illiterate and less educated were more likely to comply with their clinic appointments and adhere to their medication compared to the literate and educated. The more affluent clients are more concerned about upholding their societal image, hence many professionals choose to be treated privately than going to public health facilities. In South Africa, many people rely on

social grants provided by the government to make a living. There is a disability grant for people living with HIV whose CD 4 cell count is below 200.

HIV and AIDS is also a systematic condition because it impacts most heavily on the most productive sectors of African economies, namely productive adults. Thus, HIV and AIDS deprive these economies of scarce skills, children of their parents, and a continent of a generation in the prime of their working lives. The general response to the epidemic has concentrated on the need to decrease the level of HIV prevalence within African societies. This has imposed the imperative of targeting interventions aimed at changing individual behaviour (Commission on HIV and AIDS and Governance in Africa, 2000).

Current evidence indicates that older men are infecting younger women, who then go on to infect their partners, particularly through marriage. HIV and AIDS are destroying the very fabric of everyday life on the continent, and these have been found to have intense implications for social and economic development (Commission on HIV and AIDS and Governance in Africa, 2000). The South African government has introduced the life orientation programme through the National Department of Education. Through this programme learners are educated on the importance of prevention of HIV. Gender dynamics should also be entrenched in these lessons to empower young women with skills to protect themselves against older men's advances.

The full impact of the HIV and AIDS pandemic is mostly felt amongst families and communities. One such outcome is AIDS related poverty among households. Across the African continent, the most vulnerable people are the most economically active. As these active people die, families are struggling to cope not just emotionally, but also economically. Poverty is increasing as bread-winners die and scarce savings are utilized in the period of ill health. Children are also left orphaned and by killing mainly young adults, AIDS seriously weakens a country's tax base, and reduces its stability to finance public expenditures, including those aimed at accumulating human capital, such as education and health services not related to AIDS (Commission on HIV and AIDS and Governance in Africa, 2000). As demonstrated above, there is a very strong relationship between socio-economic factors and antiretroviral therapy. Factors such as age, literacy and poverty play a critical role.

Inequities continue across race, gender, geographical area and rural-urban sector. South Africa is rated as a middle income country. Distribution of income is highly inequitable. Inequality of income distribution between race groups is widespread. Poverty has strong gender elements in South Africa, with female-headed households having a poverty rate 50% higher than male-headed households. Poverty in rural communities is not as evident as poverty in urban communities.

According to government estimates, 72% of the poor live in rural areas, where the poverty rate reaches 71%. Household incomes are linked to the security and quality of employment and there is wide disparity in South Africa. Levels of unemployment show a discrepancy between provinces and are especially high in Limpopo, the Free State and KwaZulu-Natal. South Africa has one of the most progressive Constitutions in the world. Every South African has access to free primary health care. In practice, there are extensive inequities in the quality of health care. The greatest healthcare inequities are between the public and private sector. Within the public sector, inequity continues between and within provinces (Ntuli, Ijumba, McCoy, Padarath & Berthiaume, 2003). Those who have the means prefer private health facilities to public health facilities due to the inferior service provided at these facilities. The poor do not have a choice but to accept that inferior service. It is envisaged that the National Health Insurance (NHI) being introduced by the Minister of Health, Dr Aaron Motsoaledi will help to bridge this gap.

In rural communities, families may have to travel long distances to health facilities and these facilities also lack resources, such as ambulances. Health care workers have inadequate transport for conducting community outreach. Some of the health facilities in rural areas also experience regular electricity interruption, telephone disconnections and water shortages. Provincial discrepancies are essentially organized in nature, resulting from diverse allocation of resources during the apartheid era. Some of the nine provinces incorporate a number of academic complexes, which contribute to health services being provided to multitudes (Ntuli *et al*, 2003). If the Government is to curb the spread of HIV, continuous education to communities is essential. Telephone disconnections mean that Health Care Workers will not be able to contact clients on ART to monitor their progress. Few health facilities alleged that they were not able to follow-up on clients as the department of health had terminated their cell-phone services.

4.18 Financial Issues

South Africa has the highest number of people living with HIV and AIDS in the world. The country has assumed its responsibility in financing the response. Improving financing for the global response will require on-going efforts to mobilize domestic resources among countries that appear to be under-investing in the HIV response. Other interventions include, increasing the efficient use of funds for HIV and other related health and development programmes and increasing external aid in global environment of constrained resources (UNAIDS Global report, 2010). Donor funding needs to be used appropriately by those tasked with managing the funds as mismanagement of funds is likely to discourage donors from investing their funds. Many NGOs in South Africa depend on donor funding for them to be able to sustain their services. Financial empowerment of these organizations is crucial.

4.19 Cultural Issues Affecting ART Uptake and Adherence

According to the study conducted in Zambia, it was found that limited transport, gravel roads and paths, poverty stricken children, high number of people living with HIV and little employment for both men and women, contribute to poor treatment adherence (Grant, 2004).

The affirmation the African and Western worldviews and healing systems are separate and self-restrained entities has been challenged, as has the presupposition that western culture is rational and scientific while African culture is irrational and spiritual (Kagee, 2006).

It has been observed that current HIV prevention and treatment programmes are founded on perceptions of independence, decision-making, self-concept and assertiveness rather than the social circumstance of people (Mlungwana, 2001).

Many South Africans consult traditional healers who usually attend to the needs of many South African patients. Their treatment often includes an invocation of spirits in countering the patient's illness. In a traditional African conceptualization of health and illness, disease may be considered a supernatural phenomenon linked to a supreme deity, ancestral spirits, living persons, animals, plants and other objects (Kale, 1995).

4.20 Witchcraft and HIV and AIDS

Many incidents of sudden death in African countries are often associated with witchcraft. In South Africa witchcraft refers to the manipulation by mischievous individuals of powers inherent in persons and spiritual entities to cause destruction to others. In a study that was conducted in Soweto, South Africa, it was found that many people associated AIDS symptoms with “isidliso” poisoning (Ashforth, 2002). Those who may be infected with HIV waste valuable time searching for witches who are responsible for their illness.

According to Stadler (2012), in a study conducted in Bushbuckridge, people there made a very clear distinction between witchcraft and AIDS. One young man indicated that AIDS was more powerful than witchcraft and some people in that community felt that AIDS had replaced witchcraft. Unlike in the past where many people would be quick to associate illness with witchcraft this is no longer the case. In this particular study however, there were three respondents who indicated that when they were first diagnosed with HIV they suspected witchcraft and some even made efforts to determine who the witches were.

4.21 Stigma and Discrimination

Stigma is the idea that individuals or groups who do not fit the social norm can be subjected to negative discrimination or even violence. It is often based on misperceptions and it implies that those who are stigmatized threaten society. Sex workers, men who have sex with men, injecting drug users and others are subject to stigma because their behaviour is often seen as unacceptable. Others, such as undocumented migrants, are marginalized on economic or cultural grounds. These groups – precisely because they are marginalized and difficult to reach with appropriate prevention messages – are often more vulnerable to HIV and less likely to receive ART (Panos, 2006). Marginalized groups are not the only ones who are subjected to stigma and discrimination, even ordinary members of the community suffer from this human right violation.

Stigma and discrimination have been identified as the major obstacles to effective HIV prevention, as well as the delivery of treatment, care and support (Parker & Birdsall, 2005). Stigma may occur at the individual level, but is also exacerbated by social processes related

to assumptions, stereotypes, generalizations and labelling of people as belonging into a certain category based on who they choose to associate with (Parker & Birdsall, 2005). Stigmas associated with AIDS also breed inequalities with regard to class, race and gender (Parker & Aggleton, 2003).

HIV and AIDS-related stigma stems partly from the mistaken belief that the disease can be contracted casually and partly from the rejection of people associated with the disease. It fosters wrong assumptions, such as the idea that all women who are HIV-positive contracted the disease from having many sexual partners. The consequences of HIV and AIDS-related stigma can be appalling. People have been attacked, some fatally, because they were open about the fact that they were living with the virus. Women have lost their homes because their husbands have often wrongly accused them of bringing the virus into the home. Companies have fired or refused to hire people with HIV. Religious congregations have rejected people with HIV and villages expelled those (Panos, 2006). The South African Constitution Act 108 of 1996 and other legislative measures such as the Labour Relations Act 66 of 1995 protect ordinary citizens and employees from discrimination due to their HIV status.

Stigma strikes even the family, where people most need support, it affects adherence, as people living with HIV and AIDS are reluctant to take their drugs at a time or place where others might see them. Marginalised groups need particular attention. Injecting drug users, sex workers and others may be inhibited from seeking ART by legal sanctions as well as stigma (Panos, 2006). Families also need education on HIV and AIDS and support from NGOs.

Some of those who are living with HIV feel comfortable to disclose their HIV status to their fellow support group members and would even go to the extent of attending support group meetings and enroll for treatment at health facilities where they would not be recognized (Adedimeji, Alawode & Odutolu, 2010). Many people living with HIV take major steps to conceal their HIV positive status, as they fear being stigmatized and discriminated.

4.21.1 Internal and external stigma

Stigma manifests itself in various ways, such as internally or externally. People living with HIV can experience internalized stigma and can confront a massive and excruciating personal struggle. They may eventually stop to be who they were, instead becoming an entity an “ill person,” something in which the human being and illness have completely intertwined. The combination of external and internal intimidation of the self may inflict a heavy burden (Rankin, Brennan, Schell, Laviwa & Rankin, 2005).

The need to access a clinic or treatment area distant from or separate from other treatment areas was in itself a form of stigma (Monger, 2011). It is therefore, important to draw the distinction between internal and external stigma as their implications differ.

4.21.2 External stigma

External stigma refers to the actual experience of discrimination and stigma. It often originates from fear and perceptions of people infected with HIV as immoral or filthy (Masindi, 2004). As a result, people living with HIV suffer rejection and avoidance by family, friends, colleagues and faith communities. Stigma affects people from various backgrounds. The general perception is that HIV and AIDS is a disease of the poor, women and Africans. Women are usually the first ones to find out about their HIV status as they attend public health services. The impact of HIV is more evident in poor communities as these people have limited choices with regard to accessing health care services. Those who can afford to buy antiretroviral drugs are able to hide their HIV-positive status, by seeking health care at private health facilities (Masindi, 2004). The victim of external stigma has very little control over how people will respond to him or her, as their actions are often guided by their misconceptions.

4.21.3 Internal stigma

Internal stigma is also known as felt, imagined, or self-stigma. This is the result of the internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with being HIV-positive. Internalized stigma does not only affect people who are HIV positive, but also their family members and other care givers who may be associated with an infected

person. Internal stigma can have an intense effect on HIV prevention (USAID, 2006). This situation is exacerbated by the fact that people in the community tend to discriminate not only against the person who is infected by also against family members and other people who are associated with the infected person.

Secondary stigma may result in lack of support for people living with HIV. The situation also affects those who work with infected and affected groups and may discourage professionals and volunteers and make their work more challenging and traumatic (Herek, Cogan, Gillis & Glunt, 1998). In South Africa secondary stigma is more evident amongst Home-based carers, as they wear uniform that is easily recognizable. For instance in the Mopani District when people in the community see Home-based carers wearing red T-shirts going into a particular home they already conclude that there is a person infected with HIV in that home.

Internal stigma is innately linked with external stigma, as the fear of judgment or discrimination from others can profoundly influence the way in which people living with HIV view themselves and cope with their HIV status (USAID, 2006). This may manifest itself by an individual isolating themselves from other people.

Internalized stigma associated with HIV and AIDS have very negative effects for people who are infected with HIV as they may be discouraged from seeking treatment and care services (Chesney & Smith, 1999). Even in instances where treatment is available free of charge, people may be reluctant to access such services.

Previous experiences of being humiliated and blamed can lead to internal stigma. Research findings indicate that many people who experience high levels of stigma do so in the context of recent diagnosis, have families who are less accepting of their illness and generally have not been exposed to support groups of people living with HIV and know few people who are also infected. They may also have concerns about infecting other people (Lee, Kochman & Sikkema, 2002). Being accepted is thus crucial for people diagnosed HIV positive, hence health care providers need to constantly strive to connect such people with relevant social structures such as support groups of people living with HIV.

Isolation may promote internalized stigma, because the individual may not have supportive networks that may be encouraging and can help boost their self-esteem. In a study conducted in the United States of America, it was found that internal stigma was responsible for high levels of depression, anxiety and hopelessness in people living with HIV (Lee, Kochman & Sikkema, 2002). In extreme cases people suffering from stigma can even resort to committing suicide due to desperation.

Internal stigma is very destructive, in that the infected individual may also blame themselves for the cruel experiences that they may be exposed to. People may even stop exercising their right to have access to health care (Herek *et al*, 1998). It is therefore appropriate to conclude that; internal stigma is also responsible for people's reluctance to be tested for HIV, thereby continuing to spread the epidemic.

4.21.4 Stigma within the family

Many people in developing countries receive care and support from their immediate family members (Warwick, Bharat, Castro, Garcia, Leshabari, Singhanetra-Renard & Aggleton, 1998). Unfortunately, not all family members would be supportive of the person who is infected with HIV, some experience stigma from their own homes, females are likely to be severely ill-treated than males (Bharat & Aggleton, 1999). HIV and AIDS related stigma and discrimination also extends to family members of the infected person (Parker & Aggleton, 2002). Even if the family members are supportive, the fear of being stigmatized and discriminated may prevent them from disclosing the individual's HIV status outside the home (Parker & Aggleton, 2002). Some family members are even treatment supporters of the person who is on antiretroviral therapy, but usually provide such support privately.

Many people living with HIV depend on their families for care and support. Negative reactions by family members are very widespread. People infected with HIV are often stigmatized and discriminated against within their own homes. Women are ill-treated the most compared to men and children. Many women carry the guilt on HIV by being held responsible and thrown out from their homes and may be suspected of being morally loose. HIV and AIDS stigma is also extended to family members. People affected by HIV are socially segregated (Parker & Aggleton, 2002). The HIV epidemic has fuelled women's oppression, in that even if it was a

male who infected them with HIV they are the ones who usually carry the blame and shame associated with having HIV.

4.21.5 Stigma in the community

These days immense emphasis is placed on individualism and therefore contracting HIV may be viewed as personal irresponsibility. Certain societies place more focus on collectivism and thus HIV may be regarded as bringing disgrace to the family or the community. In some instances, HIV may be seen as a result of being morally wrong and this may reinforce underlying stigma of those whose behaviour is considered to be unusual. People living with HIV are often rejected or gossiped about and in some intense cases, it has taken the form of violent behaviour (Parker & Aggleton, 2002). The irony here is that usually, those who discriminate against people infected with HIV may be unknowingly living with HIV themselves.

A South African study revealed that the communities had the tendency to discriminate against people who had lost weight, experienced hair loss, had a cough, had sores in the body, or those who demonstrated some changes (Policy project, 2003). At the beginning of the epidemic, community members in some countries in Africa would refer to HIV as “the slimming disease”. Thus, those who were seen to have lost weight were labelled as HIV positive.

4.21.6 Stigma within the religious sector

Faith Based Organizations (FBOs) play a critical role in fighting the HIV and AIDS epidemic. Pastors within the church educate their members about the meaning of HIV and AIDS, when community members realize that their church leaders take HIV seriously they are likely to make an effort to understand the disease as well (Parker & Birdsall, 2005). It is therefore very important for pastors not to underestimate the level of influence that they have over their church members and communities.

Religious leaders reinforce stigma and discrimination within the religious sector. They use their power and influence to maintain the equilibrium rather than challenge the negative attitudes (Policy project, 2003). Church leaders need to openly talk about HIV within their

churches so as to educate other people about the importance of supporting those who are infected with HIV and assist those who are not infected to prevent HIV. The study revealed that many people who are diagnosed HIV positive view the church as their place of refuge, some even go to the extent of affiliating with churches that are believed to be more spiritual after being diagnosed HIV positive.

4.21.7 Stigma and discrimination within the workplace

Some employers practice pre-employment testing amongst their employees. They also deny employing people living with HIV and they are often stigmatized. There have been reports of employees who refuse to work with colleagues who are infected (Policy project, 2003). South Africa has one of the most progressive Constitutions in the world and has passed legislative frameworks that are supportive of people infected with HIV, such as the Employment Equity Act (EEA).

Refusal to appoint people living with HIV and AIDS, termination of their employment once it is discovered that they are infected with HIV and stigmatization of people who live openly with HIV are very common practices in some communities (Gostin & Lazzarini, 1997). Many people, who are discriminated against within the workplace because of their positive HIV status, are afraid to challenge their employer as they would like to keep their HIV status confidential. Even in situations where the employer provides HIV counselling and testing and antiretroviral therapy within the workplace, many would still not feel comfortable to access such services because of stigma and discrimination.

4.21.8 Stigma within the Health Care System

Many people in the Health Care system have been counselled and tested without their consent. Confidentiality is also not maintained and some clients are denied treatment. Some health care workers disclose the status of their clients to their partners without their consent (Policy project, 2003). Lack of confidentiality amongst health care workers may deter the public from accessing health care services. Health care workers and lay counsellors therefore need to uphold the code of ethics of their professions.

Stigma is frequently encountered in healthcare. Treatment and other forms of care may be delayed or denied or inappropriate treatment given. Clients may be tested without consent and discharged prematurely. Confidentiality may be breached and medical staff may behave inappropriately, shouting or being rude, by intentionally disclosing the HIV status of a client. Stigma can be overcome, as large-scale treatment programmes have a snowball effect. The more people come forward for treatment, the less they feel stigmatised and the more likely others are to come forward for testing (Panos, 2006). If people observe their acquaintances' health improving as a result of antiretroviral therapy, they also become motivated.

The fear of stigma makes people at risk of contracting HIV reluctant to seek counselling and testing and people living with the virus less likely to seek ART. It can affect adherence, people may be reluctant to visit treatment centres or take ARVs regularly if they think others will become aware of what they are doing (Panos, 2006). Comprehensive programmes are needed which advocate and promote appropriate prevention and treatment for these and other vulnerable groups.

4.21.9 Stigma and Discrimination and Antiretroviral Therapy Programmes

Stigma and discrimination have negative effects on diagnosis and treatment options. An individual may delay to access HIV counselling and testing and thereby delay to access antiretroviral therapy and there will be no motivation for the individual to change their risky sexual behaviours (Skinner & Mfecane, 2004). HIV counselling and testing is an entry to treatment, care and support. If an individual is unaware of his or her HIV status they are likely to transmit the virus to their sexual partners or acquaintances.

There will be no motivation to be counselled and tested if the client feels that they will be discriminated (Abdool Karim, Tarantola, Sy & Moodie, 1992). For some people they would rather remain unaware of their HIV status and risk transmitting the virus to other people than be discriminated.

HIV stigma and discrimination are therefore, barriers to HIV prevention and provision of treatment programmes (Mahajan, Sayles, Patel, Remien, Sawires, Ortiz, Szekeres & Coates, 2008). People are not only prevented from knowing their HIV status, but they are also

prevented from accessing life-saving drugs. In some instances, clients have demonstrated to be more concerned and scared of the stigma, than of the disease itself, therefore even if treatment would be available, they would still be afraid to access it (Lie & Biswalo, 1994). Stigma and discrimination have very negative implications for HIV and AIDS programmes and need to be addressed promptly to prevent more HIV infections and unnecessary deaths.

4.22 Resistance to ART

According to Chopra (2006), the stakes are very high for the ART programme. The government is not being able to meet the demands and there is also pressure to meet the Millennium Development Goals (MDGs) and National Strategic Plan (NSP) targets. The challenges could lead to clients resorting to mono-therapy, dual-therapy regimens or intermittent and interrupted treatment being common, particularly in rural communities. When all these predicaments are combined with poor treatment compliance and adherence, they could easily lead to ART resistance. The price for the first line of treatment has declined, however, prices for the second and third line treatment continue to be very high. Health Care providers may face a challenge that could result in them developing perpendicular systems that focus on the provision of treatment. Hence, quality would be compromised.

There are many factors that trigger the occurrence of resistance to various anti-retroviral agents in HIV. First, HIV progresses quickly because it mutates and replicates very fast. Second, virus multiplicity is controlled by selective pressures that include the need to evade the host immune system response and by exposure to anti-retroviral agents. The key fact is that the evolution rate is proportional to the replication rate. Intense virus suppression is attainable due to highly active antiretroviral therapy (HAART regimens slow or may prevent emergence of resistance, which allows durable virus suppression (low or undetectable viral load) and can lead to immunologic recovery (increased CD4 cell count) (McNicholl, 2008).

4.23 The Impact of ART

In a study conducted in Zambia on cultural issues affecting ART uptake and adherence, it was found that many people had decided that they wanted to be on ART regardless of the risks that were involved. It was also found that what persuaded most people to initiate

therapy was that they saw other people doing well. What was interesting in this study was that, it was not the education or the information but the modeled success in other people's lives that made the difference (Grant, 2005). Continuous education on HIV and antiretroviral therapy is of utmost importance. Encouraging those who are on treatment to share their experiences needs to be promoted as they can act as positive role models and motivate other people.

4.24 Support Groups

“A support group is a structure/meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning – emotional, spiritual, physical and psychological – and to share information, knowledge, ideas and experiences. Members of the group are bound by group norms, goals and objectives as agreed upon by the group” (Department of Health, 2000b). In the Isubilo project in Zambia, clients had the alternative of joining a “closed support group” of about 10 people. During support group meetings, the members are empowered in various ways. The group receives education, emotion and spiritual support and practical advice. At the end of 10 weeks group members can decide to move to the open group. This is a large group of people who have openly disclosed their HIV status. Support group members are encouraged and motivated in various ways, such as being provided with a small plot to grow vegetables. Those who cannot afford to buy seeds are given (Grant, 2005). In the Limpopo Province support groups of people living with HIV and AIDS are initiated by HIV counsellors in health facilities and supported by NGOs. There is however, a need to revive these groups as most of them are no longer functional.

4.25 The Role of NGOs in ART Provision

Since the year 2000, various “operational research” projects, primarily exploring the integration of HAART with existing public sector services, were conducted at different levels of care within the public sector and in different provinces of South Africa. An endeavour was made, through the Generic Antiretroviral Procurement Project (GARPP) to advance access to HAART through the co-ordinated procurement of generic ARV drugs of good quality, at the

lowest possible cost, for use in quality HAART projects in South Africa (Ijumba, Gamielldien, Meyer & Morroni, 2004).

According to the Senior Manager of HIV and AIDS, STIs and TB within the Department of Health in the Limpopo Province (2011), the Department has contracted nine NGOs to implement the HIV Counselling and Testing Programme. The programme ensures that lay counsellors are trained comprehensively so as to enable them to provide quality care to clients. The lay counsellors also provide Treatment Adherence Counselling to clients, to enable them to adhere to their treatment. The Department of Health is also working very closely with NGOs that are funded for providing HAART to the public.

4.26 The Role of Religion in the Management of HIV in South Africa

South Africa is a democratic country which is very passionate about human rights protection and fulfillment. Institutions such as the Medicines Control Council (MCC), protects the general public from impostors and fakes and they act as janitors of medications and remedies that are to be registered or licensed. It is therefore very important to protect clients from harmful medications and exploitation (Spiro, 1997).

Christians and Faith Based Organizations are preoccupied with prevention, cure and care and support of those who are already infected with HIV (Ryan, 2003). Responses of prevention include debates and programmes to use condoms addressing socio-economic conditions under which HIV and AIDS flourish. Care and support does not only focus on infected adults but also on orphans (Cochrane, 2006).

In a study conducted with 210 people, Landman found that 80% of the respondents related stories of having been healed by a church, 60% of the respondents believed that HIV was caused by Satan and more than 90% believed that God can cure HIV (Landman, 2009).

Farm ministries including the Hoedspruit Farm Ministries often place the health of their followers at risk by prohibiting condoms and supporting gender practices that oppress women. Similar claims of being able to cure HIV occur in other religions such as Islam, Khalifah Mokhooa from Durban claimed that she could cure HIV and AIDS (Landman, 2009).

Faith-Based responses to HIV and AIDS should intervene socially and culturally as they play a pivotal role in relation to HIV and AIDS epidemic. Earlier on in the epidemic, FBOs constituted part of the problem rather than the solution. Faith-Based Organizations have been criticized for their delayed responses, failure to acknowledge the scope and extent of the implications of an epidemic, for moralizing and judging people, stances that have contributed to silence and secrecy. The association of HIV infection with immoral behavior and the failure to openly discuss the root causes underpinning HIV transmission have contributed to stigmatization and discrimination of people living with HIV within the church. In South Africa, a review of FBOs found that FBOs that had AIDS activities at local level predominantly worked with people living with HIV and AIDS, orphans and vulnerable children (Cochrane, 2006).

Faith-Based Organizations (FBOs) promote values of compassion, tolerance and care for the needy, they are embedded within communities and understand local needs and conditions, and they have long histories of providing health care and other social services in poor and underdeveloped areas (Health Development Networks, 2001).

In 2003 a review on HIV and AIDS in faith-based organizations was conducted in South Africa. The review included interviews and focus group discussions with both Christians and Muslim religious leaders and identified a number of practical issues and challenges which remain barriers to reducing stigma and discrimination within religious communities, which included views of human sexuality as sinful, inadequate training of religious leaders on the basics of HIV and AIDS and failure to incorporate issues related to HIV and AIDS into theological training and curricula (Policy Project, 2003).

Faith-Based Organizations have been involved with AIDS-related activities for a decade. However, attention to their contributions has increased in recent years as they have come to be seen as key actors in many aspects of AIDS response. Religion is relatively less important in many developed countries in comparison to developing countries where the highest HIV prevalence rates are found. Many international donors also channel their funding to FBOs in the belief that their immediacy to affected communities and relative cost-effectiveness make them logical channels for assistance (Liebowitz, 2002).

Uganda witnessed a dramatic decline in HIV prevalence in the 1990s. A broad-based social mobilization that took place in that country included the active involvement of churches and mosques as well as NGOs and government structures. Religious leaders adapted Uganda's AIDS prevention messages to their own belief systems. Pastors who could not condone or promote prevention through condom use for religious reasons focused on abstinence, partner reduction and monogamy. Religious groups also became active in care and support activities which helped to de-stigmatize the epidemic and promote inclusiveness of people living with HIV and AIDS (Liebowitz, 2002).

4.27 Summary

Social factors also play a critical role in curbing or fuelling the spread of the epidemic and need to be critically addressed not only by the government, but also various stakeholders in communities. Compliance and adherence are the core pillars of a successful treatment intervention and need to be properly understood by people on antiretroviral therapy. The South African Government's effort to provide ART to the public free of charge has made a significant difference in many people's lives. The ultimate responsibility lies with the individual to adhere to treatment and deal with factors that are likely to interfere with adherence and compliance. Health care providers also play a vital role in encouraging adherence. Many antiretroviral therapy drugs are associated with side-effects and these need to be effectively managed. Gender issues have an impact on HIV and AIDS programmes as women are usually the ones blamed for the infection, and this may lead to non-disclosure of a positive HIV status for the fear of reappraisal. Social and provider support play a vital role in promoting adherence and support groups of people on ART need to be established and strengthened. Many South Africans consult traditional healers, there has to be a sound collaboration between the department of health and traditional healers to ensure that the public does not receive mixed messages. Certain ethnic groups such as the Shangaan people are very secretive and suspicious when there is an illness within the family. Many are likely to blame witchcraft for the illness, there has to be continuous education amongst communities so as to dispel the myth associated with HIV and witchcraft.

CHAPTER 5

THEORETICAL PERSPECTIVES AND FRAMEWORK

5.1 Introduction

This study was informed by Ivan Illich's theory on "Medicalization" (1976, 1995), Self-determination theory (Deci & Ryan, 1985) and Social Capital theory according to James Coleman (1988), Robert Putnam (1995) and Pierre Bourdieu (1986).

5.2 Three concepts that will be discussed to explain Medicalization Theory Are:

- Medicalization
- Demedicalization
- Remedicalization

5.2.1 Medicalization

The term medicalization started featuring into the social scientific literature in the 1970s. The exact meaning of the term is "to make medical," it has come to have extensive and fainter meanings. The term has been used more often in the context of an assessment of medicalization or over-medicalization than as an unbiased term simply describing that something has become medical (Illich, 1995).

Medicalization is a "process whereby more and more of everyday life have come under medical dominion, influence and supervision" (Illich, 1995). Medicalization entails describing a challenging condition in medical terms, using medical language to define a problem, embracing a medical agenda to understand a problem, or using a medical mediation to "treat" it (Illich, 1995). HIV and AIDS can only be understood in medical terms as it is a medical condition.

Medicalization, refers to the process whereby market forces, both internal and external to health care, define what is appropriate for health care. Illich (1995) argued that the medical establishment posed a "threat to health" through the production of clinical, social and cultural

aspects as well as the injuries inflicted on clients by doctors. With regard to HIV and AIDS, some health care providers have been accused of making a wrong diagnosis, in instances where a client was told that they were HIV positive when this was not the case. Some HIV positive pregnant women are forced to terminate their pregnancies or forced to undergo sterilization.

Clients' role has also changed, they are no longer regarded as passive victims, but rather as equal partners who have an important role to play. Clients are now able to empower other people living with HIV and AIDS, advocate for better services, engage in vigorous debates with the government and act as change agents (Metzl & Herzig, 2007). The Treatment Action Campaign (TAC), has been playing the advocacy role for people living with HIV in South Africa, and has been instrumental in the implementation of the Comprehensive Care, Management and Treatment (CCMT) of HIV programme in South Africa.

Medicalization was discovered by philosophers such Ivan Illich (1995), he was very passionate about the empowerment of clients. Illich (1995) was also equally passionate about maintaining human dignity, enabling clients to be self-reliant and independent. He paid more attention to the marginalized and vulnerable. People living with HIV and AIDS are stigmatized and discriminated against in their communities. Adhering to antiretroviral therapy becomes challenging as those who are on ART are often reluctant to disclose their HIV status as they fear negative reaction from those around them.

According to Illich (1995) it was very crucial for individuals to be independent as he strongly believed that this enhanced freedom of the person. Illich (1995) was of the view that people were capable of taking control of their social environment and this would ensure that they claim back their independence. Illich (1995) was of the view that modern medical care is not organized to serve human health, but only itself as an institution. Modern medicine makes more people sick than it heals. Many people have become so dependent on modern medicine that they find it difficult to function without these medications. This may also be the case in situations where antiretroviral therapy causes severe and debilitating side-effects to those who are on the treatment. Some side-effects may even lead to deformity and even death.

Therefore, this study sought to determine the challenges associated with antiretroviral therapy. Support networks are critical for those on antiretroviral therapy. For instance in South Africa, in order to meet the criteria for accreditation the potential Comprehensive Care, Management and Treatment of HIV (CCMT) site needs to have a support group of people living with HIV and AIDS (Moodley, 2003).

Illich (1982) was of the view that medicalization was a historical process that disabled ordinary people from caring for themselves and makes them dependent on the provision of a service called medical care. Medicalization is a form of social degradation through which dependence on service consumption is induced. Medicalization occurs whenever some aspect of ordinary, everyday life comes to be so defined that it requires input from an institutionalized medical system. Medicalization make people lose their personal ability to cope with reality as a result of their gain in health care (Illich, 1982). With regard to HIV and AIDS, people on antiretroviral therapy are encouraged to be independent and to cope with the treatment on their own. Health care providers prepare them through comprehensive adherence counselling.

The HIV and AIDS epidemic is medicalized, in the sense that one cannot refer to the disease without medical terms. People infected with HIV become dependent on health care providers and cannot do without them. There has to be a cordial relationship between people on antiretroviral therapy and their health care providers and independence has to be encouraged.

5.2.2 Demedicalization

Demedicalization occurs when a problem does no longer exist and medication is not required to treat it (Conrad, 1992). In this instance, for people on antiretroviral therapy (ART) structured treatment interruption (STI) is introduced with the recommendation of a specialized medical practitioner.

5.2.3 Remedicalization

The concept of remedicalization has also emerged and this occurs when medication is needed to treat an illness (Conrad, 1992). People living with HIV will at a certain point need antiretroviral therapy to prolong their lives.

Antiretroviral therapy is a life-long therapy therefore the client has to take the medication for the rest of his or her life. In this way we can say that people on antiretroviral therapy are remedicalized when their immune systems can no longer cope on their own. Remedicalization in this regard is accompanied by self-care and self-efficacy as the client is empowered to adhere and comply with their treatment regimen and cope with associated challenges.

The shift from curative to preventive medicine, could be used as a rationale for more intense medical policing (Illich, 1982), the Minister of Health in South Africa is advocating for preventive health care as he believes that this approach is cost effective. There is a need to modify the health care system from being centralized and expensive to being decentralized, accessible and affordable (Illich, 1982). In order to ensure that antiretroviral therapy is easily accessible to the general public, the Department of Health has accredited primary health facilities to provide antiretroviral therapy. If alternative medicine was recognized, it would enable ordinary people to have options other than relying on Western Medicine (Illich, 1982). Research has however, proven that in managing HIV, antiretroviral therapy should not be mixed with traditional medicine as there is a danger of drug interaction.

Self-care is now promoted by many health care providers to ensure independence of their clients (Illich, 1982). During the asymptomatic stages of HIV, there is no need for antiretroviral therapy and the infected individual can care for herself or himself without consulting health care providers. This can be done by practicing positive living, through maintaining a healthy diet, exercising, avoiding stressful situations, avoiding alcohol and smoking, adopting safer sex practices and seeking support.

Community members used to take the responsibility of caring for their own health and this has since been replaced by professional health care (Illich, 1982). Illich (1975) believed that lay people have a vital role to play in caring for the sick as they often draw on their life experiences, he also pointed out however that as a result of the professional nature of health

care, lay people's role was restricted. The national and provincial departments of health in South Africa have developed the lay counsellor HIV Counselling and Testing programme. Lay counsellors are recruited, trained and placed at health facilities to provide counselling and testing and treatment adherence counselling of good quality.

According to Illich (1982), there are diseases that are preventable and need to be given priority due to their incapacitating nature, but market forces would rather focus on medical technology due to the financial gains to be made. HIV is preventable and more funds should be channeled towards educating community members about the dangers of the disease and how to prevent it. More education on adherence and compliance to antiretroviral therapy is also vital. Home based carers are playing a critical role in this regard. Directly Observed Treatment of Antiretroviral Therapy (DOTART) needs to be widely promoted. The role of home based carers has therefore changed, from that of caring for the sick, frail and dying to that of treatment supporter and knowledgeable "lay expert."

Palliative care and hospices in particular have been criticized for not being effective in managing clients who are terminally ill (Clark, 2002). At the beginning of the epidemic, the National Department of Health relied on hospices to care for those who were dying. HIV is no longer a terminal illness, but a chronic illness that can be managed through a multi-disciplinary approach. For instance, home based carers are trained to assist people on antiretroviral therapy with adhering to their medication. Home visits are conducted so as to ensure continuous support to people on antiretroviral therapy.

The effects of medicalization could be minimized by promoting health education and ensuring that there is equal access to primary health care. Community members could also be empowered to care for themselves (Illich, 1982). Self-care can be very liberating as the client does not have to be dependent on health care providers, this can also promote self-efficacy.

5.3 The following are levels of medicalization:

5.3.1 The conceptual level

At this level medical terminology is applied to understand the problem. A medical team needs to be involved (Conrad, 1992). HIV counselling and testing is conducted and a diagnosis is made. If the client has tested positive for HIV, they are referred for CD 4 and viral load tests. They are also empowered on disclosing their HIV status.

5.3.2 The Institutional level

Non-professional people may be required to perform tasks that are usually performed by professionals (Illich, 1982). In order to prepare the client for antiretroviral therapy, treatment adherence counselling is offered by lay counsellors to clients and their treatment supporters.

5.3.3 The interactional level

At this level there is close contact between the health care provider and clients and their condition is defined as medical (Illich, 1982). With regard to antiretroviral therapy, at this level monitoring and evaluation needs to be done. Side-effects are also detected and managed by medication.

Illich (1995) was of the view that the public needed to be vigilant about services offered by market forces. He also acknowledged that more people were becoming more active in their own health care. This study also sought to examine the extent to which self-efficacy can help to promote treatment adherence. The challenges around modern medicine have motivated ordinary people to be very active in their own health. In developed, and indeed developing countries, patients are now expected to take an active role in their care, and to be treated as important stakeholders in policy debates.

Regulations and licensing processes need to be thoroughly assessed so as to determine actions that are beneficial to clients and those that are harmful (Barnet, 2003). This is a view strongly shared by the Treatment Action Campaign and other organizations of people living

with HIV. The Treatment Action Campaign lodged a complaint against the Minister of Health and the National Department of Health for their reluctance in providing antiretroviral therapy to people living with HIV in South Africa. In order for antiretroviral therapy (ART) to succeed, it is crucial for clients to be empowered so that they are able to adhere to their medication.

Differentiating the sociological investigation of how knowledge is established and maintained and how knowledge is to be assessed is critical. Medicalization researchers are interested in the interpretation of definitions rather than the interpretation of a particular behaviour (Conrad, 1992).

Medicalization transpires in both normal and abnormal situations. Sociologists are interested in secularization and the changing status of the medical profession, two significant features affecting medicalization. Many authors believe that religion is no longer a leading ethical philosophy in contemporary societies as it has been replaced by medicine (Conrad, 1992). Sociologists thus have a role in identifying strategies that are employed by communities in order to care for their health.

Medicalization may have an uncertain relation to peripheral religious groups. On the other hand, medicalization has been used to oppose and counteract trends. A dominant and vital notion in sociology is social control (Conrad, 1992). Most societies develop healing styles of social control, especially when independence is highly valued. Initial investigation indicated that medical social control would possibly substitute other forms of control. While this has not transpired, it can be argued that medical social control has continued to grow.

In the context of medicalizing non-conformity, Conrad (1992) distinguished three types of medical social control: medical ideology, collaboration and technology. Medical ideology enforces a medical model primarily because of accumulated social and ideological benefits. In medical collaboration doctors assist to provide information, to take care of, to be agents of institutions and technicians, medical technology suggests the use for social control of medical technological means, especially drugs, surgery and genetic or other types of screening. Medical investigation is also a form of medical social control and suggests that certain conditions or behaviours become perceived through a “medical” observation and that physicians may justifiably lay claim to all activities concerning the condition (Conrad, 2005).

The criticism of medicalization fundamentally rests on the sociological concern with how the medical model decontextualizes social problems, and collaterally, puts them under medical control. This process individualizes what might be otherwise seen as collective social problems (Conrad, 2005). Sociologists are therefore of the view that in order to understand the root cause of medical problem the socialization processes of the individual need to be assessed.

5.4 Medicalization and HIV and AIDS

The effect of the AIDS epidemic on medicalization has not yet been thoroughly explored. The HIV and AIDS epidemic is having a devastating impact on medicine and society, it would be interesting to discover how it affects medicalization. It is also crucial to determine how HIV counselling and testing affects the expansion of medical services.

Medicalization is a new word, Illich (1982) invented it because no old word fitted the twentieth-century reality which he wanted to express. Illich (1982) invented the term to describe the historical conditions under which the iatrogenic causation of ill-health is facilitated through environmental and cultural revolutions, rather than through pharmacological, surgical, radiological or psychotherapeutic treatments.

Medicalization must be understood as an expression of a cultural pattern, not as a simple result of medical arrogance or self-indulgence. Medicalization is a form of social dilapidation through which dependence on service consumption is persuaded. Medicalization occurs whenever some aspect of ordinary, everyday life comes to be so defined that it requires input from an institutionalized medical system (Illich, 1982).

Ivan Illich was among the first philosophers to criticize the benefits of modern medical care. He was of the view that modern medicine is a nullification of health. Illich went on to point out that medicalization was not systematized to serve human health, but only itself, as an institution.

In summary, Illich (1975) was saying that medicine, and in particular the process of the professionalization and institutionalization of medicine, had removed the need for nonprofessionals to be involved in caring for those who experience ill-health, disease, pain, suffering and death, aspects of which had been defined and re-defined by the profession itself (Illich, 1982).

Ivan Illich (1976) is of the view that during the past three generations the diseases affecting Western societies have gone through intense alterations. These days many ailments can be easily treated by antibiotics (Illich, 1976). An identical observation could also be made regarding the HIV and AIDS epidemic, as many opportunistic infections can also be treated with antibiotics. Remarkable medical technology has combined with uncensored pomposity to create the impression that modern-day medicine is highly effective (Illich, 1976). In the recent past many people who would be diagnosed with HIV would consult traditional healers, but not anymore as those who are infected with HIV choose to be treated by modern medicine.

Modern medicine has always been possibly toxic and most of this medication comes with side effects and these side effects are common as the medications are also widespread (Illich, 1976). Many people on antiretroviral therapy also experience side-effects that are managed by health care providers, hence treatment adherence counselling is crucial to enable the client to be empowered with information. It has been established that a huge number of clients admitted to a research hospitals in the United States acquire an iatrogenic disease and usually requiring special treatment, many of these incidents come from diagnostic procedures. Usually hardly any action is taken against the perpetrators (Illich, 1976), this practice could easily be compared with the practice in South Africa, whereby many people rely on public health care services as they cannot afford private health care. The quality of the services offered in public health facilities are inferior compared to those offered in private health facilities. There are also many incidents of negligence by medical doctors in the public sector and the sector is also plagued by many challenges. Hence the Minister of Health, Dr Aaron Motsoaledi has introduced the National Health Insurance (NHI) which will hopefully benefit all South African citizens and enable ordinary people to have access to quality health care.

However, medical doctors are not licensed to dispense medication. The society needs to be wary of becoming prey to pharmaceutical invasion. There is a shortage of pharmacists in South African public health facilities and as a result health care workers at times are forced to dispense medication to clients, which is a prerogative of trained pharmacists. In order for the National Health Insurance programme to be successful, more pharmacists should be trained and placed at public health facilities. Health care workers prescribe antibiotics on a daily basis to clients who consult at public health facilities.

5.5 Self-Determination Theory

Self-determination theory assumes that human beings are naturally active. It is based on the notion that they have in-born tendencies toward psychological growth and development. People also strive to master on-going challenges and to integrate their experiences into a coherent sense of self (Deci & Ryan, 1985).

Self-determination theory (SDT) focuses on human development and their socialization processes within the society. The theory is also concerned with how human interactions are determined by the individuals. The theory posits a distinction between autonomous behaviours (those believed to be performed voluntarily and because of personal importance) and controlled behaviours (those that are performed due to pressure or coercion). The same notion also applies in HIV and AIDS programmes in instances where clients will be motivated to test and disclose their HIV status so that they access ART and improve their well-being. On the other hand there are those clients who will only be motivated by the need to save the life of the unborn baby. HIV positive clients are also encouraged to continue seeking counselling services even after the diagnosis to enable them to cope well with the diagnosis.

Adherence to self-care is critical in determining the success of the strategies implemented to advance health care. The most crucial challenge is compliance and adherence (Ryan, Patrick, Deci & Williams, 2008). According to the Self-determination theory, clients need to internalize values and skills in order for them to change their destructive behaviour. The theory also suggests that clients need to be given room to exercise their autonomy, competence and relatedness in health care facilities and that if instructions given by health

care providers are clear they are likely to make an impact and thus result in behaviour change (Williams, Deci & Ryan, 1998).

The theory also argues that certain factors such as rewards for good behaviour (e.g. adherence) motivate clients to follow health care providers' instructions and sanctions also play a critical role in ensuring that they comply and change behaviour accordingly (Deci & Ryan, 2000). In South Africa, some health facilities have introduced this practice of rewards and sanctions in promoting adherence to antiretroviral therapy. In instances where clients are adherent and compliant they are given two months' supply of their treatment, but those who are not adherent are closely monitored and required to make monthly visits to their health care facilities.

Relatedness is very significant as many people are likely to embrace values and behaviours encouraged by those they trust. Therefore, with regard to antiretroviral therapy, clients are likely to identify close family members as their treatment supporters as they believe that they will maintain confidentiality. People on antiretroviral therapy are also likely to open-up amongst other people who are also on antiretroviral therapy. Stigma and discrimination against people living with HIV is still rife and in order to prevent being isolated people would rather only open up about their HIV status to those that they trust and those that have a similar condition. Hence, support groups of people on antiretroviral therapy need to be encouraged and promoted.

Many models of intervention and change have suggested that the doctor-client relationship is a critical aspect of promoting change (Ryan & Deci, 2008). There has to be a good working relationship between the health care provider and the client in order for treatment adherence to be promoted. If attributes such as respect and confidentiality are demonstrated by the health care provider, the client on ART is likely to follow their instructions regarding adherence and compliance.

Adherence to antiretroviral therapy needs one to adjust their daily routine and to be prepared for the many side-effects that are associated with the treatment (Kennedy, Goggin & Nollen, 2004). It is the prerogative of the client to choose or identify times that are suitable for them, so that the treatment plan does not have to interfere with their daily schedule. In South Africa,

all clients who are eligible for antiretroviral therapy are offered treatment adherence counselling so as to prepare them regarding the possibility of experiencing side-effects.

Many people on antiretroviral therapy complain about dosing schedules and side-effects (Kennedy et al, 2004). It is thus important for health care providers to ensure that all clients are thoroughly prepared prior initiation of therapy. In some instances, certain antiretroviral therapy needs to be taken with certain food and some need to be taken with a lot of water (Chesney, Morin & Sherr, 2000). During HIV counselling and testing, positive living is discussed with clients and this comprises the nutritional aspects.

In some instances where clients experience severe side-effects, the medication is likely to cause discomfort and some clients end up discontinuing the treatment. Many clients find it difficult to adjust their life-style to accommodate their treatment regimen (Kennedy, Goggin & Nollen, 2004).

However, drug interruption should only be recommended by a trained and qualified physician. In many instances the medication is changed and many clients cope much better thereafter. Catz, Kelly, Bogart, Benotsch and McAuliffe (2000) believe that there is a very strong association between social support and adherence. In their study, half of their respondents indicated that they were not comfortable with disclosing their HIV status to other people that they did not trust. Many people who are HIV positive do not enjoy the benefits of social support as they do not disclose their HIV status (Kennedy *et al*, 2004). The fear of being rejected may deter people from disclosing their HIV status.

Clients on antiretroviral therapy need to be included in decisions regarding their treatment plan as planning an active role promotes adherence. If they feel that their views and opinions are respected by health care providers, their attitudes towards the therapy also improve (Sikkema & Kelly, 1996). Counselling is a two-way process, whereby clients are also given an opportunity to discuss their feelings.

Perceived support for clients' autonomy predicted autonomous motivation, which in turn predicted adherence to medications. Those who choose not to disclose their HIV status to people in their support network need to rely on internal motivation to adhere to treatment. Therefore, autonomous motivation becomes critical in this regard (Kennedy *et al*, 2004).

There are those clients who feel that they do not need treatment supporters as they can adhere on their own without assistance. Health care providers are also very important in promoting adherence. Due to the fact that they have not disclosed to their significant others, some clients may only have health care providers to discuss their treatment with (Kennedy *et al*, 2004). This may not always be feasible as health care providers do not interact with their clients on a daily basis. Some studies on adherence indicate that people who are in the client's support network are more likely to promote adherence if they know about the client's HIV status (Roberts & Mann, 2000). The people that the client interacts with on a regular basis are a reliable source of support than those who only interact with them occasionally, as they are able to remind the client when it is time to take their medication.

Those who are adherent are also less likely to suffer from psychological distress. Internal motivation is crucial in ART adherence because of the stigma associated with the disease (Kennedy *et al*, 2004). Antiretroviral therapy restores the immune system and enables clients to lead productive lives. Self-efficacy is also important as the client has the right to choose how they intend responding to the disease. Self-motivation plays a crucial role in this regard and adherence to antiretroviral therapy depends on the individual's psychological well-being and their belief in their own ability to adhere to their medications.

Health care providers are also sources of autonomy support, which leads to perceived competence and adherence (Kennedy *et al*, 2004). It is also the responsibility of health care workers to identify factors that may interfere with treatment adherence. Hence, proper screening of clients is crucial. Family members of the client on ART also need to be educated about the treatment so that they assist with supporting client autonomy. Other than playing the role of being a health care provider, they could also assist in implementing interventions that may directly support clients in affirming their autonomy in making decisions related to HIV treatment (Kennedy *et al*, 2004). It is for this reason amongst others that in South Africa a multi-disciplinary approach to treatment of HIV is applied. Many clients who are living with HIV or any other chronic condition do not depend solely on their health care providers, but practice self-care and take responsibility for their own health care. Client motivation is also critical in this regard.

There has to be continuous encouragement and support by other people and institutions for human beings to enable them to perform to the best of their ability. If people are praised and applauded they will be encouraged to perform effectively. However if they do not have support and are criticized and not supported they are also likely not to co-operate (Deci & Ryan, 2000). The relationship between the health care provider, both professional and non-professional is very crucial. It is therefore, important for HIV and AIDS counsellors to continuously reassure clients of the confidentiality of the counselling process so that clients develop trust and may also be able to encourage others to come forward for counselling and testing. It is also vital to reinforce the fact that disclosure should be done with the aim of attaining support.

With human beings aspects such as curiosity, vitality and being self-motivated are in-born. Human beings are naturally curious, vital and self-motivated. It is true that most people are serious about life and always seek advancement. This view therefore suggests that naturally human beings are inherently optimistic and persistent. Regardless of the social or educational background, it is also evident that in order for the human spirit to thrive, it needs to be stimulated, as it is very easy to crush it. Human beings at times also reject growth and responsibility, more especially if they feel marginalized (Deci & Ryan, 2000). The study therefore sought to examine the role that stigma and discrimination have in preventing treatment adherence.

Social contexts stimulate change both within and between individual differences. Socialization processes also enhance personal growth, resulting in people being more self-motivated, energized and integrated in some situations, domains and cultures. Much of the research guided by SDT has also examined environmental factors that act as barriers or undermine self-motivation, social functioning and personal well-being (Deci & Ryan, 2000).

Motivation involves energy, a sense of direction, being persistent and perseverance, all aspects of activation and intention. People can be motivated because they value an activity or because there is strong external coercion. Factors that motivate people to perform also vary, some may excel due to a sense of personal commitment or from fear of being judged. Therefore, the knowledge that antiretroviral therapy can help to enhance the lives of people living with HIV, can act as a motivator to adhere. Witnessing people whose health had

deteriorated before the onset of therapy regain their health, can also motivate people to adhere. The fear of rejection and being stigmatized can also motivate people on antiretroviral therapy to adhere to their treatment.

When a comparison is made between people who are genuinely motivated and those who are acting due to external factors, it is clear that the ones who are acting authentically are excited, persistent, show interest and this is manifested in improved well-being and enhanced performance (Deci & Ryan, 1991, Sheldon, Ryan, Rawsthorne & Ilardi, 1997). This confirms the notion that, adherence is behaviour and that in order for this behaviour to be realized the individual should have the intention to adhere. It is therefore, a personal choice that the individual has to make hence the researcher is of the view that antiretroviral therapy is “individualized therapy.”

Intrinsic motivation is the inborn tendency to seek out challenging situations, to extend and exercise one’s capacities, to explore and to learn (Deci & Ryan, 2000). Yet, despite the fact that humans are liberally provided with intrinsically motivated tendencies, the evidence is now clear that the maintenance and enhancements of this inherent propensity requires supportive conditions, as it can be fairly readily disrupted by various non-supportive conditions. The theory of intrinsic motivation does not concern what causes intrinsic motivation, rather, it examines the conditions that bring-forth and maintain versus suppress and weaken, this instinctive tendency. People according to cognitive evaluation theory (CET), must not only experience competence or efficacy, they must also experience theory behaviour as self-determined for intrinsic motivation to be in evidence. The term, extrinsic motivation refers to the performance of an activity in order to reach some separate result and thus, contrasts with intrinsic motivation, which refers to doing an activity for the inherent satisfaction of the activity itself (Ryan & Deci, 2000).

As social support is a reliable correlate of adherence, the study determined whether clients’ adherence improve as a result of adherence-specific social support, provided by health care workers, client-identified support partners, including family members, friends, colleagues and support groups.

The theory of Self-determination depicts a distinction between autonomous behaviours and controlled behaviours. This notion is also true for the CCMT programme, whereby we find that there are clients who will come forward voluntarily for counselling and testing so as to determine their HIV status. On the other hand there are those who will be forced by circumstances, which may include the need to save the unborn baby from being infected with HIV in case of pregnant women. Some may be motivated by the death of a husband or partner.

Ryan and Deci (2001) maintain that wellbeing is not best captured by notions of 'happiness' alone. Instead, SDT has adopted the concept of wellbeing defined as vibrant, full functioning, as a complementary approach. Autonomy is facilitated by reflective awareness, SDT stresses the role of mindfulness in self-regulation and wellness.

Self-determination theory is an 'organismic psychology' (Ryan, 1995), one of a family of holistic psychological theories including Jean Piaget and Carl Rogers, and thus assumes that people are active organisms with inherent and deeply evolved tendencies toward psychological growth and development. This active human nature is clearly evident in the phenomenon of intrinsic motivation. The natural tendency manifests from birth to seek out challenges, novelty and opportunities to learn. It is also evident in the phenomenon of internalization, or the lifespan propensity of individuals to take on and attempt to integrate the social practices and values that surround them.

Many historical and contemporary theories of motivation have treated motivation primarily as a unitary concept, focusing on the overall amount of motivation that people have for particular behaviours or activities. Self-determination Theory (SDT) began by differentiating types of motivation. The initial idea was that the type or quality of a person's motivation would be more important than the total amount of motivation for predicting many important outcomes such as psychological health and well-being, effective performance, creative problem solving, and deep or conceptual learning (Deci & Ryan, 2002).

Indeed, an abundance of research has now confirmed that the initial idea was sound. The most central distinction in SDT is between autonomous motivation and controlled motivation. Autonomous motivation comprises both intrinsic motivation and the types of extrinsic

motivation in which people have identified with an activity's value and ideally will have integrated it into their sense of self (Deci & Ryan, 2002).

When people are autonomously motivated, they experience preference, or a self-endorsement of their actions. Controlled motivation, in contrast, consists of both external regulation, in which one's behavior is a function of external contingencies of reward or punishment, and there are also regulations, in which the regulation of action has been partially internalized and is energized by factors such as an approval motive, avoidance of shame, contingent self-esteem, and ego-involvements. When people are controlled, they experience pressure to think, feel, or behave in particular ways. Both autonomous and controlled motivation, energize and direct behaviour, and they stand in contrast to being demotivated, which refers to a lack of intention and motivation (Deci & Ryan, 2002).

Self-determination Theory (SDT) has always maintained that the development of incorporated, independent functioning depends on awareness. Recently SDT researchers have begun to incorporate that idea through studies of mindfulness, defined as an open awareness and interested attention to what is happening within and around oneself (Brown & Ryan, 2003). Mindfulness has been related to independent motivation and with a variety of positive psychological and behavioural outcomes. Accordingly, promoting mindfulness or awareness has been theorized to be a central element in psychotherapy, one that allows inner exploration, reflective examination of needs and feelings, and the development of a more autonomous orientation.

Some individuals on antiretroviral therapy (ART) choose not to disclose their HIV status to all the people in their social support network. Internal or self-motivation is therefore, very critical. With regard to people on antiretroviral therapy (ART), self-efficacy has proven to be a predictor of good adherence (Mehta, Moore & Graham, 1997). In this particular study, it was revealed that trust is very important and that many people who are living with HIV decide carefully who to disclose their HIV status to before they choose the individuals.

Research outcomes on antiretroviral therapy (ART) adherence indicate that there are many factors that influence adherence. People who are very close to the individual on treatment and are aware of their condition can also play a significant role in assisting them to adhere

(Roberts & Mann, 2000). In this regard, family members and friends of people on ART can work closely with health care workers to support daily adherence. In this study, some health facilities relied on the support of family members and treatment supporters to ensure that people on ART complied with their clinic appointments. In some cases, respondents indicated that they were sometimes unable to fetch the treatment themselves due to work commitments and their family members and treatment supporters would fetch their medication on their behalf. In certain instances, the aid of social workers and home based carers is sought.

One of the requirements for a client to qualify for antiretroviral therapy (ART) in South Africa is that they should not be suffering from psychological distress such as depression. Autonomy support and autonomous motivation are important in attaining durable adherence, the effects of such support may be neutralized by the client's level of psychological distress. An individual's psychological state is crucial in determining whether one will adhere or not (Kennedy, Goggin & Nollen, 2004).

5.6 The Theory of Social Capital

“Social capital theory can be sourced to the works of three main authors- James Coleman (1988), Robert Putnam (1995) and Pierre Bourdieu (1986).” (O'Brien & O' Fathaigh, 2005: 3). Therefore, for the purposes of this study, the focus will be placed on the perspectives of the three authors.

The social capital concept is a necessary prerequisite for promoting human capital development and educational achievement. Social capital also promotes integration and exists as a set of lasting social relations, networks and associates. According to social capital theory, economic and political commitment is critical in building sustainable communities.

Social capital theory, as used by Coleman, has strong structural-functionalist roots. His work is often referred to in support of a particular kind of community. The social capital concept is presented as a necessary requirement for promoting human capital development and educational achievement (O'Brien & O' Fathaigh, 2005).

According to Coleman (1988), there are two broad categories in the depiction and clarification of social action. The first one is the sociological approach, which sees the individual in a social and cultural environment. The second one is economic approach, which is about self-interested, independent individuals seeking to fulfil their goals.

Putnam's (1995) theory of social capital also has functionalist roots, especially its focus on social integration. His point of view is that a society that functions well economically, coupled with a very high level of political commitment is the result of that society's capacity to successfully collect social capital. Social capital according to Putnam's view has three components. That is, moral obligations and norms, social values and social networks (Putnam, 1995). These forms of social capital are central to the promotion of civil communities and civil society in general.

People who are diagnosed HIV positive have a moral obligation to disclose their HIV status to their significant others including sexual partners. Those that are disclosed to need to maintain confidentiality by ensuring that they do not violate the client's right to confidentiality. Once antiretroviral therapy is initiated, it is the responsibility of the client to ensure that they adhere to treatment and join support groups of people living with HIV so that they can receive continuous support. The government has an obligation to provide ART and the community has an obligation to support and respect government programmes.

The general consensus from both Coleman and Putnam is that social capital constitutes positive social control. They are of the view that it is the family's and the community's responsibility to foster such characteristics as trust, shared information and positive norms of behaviour for everyone's mutual benefit (O'Brien & O' Fathaigh, 2005). The family is therefore viewed as the primary socialization agency. Many people who test positive for HIV turn to their families for support and often identify family members as treatment supporters.

Putnam (1993) indicated that social capital has characteristics of social organization, and these comprise trust, norms and social networks that have the ability to enhance the productivity of the society by aiding harmonized actions. Through interacting community members are able to share their beliefs and strengthen their environment. Support groups of people living with HIV enable those that are infected and on antiretroviral therapy to have a

platform where they can share their challenges and experiences of being on antiretroviral therapy with other people in similar circumstances. People infected with HIV are stigmatized and discriminated against in their communities, hence the need to promote social networks so as to strengthen the bond within the family and community. HIV can be debilitating, antiretroviral therapy enables those who are infected to recover from illness and lead productive lives and assist in building the economy of their country (Haacker, 2004). Therefore empowerment of people on antiretroviral therapy is crucial to enable them to practice self-care.

Social capital may also encourage information dissemination and learning by ensuring that those who have information share it with other people. Professionals can also conduct community mobilization campaigns so as to educate various communities (Antonio & Carmen, 2008). As more people are put of treatment, more information about antiretroviral therapy needs to be disseminated amongst community members.

The following three key theoretical concepts need to be explained in relation to Bourdieu's perspective on social capital:

- Habitus
- Capitals
- Fields

"The habitus concept is a way of explaining how social and cultural messages shape individuals' thoughts and actions." (O'Brien & O' Fathaigh, 2005: 5). The concept of capitals is subdivided into: economic, social, cultural and symbolic categories. Economic capital refers to income and other financial resources and possessions. Social capital exists as a set of enduring social relations, networks and contacts. "Cultural capital, comes in three forms- objectified, embodied and institutionalized. The objectified form is evident in such items as books, qualifications and computers. The embodied form is connected to the educated character of individuals, such as accent and learning dispositions, and the institutionalized form represents the places of learning one may attend. Symbolic capital is used by Bourdieu to explain the ways in which capitals are viewed in the social structure. The worth attached to certain books, values and/or places of learning." (O'Brien & O' Fathaigh, 2005: 5). The

second characteristic of social capital is that it is based on reciprocal cognition and recognition. This is how it acquires a symbolic character, and is transformed into symbolic capital. Bourdieu stresses that the habitus cannot be reduced to structures because it is designed as practices. It is creative and thus the reproduction of social structures is never one-to-one reproduction but extended and creative reproduction directed by the habitus (Bourdieu, 1977).

For social capital to thrive, it needs to enjoy the support of families. The family and the community are the backbone of social capital, but these have had challenging periods. The nuclear and the extended family are longer able to provide the support that they used to provide to the community (Bourdieu, 1977). Interaction between neighbors has also deteriorated due to economic hardships. If one's neighbors learn of one's HIV status they are often reluctant to interact with such an individual due to the stigma associated with HIV. Disclosure also becomes a challenge and so is adherence to antiretroviral therapy.

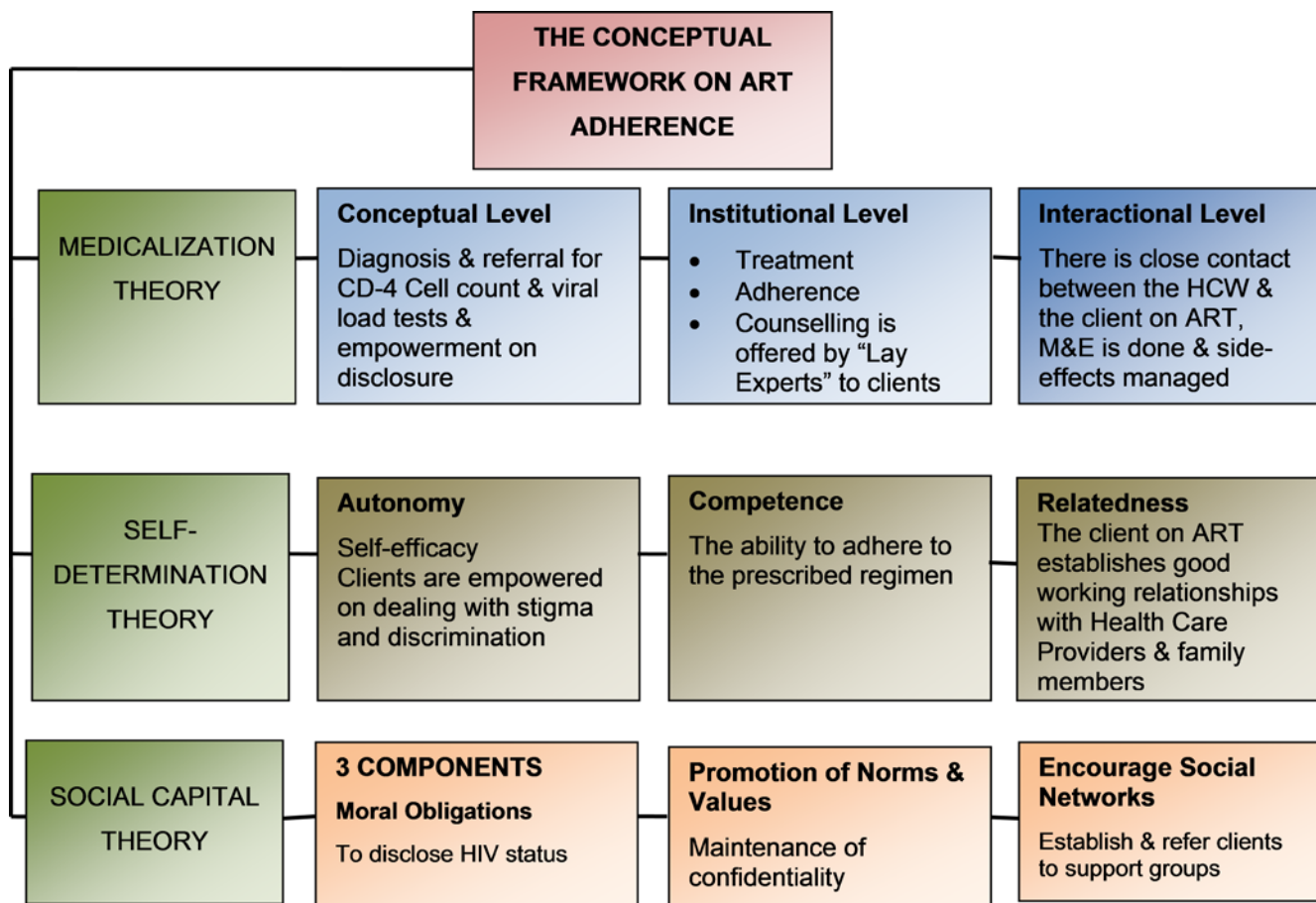
According to Putnam (1995), moral obligations and norms, social values and social networks are critical for the social capital theory. These components are also critical for the success of the CCMT programme, as the importance of confidentiality and the provision antiretroviral therapy by the government cannot be overemphasized. The government has an obligation to provide health care services and to ensure that the right to life of all the citizens of South African is respected (The Constitution, 1996).

Social capital describes circumstances in which individuals can use membership in groups and networks to secure benefits. According to Pierre Bourdieu (1986), "Social capital is an attribute of an individual in a social context." One can acquire social capital through purposeful actions and can transform social capital into conventional economic gains. Disclosure of HIV status enables the client on antiretroviral therapy to receive the necessary support. Within support groups, members are supported emotionally and materially as well.

The extent to which an individual has access to resources through social capital depends on the person's connections (whom they know, but also connections through common group membership), the strength of these connections, and the resources available to their connections. Individual choice can to some extent determine the strength and extent of

connections, although not all of these connections are subject to choice. If a client feels that they are likely not to receive support after disclosure, they are less inclined to disclose their HIV status.

The family-centred treatment adherence model was developed by incorporating the ideas outlined in the three theories that are applied in this study.



Flow Chart 1: The Development of a Family-Centred Treatment Adherence Model: The Conceptual Framework

5.7 Medicalization Theory

Clients are no longer passive and but equal partners in their own health care. They also interact with the government, advocate for better services and make valuable contributions regarding policy development (Metzl & Herzig, 2007). Professionalism is demonstrated by health care providers.

Self-reliance, self-care and self-efficacy promote adherence (Ilich, 1995). People on antiretroviral therapy are empowered with skills to deal with stigma and discrimination by their health care providers. Disclosure of HIV status is also encouraged to enable them to obtain

support. Clients benefit from their close relationship with their health care providers (Biley, 2010). Dealing with side-effects associated with antiretroviral therapy becomes easier. Adherence counselling is also offered by health care providers and confidentiality is maintained.

Illich (1982) was of the view that medical approach needed to be preventive and not curative. In this regard a multi-disciplinary approach is required and the services of “lay experts” such as home-based carers and lay counsellors are sought. Home visits need to be conducted by home-based carers as they implement the Directly-observed Treatment of antiretroviral therapy (DOTART). The implications here are that the referral system needs to be efficient. There is a need also to ensure that health care services are decentralised, accessible and affordable. The National Health Insurance programme proposed by the Minister of Health in South Africa, will enable the poor to access health care of good quality. There is also a need to promote “support seeking behaviour” amongst community members and to provide them with information on antiretroviral therapy adherence and compliance.

The three levels are:

The conceptual: disclosure of HIV status is done

Institutional: there is a working relationship between health care providers and clients

Interactional: social networks are forged to encourage support to clients on antiretroviral therapy.

5.8 Self-determination Theory

Self-determination theory focuses on human development and the socialization processes within the community. The theory points out that there are autonomous or self-directed behaviours and controlled behaviours (Deci & Ryan, 2000). Clients need to internalize certain values in order for them to modify their behaviour (Williams, Deci & Ryan, 1998). Three concepts that are critical regarding this theory is; **autonomy, competence and relatedness** (Williams et al, 1998). This suggests that clients need to be independent, self-reliant and to

be able to make their own choices, they need to adhere to treatment and cultivate healthy working relationships with their health care workers.

Rewards for good behaviour and punishment for bad behaviour could also motivate clients to adhere (Deci & Ryan, 2000). There is still stigma and discrimination associated with HIV, and those who are HIV positive would rather disclose their HIV status to people that they trust. If there is trust and respect between the client and the health care provider this would encourage adherence.

Clients on antiretroviral therapy are encouraged to live positively with HIV. Healthy nutritional practices are promoted. According to Catz *et al* (2000) there is a very strong relationship between social support and adherence. Support groups of people on antiretroviral therapy need to be established so that clients can be referred. Disclosure of HIV status is a choice and those who choose not to disclose can rely on their own internal motivation (Kennedy *et al*, 2004). Internal motivation can help clients to cope much better with stigma and discrimination. Adherence enables clients to prevent stress. Health care providers work with family members as a team to assist the client to adhere. Clients are also assisted to cope with associated side-effects.

5.9 Social Capital Theory

Social capital promotes integration and social relations, social networks and associations are established (O'Brien & O'Fathaigh, 2005). Economic development and political will are very important. The government needs to ensure that there is provision of antiretroviral therapy. The individual is as a social and cultural being. The three components of social capital, according to Putnam (1995) are:

Moral obligations: those who are infected with HIV, have the obligation to disclose their HIV status.

Norms and social values privacy and confidentiality need to be maintained.

Social networks: support structures such as support groups need to be established and be maintained to ensure support for people on antiretroviral

therapy. In a support group, members are able to share their experiences and challenges of being on antiretroviral therapy. They also assist one another to develop coping strategies that can promote adherence.

The family and community work together to promote trust, and also share information as well as norms and values. When people are diagnosed HIV positive, the first person to disclose to is usually a family member.

5.10 Summary

Medicalization, Self-determination and Social capital theories were applied. Medicalization is more concerned with the independence of the client and their ability to make informed choices regarding their health. It is thus an individual's choice to determine whether they would like to be enrolled for the ART programmes or not. Self-determination theory asserts that human beings are naturally optimistic and strive to overcome challenges that they confront in life. Clients on ART need to be conscious of all the choices that they make as these could determine the outcome of therapy. Social capital is about the social networks that people in various societies form. These social networks are crucial in providing the necessary support for those who are on ART.

CHAPTER 6

RESEARCH DESIGN AND METHODOLOGY

6.1 Introduction

The aim of this chapter is to describe the study sites, research design and methodology, explain data collection tools used and discuss the method of data analysis. Social researchers are concerned with what is going on and why it is going on as well as causal relationships between variables. In other words the studies are descriptive, exploratory or explanatory in nature. Social research requires a design or a structure before data collection or analysis can begin.

6.2 Description of the Study Site

This study was conducted at the Mopani district. A list of health facilities from the Mopani district was obtained. There are currently 131 health facilities in the Mopani district, which comprise of 6 district hospitals, 1 regional hospital, a specialized hospital, 8 community health centres, 88 clinics and 27 mobile clinics and the Private health Project which is the only NGO providing ARV's in the Mopani district. Target sampling was applied to select the health facilities.

The Mopani District is adjacent to the Kruger National Park. It is predominantly a fruit and game farming area with a large population of seasonal and migrant workers (Du Preez, 2013). The Mopani District municipality is 70 km away from Polokwane, the capital city of the Limpopo Province. The district Municipality is situated in the North-Eastern part of the Limpopo province. The district has several borders, for instance, in the east it is bordered by Mozambique, by Zimbabwe and the Vhembe District in the North, by Mpumalanga in the East and to the West by Capricorn District Municipality and in the South-West, by Sekhukhune District municipality. The district has been named Mopani because of the abundance of Mopani trees and nutritional worms found in the area (Mopani District Municipality, 2006 to 2011).

The district is located in a region where there are exceptional natural resources, including forests, Bushveld, sweeping plains and wild life. The Mopani District municipality comprises five local municipalities: Ba-Phalaborwa, Greater Giyani, Greater Tzaneen, Maruleng and Greater Letaba. The three major towns in the district are Tzaneen, Phalaborwa and Modjadjiskloof.

The mining sector in the Mopani district contributes 30% to the GDP, followed by the general government services sector (17%) and finance and business services (15%). Retail is an important secondary economic sector, especially in Giyani which serves a large rural area. Agriculture is the most important economic sector in Greater Tzaneen, Greater Giyani, Maruleng and Greater Letaba (Mopani District Municipality Profile: Cooperative Governance and Traditional Affairs, Republic of South Africa).

6.2.1 Description of the Private Health Facility

The private health facility is an HIV and AIDS educational and treatment site. Its main target groups are; workers, including foreign migrants, those in the agricultural sector, nature conservation and tourism sectors in Hoedspruit, Limpopo Province. The programme aims to reduce the HIV vulnerability through peer education, awareness raising, prevention and treatment (Du Preez, 2013).

The facility currently provides services to workers and their families at 69 sub project sites in the Hoedspruit community, as well as to a number of employees on private nature reserves adjacent to the Kruger National Park. An estimated 12 000 farm workers and their families benefit directly from the facility' services. Every month, the private health facility helps about 500 people access voluntary HIV counseling and testing services. There are 488 people who are on anti-retroviral therapy. There are three wellness clinic sites where people living with HIV and AIDS receive their treatment (Du Preez, 2013).

6.3 Research Methodology

Research methodology refers to the range of approaches used in research to gather data which are to be used as a basis for inference and interpretation, explanation and prediction (Searle, 1999). Both qualitative and quantitative approaches were employed in data collection, as both approaches tend to complement each other. In this regard, the following qualitative data collection methods were used: semi-structured in-depth interviews, focus group discussions and secondary data review. The quantitative data was collected through a questionnaire which was designed and distributed amongst seventeen (17) health care workers. A structured socio-demographic interview guide was administered to the same sample (17) for triangulation purposes.

The bulk of data for this study is based on qualitative methodologies. The reason is that the key problem for this study, namely, challenges to treatment adherence for people on anti-retroviral therapy (ART) can best be captured using qualitative methodologies.

The use of both qualitative and quantitative research methods in a study is called triangulation. There are advantages in adopting this approach and these are; it could be used to achieve advancement of conceptual frameworks, it could assist in ensuring that research was interdisciplinary and holistic. Triangulation is also aimed at intensifying and broadening one's understanding (Olsen, 2004).

6.3.1 Research Design

Research design is the structural framework or blueprint of the study (Burns & Grove, 1997). This framework guides the researcher in the planning and implementation of the study, while achieving optimal control, over the factors that influence the study. Research design deals with a logical problem and not a logistical problem (Yin, 1989). The research designs of this study were phenomenological, exploratory and descriptive.

6.3.1.1 Phenomenology

Phenomenology was founded by Edmund Husserl in 1912 and was later advanced by Alfred Schutz in 1932, the two social scientists worked together in developing the field of phenomenology. Their aim was to explain how people's conscious experience of everyday life and social interaction affect their lives. A phenomenological study describes the meaning of lived experiences regarding a particular event for several individuals (Creswell, 2007). When a researcher applies phenomenology they seek to understand the trend under study on their own terms and therefore to provide a depiction of human experiences (Bentz & Shapiro, 2001).

Phenomenology is about the participant's viewpoint of an event. The foundation of phenomenology is that there are numerous ways of interpreting the same experience. The meaning of the experience for each participant is what comprises reality. The researcher focuses on the consciousness of human experiences and needs to ignore preconceived ideas (Research Development and Administration, 2011). In this particular research, the researcher treated each respondent individually taking into consideration the fact that their experiences are different and unique.

The researcher interacted with respondents through in-depth interviews and focus group discussions. Respondents were given an opportunity to share their personal experiences of being on antiretroviral therapy. Even though the questions posed to them were the same, their responses varied in that each individual related their own experiences and understanding of antiretroviral therapy. Phenomenology is particularly keen on social relationships. Human beings are intertwined with their personal experiences and these are influenced by the environment. This method has also been used to reach a clearer comprehension of chronic illnesses. More especially, how people adjust their lives so as to cope better with the disease and lead normal lives (Terre Blanche, Durrheim & Painter, 2006). The phenomenological approach in this particular study helped us understand why certain individuals find it difficult to practice safer sex even in instances where they are aware that they are HIV positive. Amongst people on antiretroviral therapy, some internal and external factors interfere with the client's schedule in that they end up being non-adherent.

6.3.1.2 The Exploratory Research Design

Exploratory research is conducted to advance new perceptions, discern new ideas and intensify knowledge of a phenomenon (Burns & Grove, 2005). In this particular study, the researcher used the exploratory research design so as to discern new developments, ideas and develop strategies on treatment adherence. The researcher explored the experiences of clients on antiretroviral therapy through conducting in-depth interviews and focus group discussions. The insights uncovered assisted in developing a model on ART treatment adherence.

6.3.1.3 The Descriptive Research Design

Descriptive research seeks to accurately portray the characteristics of people, situations or groups (Polit & Hungler, 2004). This approach is used to describe variables rather than to test a predicted relationship between variables. In this study the researcher used the descriptive design as well. Descriptive design was used to profile respondents' demographic data. The descriptive design was also adopted for collecting data of experiences of health care providers and lay counsellors responsible for implementing the ART programme at various health facilities in the Mopani district of the Limpopo province. This approach was particularly appropriate as an accurate and authentic description was required of the experiences of health care providers and lay counsellors.

6.4 Population

A population is described as an entire group of elements, persons or objects that meet the study criteria (Denzin & Lincoln, 2005). The study population of phase I comprised of three populations. Population A, consisted of selected health facilities, population B consisted of HIV positive clients who were on antiretroviral therapy, both males and females. The researcher conducted in-depth interviews with them. Population C, comprised of HIV positive clients who were on antiretroviral therapy or being counselled on treatment adherence, the researcher conducted focus group discussions with them and the groups comprised of both males and females. Phase II consisted of population D which comprised of the health care

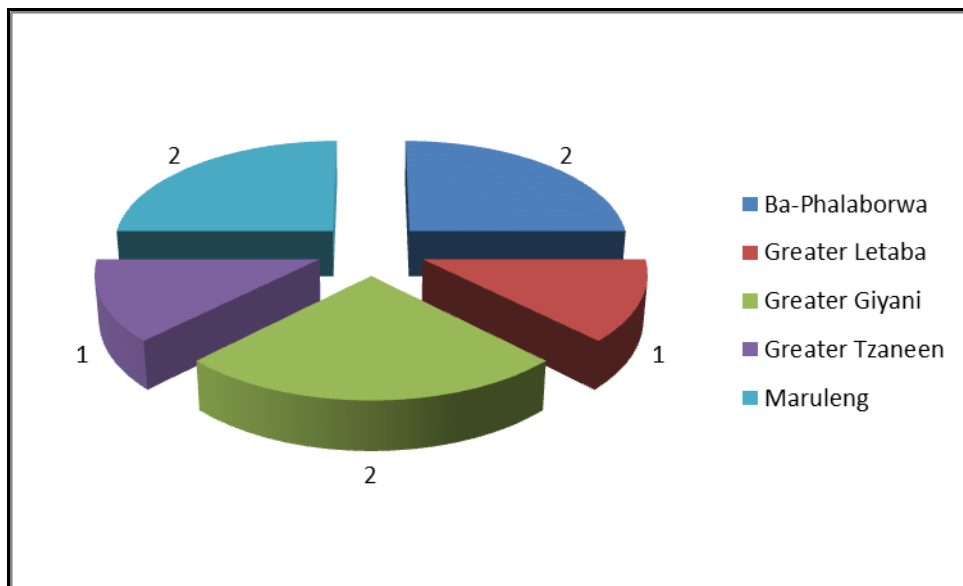
providers who are placed at ART clinics. The researcher distributed questionnaires amongst them.

6.4.1 Sampling

6.4.1.1 Sampling of health facilities: Sample A

Health facilities were selected through the target sampling method. Target sampling involves strategies to ensure that institutions or people with specific characteristics within a specific geographical area have an enhanced chance of appearing in the sample (Monette, Sullivan & DeJong, 2005).

6.5 Sampling of Health Facilities (N=8)



Pie Chart 1: Sampling of Health Facilities

As evident from the pie-chart, two (2) health facilities in the Ba-Phalaborwa local municipality were sampled, two (2) in the Greater Giyani local municipality, one (1) in the Greater Letaba local municipality, one (1) in the Greater Tzaneen local municipality and two (2) in the Maruleng local municipality.

For inclusion in the study the health facilities met the following criteria:

- Accredited by the National Department of Health as a Comprehensive, Care, Management and Treatment (CCMT) site.
- Providing antiretroviral therapy for at least a year.
- Have HIV and AIDS counsellors or lay counsellors.

6.5.1 Sampling of clients for in-depth interviews: Sample B

The objective of the study was to develop in-depth information as a result only thirty-one (31) respondents participated in this study. Purposive sampling was used to select the respondents. The sample comprised of 22 females and 9 males. The purposive sampling method was used to select respondents from a group of adults on antiretroviral therapy at selected health facilities. This method relies solely on the judgment of the researcher. The sample is made up of elements that contain similar characteristics and the characteristic is that the respondents must be on ARV treatment regardless of being a member of a support group (De Vos, Strydom & Delport, 2011). All respondents were people who have been on antiretroviral therapy for at least six months and are 18 years or older. The respondents must have been:

- HIV positive.
- On antiretroviral therapy for at least six months.
- Be 18 years of age or older.

6.5.2 Sampling of clients for focus group discussions: Sample C

Sample C was selected through convenience sampling from a group of individuals on antiretroviral therapy at a public and private health facility. These facilities have varying strategies regarding the implementation of the ART programme. The researcher intended to uncover such differences. Convenience sampling is different from purposive sampling as the expert judgment of the researcher is not used to select the sample. The primary selection criterion in this regard is the convenience or ease of obtaining the sample (Battaglia, 2011). Fourteen (14) people were selected to participate in focus group discussions. There were 9

females and 5 males and the sample was drawn from HIV positive clients registered at a public and private health facility as ART clients.

Sample C consisted of people who were HIV positive and were on antiretroviral therapy or attending treatment adherence counselling sessions. The respondents must have been:

- HIV-positive.
- On antiretroviral therapy or attending treatment adherence counselling sessions.
- Compliant with regard to clinic appointments.
- Be 18 years of age or older.

The respondents were approached through health care professionals at the eight health facilities. Both the respondents and health facilities consented to participation in the study after the researcher had submitted the ethical clearance certificate, letter of approval from the Provincial Department of Health and also took time to brief them regarding the study. A repetition of themes related to the experiences of clients on antiretroviral therapy, as in-depth interviews and focus-group discussions were conducted.

6.5.3 Sampling of health care providers and lay counsellors: Sample D

Sample D was selected through the simple random sampling method from a team of professional nurses and lay counsellors working at ART clinics at selected health facilities. Two separate lists of professional nurses and lay counsellors working at ART clinics were provided to the researcher. Each potential respondent was assigned a number and the researcher then drew her sample from these lists. Every third number was selected to participate in the study. In simple random sampling each individual case in the population has an equal chance of being selected (Jackson, 2003). It is also necessary to assign a unique number to each respondent within the population (Grinnell & Unrau, 2005). In this regard the health care providers and lay counsellors who are working at ART clinics at the selected health facilities in the Mopani district were sampled and participated in the study. There were 16 females and only 1 male in the sample.

Respondents must have been:

- Male or female health care providers who have been working in the ARV clinic for over one year.
- They should be placed at the ARV clinic.
- They can either be a professional nurse, medical doctor or lay counsellor.

Respondents were approached through their clinic managers. The researcher also introduced herself to the respondents and briefed them about what the study was all about. Seventeen (17) health care providers were selected to participate and a questionnaire was distributed amongst them.

6.6 Data Collection

The researcher sought permission from the Limpopo Provincial Department of Health's Ethics Committee, the Mopani District Manager and CEOs of health facilities that were sampled. The managers of ART sites were very helpful in identifying suitable respondents. The researcher asked for permission to address the support group members and other clients on ART, so as to explain about the study. The researcher made it a point to emphasize the fact that names and addresses will not be recorded and that confidentiality of their HIV status will be treated with the utmost respect. Each respondent was informed prior the interview that the research is conducted for academic purposes. The researcher asked questions in the local languages of the Mopani District in order to get the best responses and the respondents' maximum participation.

Semi-structured in-depth interviews were conducted with the clients on ART. An interview tool was developed and the researcher put questions across to the respondents using an interview guide. The respondents were allowed to talk freely about various aspects of the topic. All in-depth interviews were conducted at the selected health facilities. Each interview lasted for about an hour. The whole process of data collection lasted for two weeks. The researcher conducted the interviews.

Two focus group discussions were also conducted with clients on ART. Some respondents were in support groups and some were not in both groups. The researcher was seeking to determine whether being in a support group enhances one's chances of adhering to treatment. Each focus group discussion consisted of 7 clients. A focus group tool was developed in order to guide the researcher and keep the discussion focused. A consent form was designed and handed over to the participants who completed the forms and handed them back to the researcher. A demography form was also handed out to the respondents to obtain their personal details. Prior the focus group discussion (FGD) respondents were briefed on what the topics were about so that they could participate to their maximum ability. A digital audio tape was used to capture all the information and discussions. The focus group interview technique is a qualitative data collection method. Decisions on group composition should take into account gender identity, relationships and behaviour.

Existing support groups were approached to participate in the study. Smaller groups of a maximum of 8 participants appear to result in better control of the discussion, fewer distractions and side conversations and more satisfaction within the group. The focus group should be comprised of people who have similarities but not too familiar with each other. According to Kitzinger (1994), the group will function more effectively if members feel comfortable with the researcher. The researcher made it a point to explain her background and credentials so as to reinforce perception of a non-judgmental attitude and to legitimize herself.

The researcher took detailed notes during data collection, a digital tape recorder was used to capture the conversations. The researcher made it a point that she was acquainted with the use of the modern digital recorder prior the data collection process. It is the responsibility of the researcher to transcribe the data so as to ensure that confidentiality is maintained. Transcription can be extremely time-consuming, but it is necessary (Bless, Higson-Smith & Sithole, 2013). Transcription refers to the process of reproducing spoken words that may be from audiotapes of an interview into written text. Other authors have also pointed out that non-verbal communication should also be incorporated into transcribed text (MacLean, Meyer & Estable, 2004). Verbatim transcription occurs in instances where the researcher reproduces communicated information word-for-word and the written words are exactly as the

recorded information (Poland, 1995). In order to ensure that confidentiality was maintained, the researcher replaced the names of the respondents with codes.

During in-depth interviews and focus group discussions, field notes were taken so as to back up data from both data collection methods. Field-notes are gnomonic, shorthand reconstructions of events, observations and conversations that took place in the field (Van Maanen, 1988). The researcher made it a point to capture all vital information such as the respondents' behaviour, the way they responded to questions and any other incidents that took place during data collection.

A register of HIV-positive clients at each health facility was used with the health facility's permission to help back up findings from focus group discussions and in-depth interviews. Review of clients' records helped to determine the level of treatment adherence and to gather clinical data of clients. Clinical data such as CD 4 cell count and viral loads levels was reviewed and analyzed so as to determine adherence or non-adherence.

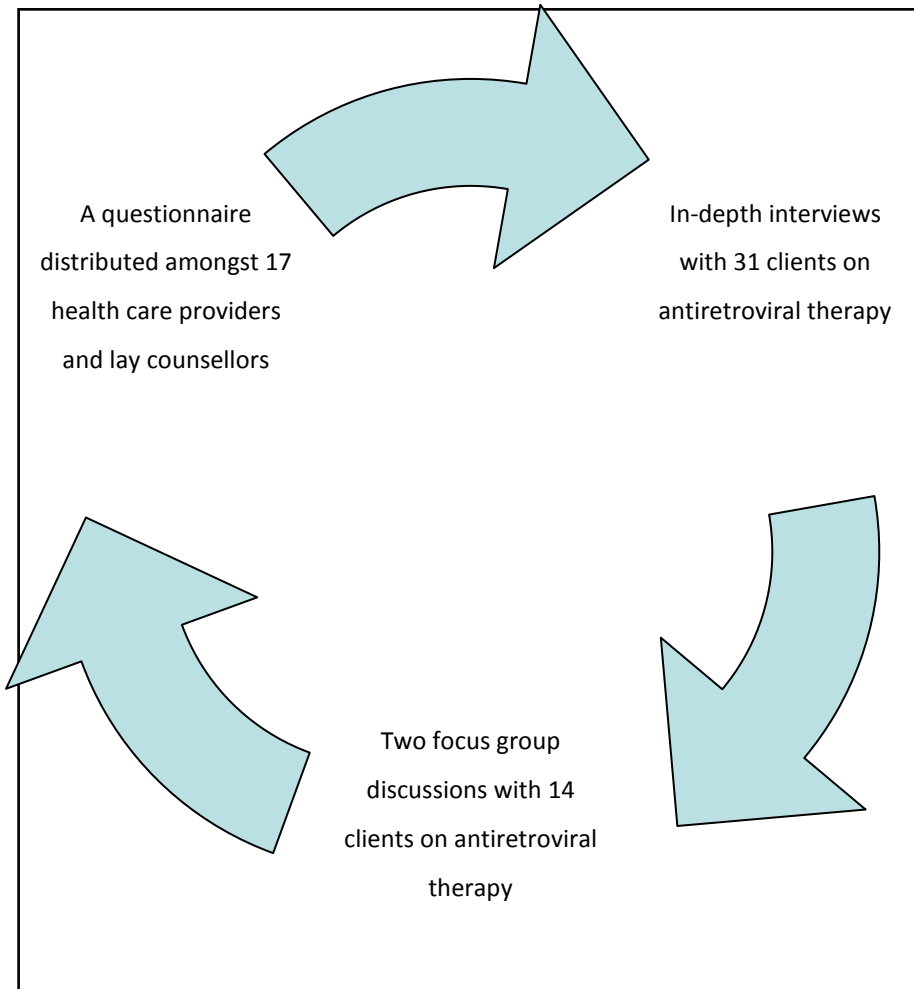
Demographic variables such as age, race, marital status, employment status, religious background, knowledge on HIV and AIDS and ARVs, attitudes, perceptions, socio-economic background, and level of adherence was collected (See annexure E: Questionnaire).

This phase seeks to discuss the procedure followed in collecting data from the health care providers and lay counsellors. Quantitative research can be defined as a type of educational research in which the researcher is in control and chooses what to study. The researcher asks specific and narrow questions to the respondents and the information collected is quantifiable, analysis is done through statistics and the study is objective and unbiased (Targett, 2012).

Questionnaires were presented to seventeen (17) Health Care Professionals and lay counsellors who are responsible for administering antiretroviral therapy. The aim of the questionnaires was to afford them the opportunity to indicate their assessment of the clients' adherence levels over the previous year and also to elicit their views on the principal barriers to treatment adherence. The advantage of using a questionnaire is that, responses are gathered in a consistent way and questions are more objective (Milne, 2005).

6.7 Triangulation/ Mixed-Methods Research Approach

6.7.1 Triangulation



Flow Chart 2: Triangulation

The main reason for applying triangulation design was that the combination of both qualitative and quantitative research methods would address the research problem from different perspectives. The rationale hence forth was as follows:

Triangulation is the collaboration of data collection methods to ensure that various perspectives shed light on a subject. In order to authenticate the assertions that might have arisen from the pilot study, it is critical for the researcher to combine data types. The

combination of survey data with in-depth interviews is a more intense form of triangulation (Olsen, 2004).

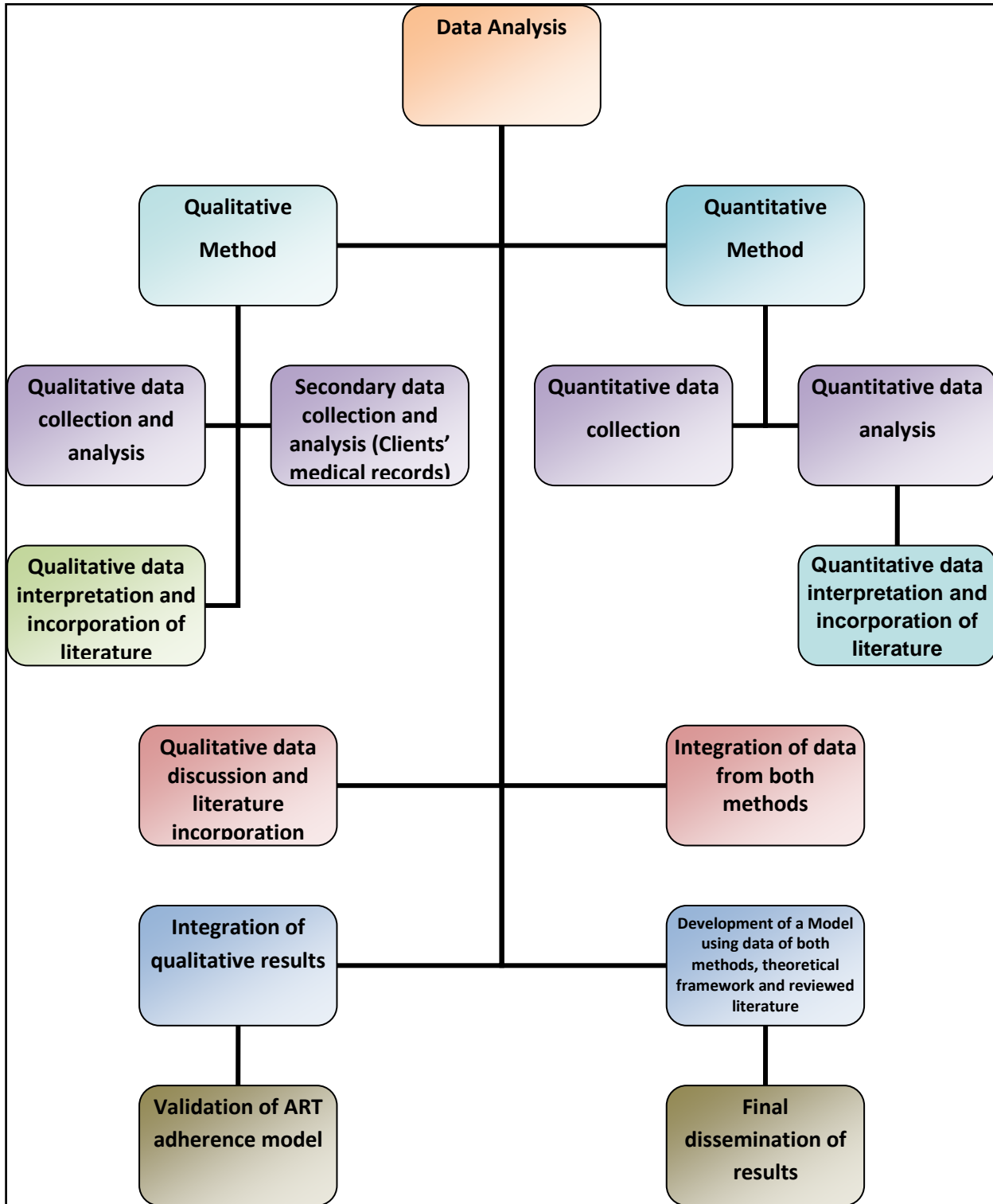
By collecting different kinds of data bearing on the same phenomenon organizational researchers can improve the precision of their judgments. Campbell and Fiske (1959) are the founders of triangulation in the social sciences. The two philosophers advanced the idea of multiple operationism. In order to guarantee that the variance mirrored that of the feature and not of the method more than one method should be used in the validation process. The quality of the quantitative elements of the data is evaluated according to the various aspects of reliability and validity (Campbell & Fiske, 1959, Bless, Higson-Smith & Sithole, 2013).

Triangulation can have other connotations and practices as well. There is the within-method kind which uses multiple techniques within a given method to collect and interpret data. In quantitative methods such as survey research, triangulation can take the form of multiple scales. For qualitative methods such as participant observation, this can be reflected in multiple comparison groups (Glaser & Strauss, 1967). The within-method triangulation involves validating for internal consistency or reliability, while the “between-method” triangulation tests the degree of external validity. Triangulation may be used not only to examine the same phenomenon from multiple perspectives but also to enrich our understanding by allowing for new or deeper dimensions to emerge (Jick, 1979).

In triangulation data collection methods complement one another. Researchers using qualitative methodology are encouraged to systematize observations, to utilize sampling techniques and to develop quantifiable schemes for coding complex data sets. Quantitative-oriented researchers are encouraged to explore the capabilities of social observation (Reiss, 1968). The idea of triangulation is associated measurement practices in social and behavioural research (Bryman, 2004). The study applied the triangulation method so as to gain more insights about the respondents' experiences of living with HIV and being on antiretroviral therapy.

6.8 Data Analysis

6.8.1 Flow Chart: Data Analysis



Flow Chart 3: Data analysis

6.8.2 Qualitative data Analysis

Data analysis is defined as a practice in which unarranged or incomplete data is categorized and arranged so that crucial information can be highlighted from it. It involves processing and working on data, in order to ensure that all the important data is available and has been captured (Lacey & Luff, 2001).

The presentation of data, the exploitation thereof and the analysis was integrated into a coherent unit. Information gathered from focus group discussions and in-depth interviews was transcribed and translated. The data was coded and a list of topics was developed and similar topics were grouped together. During the process of identifying the themes, new topics emerged and these described the data in a coherent manner. Each category was abbreviated.

Qualitative data were analyzed using grounded theory techniques. Grounded theory was founded by Sociologists Glaser and Strauss in the 1960's and the theory was later refined by Strauss and Corbin (Bowen, 2006). Grounded theory is based on a process that assists the researcher to systematically discover categories, themes and patterns that emerge from the data through coding and categorizing data into manageable units of analysis (Strauss & Corbin, 1998, Terre Blanche, Durrheim & Painter, 2006).

Major trends and cross-cutting themes were identified and issues for further exploration were prioritized for final analysis. Grounded theory is generated by themes, and themes emerge from the data during analysis, capturing the essence of meaning or experience drawn from diverse circumstances and perspectives (Morse & Field, 1995). This approach ensures that the researcher does not omit any essential information that he or she gathered.

All relevant sources of data were considered to allow for triangulation. Differences or contradictions between data sources were examined and explanations sought. Qualitative data was analyzed progressively as they got collected from the field.

6.8.3 Quantitative data analysis

Quantitative data analysis can be defined as the methods through which researchers transform data to a numerical form and expose it to statistical analysis (Rubin & Babbie, 2005). The purpose of analysis is to decrease data to a logical and interpretable form so that the relations of research problems can be studied and tested and assumption are made (De Vos *et al*, 2011).

The coding system was used for quantitative data and entered into the computer using the SPSS programme with the assistance of the Statistician. The data is supposed to be thoroughly checked and cleaned by the researcher before it is entered into the computer statistical programme SPSS (Babbie, 2004). Analysis included descriptive and inferential statistics. The researcher applied a variety of methods to present the data, such as composite frequency tables and pie and bar graphs. However, in developing graphs, the excel programme was used so as to allow variety instead of SPSS.

6.9 Reliability

Reliability occurs when an instrument measures the same thing more than once and results in the same outcomes. The reliability of a measurement procedure is the stability or consistency of the measurement (De Vos *et al*, 2011). Data collection tools were carefully designed to enable the researcher to ask relevant questions. The researcher was the only one collecting data as a result reliability was achieved.

Various methods can be applied to ensure reliability, the alternate-form method is one such method, as it measures the correlation between alternative instruments, designed to be as equivalent as possible, administered to the same group of subjects (Zikmund, 2003). In this particular study, the researcher used various data collection tools amongst the same group of respondents so as to ensure reliability. Low internal consistency estimates are often the result of poorly written items or an excessively broad content area of measure (Crocker & Algina, 1986). The researcher made it a point that all data collection tools are written in simple language that would be easy for respondents to understand. The data collection instruments were also divided into sections to make it easy for the respondents to follow the logic.

Imposed time constraints also pose a challenge to respondents, for instance time limits affect a test taker's ability to fully answer questions or to complete the instrument (Crocker & Algina, 1986). Sufficient time and was allocated for each respondent to ensure that all questionnaires are completed successfully and convenience of the respondents was also taken into consideration.

6.10 Validity

Validity refers to the context to which an empirical measure adequately reflects the real meaning of the concept under construction (De Vos *et al*, 2011). In developing the data collection tools, the researcher ensured that there was an alignment between the literature review and the questions asked, this contributed to content validity as appropriate questions were developed at posed to the respondents.

Content validity considers whether or not the items on a given test accurately reflect the theoretical domain of the latent construct it claims to measure. Items need to effectively act as a representative sample of all the possible questions that could have been derived from the construct (Crocker & Algina, 1986). In this regard there was alignment with the aim of the study, the objectives and research questions, literature review, theoretical frameworks, research methodology and data analysis.

6.11 Bias

Bias is any trend or deviation from the truth in data collection, data analysis, interpretation and publication which can cause false conclusions. Bias can occur intentionally or unintentionally. Intention to introduce bias in someone's research is immoral. It is therefore, the responsibility of editors and reviewers to detect any potential bias (Simundic, 2012). In order to avoid biasness, the researcher applied appropriate scientific methods in identifying the respondents and the health facilities, thereby greatly reducing the possibility of being bias. Appropriate statistical tests were used and results were presented correctly so as to prevent bias. In analysing qualitative data, verbatim statements from respondents were outlined and backed-up by relevant literature, to ensure objectivity.

6.12 Ethical Considerations

Researchers are accountable for upholding the dignity and wellbeing of all participants. This obligation also involves protecting them from harm, unnecessary risks, or mental and physical distress that may be intrinsic in the research procedure (Wax & Cassell, 1981). Approval to conduct the research was requested from the Turfloop Research Ethics Committee (TREC), Limpopo Provincial Department of Health's Research Ethics Committee and the Department of Health in the Mopani District. Various Chief Executive Officers (CEOs) of hospitals and managers of primary Health Care facilities were also approached to request permission to conduct research.

6.12.1 Informed consent

Informed consent is the kind of agreement made by a person with decision making powers, who has extensive understanding of the relevant information and who is liberated from controlling influences in making the decision (Pedroni & Pimple, 2001). The nature, objectives and anticipated duration of the study were explained to all respondents verbally. The researcher ensured that respondents were alerted of the sensitivity of the study. Respondents were also informed from the beginning that participation is voluntary.

6.12.2 Confidentiality

Confidentiality originates from a relationship when an individual gives private and personal information to another, on the condition that the other person will not disclose it (Chemtob, Tomas, Law & Cremniter, 1997). Anonymity was maintained throughout the study, to prevent disclosure of respondents' HIV status. It was also explained that all information would be treated with utmost confidentiality and that the results would only be used for the purpose of the study and to strengthen interventions.

6.13.3 Debriefing

Due to the nature of the sensitivity of the topics that were discussed during focus group discussions, HIV and AIDS counsellors comprising of professional nurses, social workers and lay counsellors were commissioned to assist with the de-briefing of the respondents. Respondents were also required to sign a contract, to ensure confidentiality. Debriefing relies on ventilation in the group support context, normalization of feedback and education about past-incidents and emotional responses (Chemtob, Tomas, Law & Cremniter, 1997).

6.12.4 Protection of respondents' identity

Participants in any research project have the ability and right to make decisions about their bodies and personal integrity. People of lessened independence who are dependent or defenseless should be protected against harm or abuse (National AIDS Control Program/WHO: 2004).

The privacy of participants in this particular study was protected and confidentiality was maintained by applying a coding system instead of using participants' personal details. Participants were informed that the researcher will review their medical records and that their data will be kept confidential. The researcher worked very closely with Comprehensive Care Management and Treatment of HIV managers at all sampled health facilities, therefore, all retrieved medical records were kept in a safe lockable cabinet and were only accessible to the Health Care Workers, lay counselors and the researcher.

6.12.5 Dissemination of the Information

A finalized copy of the research report will be submitted to the Department of Sociology and Anthropology at the University of Limpopo. The researcher plans to publish in relevant sociological and health journals. The participants will be informed about the outcomes of the study if they desire to know. Copies of the thesis will also be submitted to the Provincial Department of Health and the private health facility. The researcher has developed papers from the thesis that were presented at a national sociological conference in South Africa and an international conference on HIV and AIDS and STIs in Orlando Florida, the United States

of America in 2013. More papers will be generated from the thesis and presented at other national and international conferences. The researcher has also extracted information from this thesis to contribute a chapter in a book entitled “Everyday Feminist Research Praxis” a book that has been published by the Cambridge Scholars Publishing. This is an initiative of scholars from Utrecht University, at the Netherlands Research School of Gender Studies. Articles will be generated from the thesis and published in SAPSE accredited journals as well as international journals.

6.12.6 Significance of the Study

As yet, in the world, Southern Africa and South Africa, there is not sufficient research that has been conducted in terms of HIV and AIDS treatment and the associated social aspects. There is however evidence from some research studies that, patients often have their own models of disease and treatment and this may be based on cultural beliefs. If this model conflicts with the regimen prescribed for the patient, non-adherence is likely to occur. For example, if a patient believes that HIV and AIDS is a curse from a family member or a friend, such a patient is most likely going to default on treatment and will believe or rely more on a traditional practitioner or herbalist (Fomundam, 2005). The results of this study could be very useful in the successful implementation of the Comprehensive Care, Management and Treatment (CCMT) of HIV Programme, as strategies applied by health facilities will be shared amongst those facilities.

Antiretroviral therapy is usually provided at public health facilities, there are very few NGOs that are accredited to provide such services in South Africa and in particular the Mopani District of the Limpopo Province. This study collected data from 7 public health facilities and 1 private health facility. The findings of the study have shed some light on the differences and similarities between private and public institutions in the provision of such services. The researcher identified best practices that can be shared with other health facilities to enable them to improve their services.

6.13 Support Networks

HIV is incurable and therefore a heavy burden for a person who is infected to carry alone. Thus, those who are diagnosed HIV positive are encouraged to disclose their status to other people, preferably people who they trust and those that can provide them with support. Antiretroviral therapy is a lifelong commitment and people on ART need to have treatment supporters. The National Department of Health (NDoH) places a lot of emphasis on the importance of support structures for those that are HIV positive and on antiretroviral therapy. The role of treatment supporters is not only to remind their clients on ART to take their medication, but also accompany them to health facilities to collect their medication. If the client is unable to collect their medication on their own, a treatment supporter collects the medication on their behalf in some instances. During treatment adherence counselling, the treatment supporter is also counselled together with the client on ART. Support groups play a crucial role in ensuring that those on ART have a platform where they can be provided with an opportunity to share their experiences of living with HIV and being on ART. The researcher revealed the strategies employed by those 8 health facilities in establishing, maintaining and facilitating such groups.

6.14 Stigma

There are different modes of HIV transmission. Having unprotected sexual intercourse with an infected person is the most common mode of transmission, hence there is a stigma associated with HIV. There are two different types of stigma, internal and external stigma. Internal stigma is whereby an individual who is infected isolates himself/herself from other people due to their HIV positive status. External stigma is the segregation of those who are known to be infected with HIV or those who are suspected to be HIV positive, by those who believe that they are HIV negative. External stigma is usually accompanied by sarcasm and labelling. The researcher has applied the stigma scale as one of the data collection tools. The scale enabled the researcher to determine the level of stigma amongst the respondents and to identify strategies that are used in order to cope with stigma. The findings of the study will assist other people living with HIV to cope with the disease.

6.15 Discrimination

It is widely acknowledged that South Africa has one of the most progressive Constitutions in the world. The Constitution of South Africa, Act 108 of 1996 guarantees each citizen certain rights. Some of those rights include the right to life, health care, privacy, human dignity and the right to equality. There are still nonetheless incidents of discrimination against people living with HIV. The Government has established Chapter 9 institutions such as the South African Human Rights Commission (SAHRC) to ensure that people's rights are respected, protected, promoted and fulfilled. Enforcing these rights is not easy hence there are still human rights violations. The first incident of HIV in South Africa was recorded in 1981. The apartheid Government did very little to curb the spread of the epidemic. The democratically elected Government that came into being in 1994 was similarly very slow and reluctant to implement programmes that could have curbed the spread of the epidemic and thus saved life. It should however, be acknowledged that the democratically elected Government has since made tremendous strides in educating people in various communities in South Africa about HIV and AIDS. The researcher ascertained from the respondents how they cope with living with HIV and whether they have experienced incidents of discrimination. Strategies employed to deal with discrimination were identified with the aim of empowering other people in the same predicament. Discrimination of those that are infected with HIV takes place at various levels, within the family, at the workplace and within the community. The extent of discrimination against people living with HIV was exposed, in order to establish the magnitude of such abuses.

6.16 Self-efficacy

Clients on ART are encouraged to take an active role in their own health care. For ART to work effectively, the client needs to have accepted that they are living with HIV. Depression is one of the criteria used to exclude people from initiating ART. The wellbeing of a client is thus considered of utmost importance. Personal commitment needs to be demonstrated by a client on ART. Even though a client may be having treatment supporters, it is crucial that they should play an active role in their own health care. Complying with clinic appointments, adhering to their medication, attending support group meetings regularly and consulting

health care workers if they experience side effects are some of the commitments that need to be demonstrated. The focus group discussions as some of the data collection methods in the study enabled people on ART to learn from one another about what they need to do to take the medication effectively.

6.17 Disclosure

During HIV Counselling and Testing, those who test HIV positive are encouraged to disclose their HIV status to their significant others, so that they can offer them support. Those on ART usually choose close family members to disclose to. Female family members are preferred. The study unveiled reasons for such preferences and exposed the reasons for the reluctance in disclosing to male family members, particularly fathers. The reaction that people get after disclosure was uncovered so as to assist other people who may be in the same quandary.

6.18 Strategies to improve treatment adherence

As stated earlier, 8 health facilities participated in this study. A questionnaire was distributed amongst health care providers and lay counsellors. These health care facilities identified various strategies that they employ in order to promote adherence. The researcher will then develop a treatment adherence model applying the information obtained from the theoretical frameworks, strategies identified by clients on ART and health care providers. These strategies will be shared amongst the facilities to enable them to improve their services.

Antiretroviral Therapy (ART) is fairly new in the SADC region and remains under-researched. The results of this study could provide important insights into what strategies should be put in place in order to assist people who are on ART to adhere to their treatment. Other scholars will be able to draw from this study and will act as a source of referral for those who will seek to undertake a similar study. The study will help us understand the complicated relationship between HIV treatment adherence and social support, which will ultimately help to prevent non-adherence which may lead to resistance.

6.19 Summary

This chapter covered various topics associated with research design and methodology. Study sites were well articulated. A clear distinction between a research design and research methodology was drawn. The researcher applied the triangulation method to allow for the accuracy of her judgement. The sampling methods in the selection of respondents and health facilities were clearly articulated. In order to gain more information, the researcher conducted in-depth interviews with people on ART, administered questionnaires to Health Care Workers working at CCMT sites, conducted Focus Group Discussions and reviewed clients' medical records so as to back-up information obtained from clients and Health Care Workers. The methods for data analysis were also clearly outlined. Ethical consideration is very crucial in a study of this nature, hence it was also factored into the study. The reliability, validity and objectivity of the study were clearly outlined. In order to prevent biasness the researcher applied scientific research methods. Antiretroviral therapy (ART) was only introduced in 2003 in South Africa, hence the topic on the challenges of ART treatment adherence remain under-researched. The study identified the causes of non-adherence and developed a model for ART adherence that will be recommended for the Department of Health. The researcher has made recommendations for further research. The study will also enable other scholars to draw from its findings. The analysis, presentation and findings from in-depth interviews, focus groups and questionnaires are discussed in chapters 7, 8 and 9 respectively.

CHAPTER 7

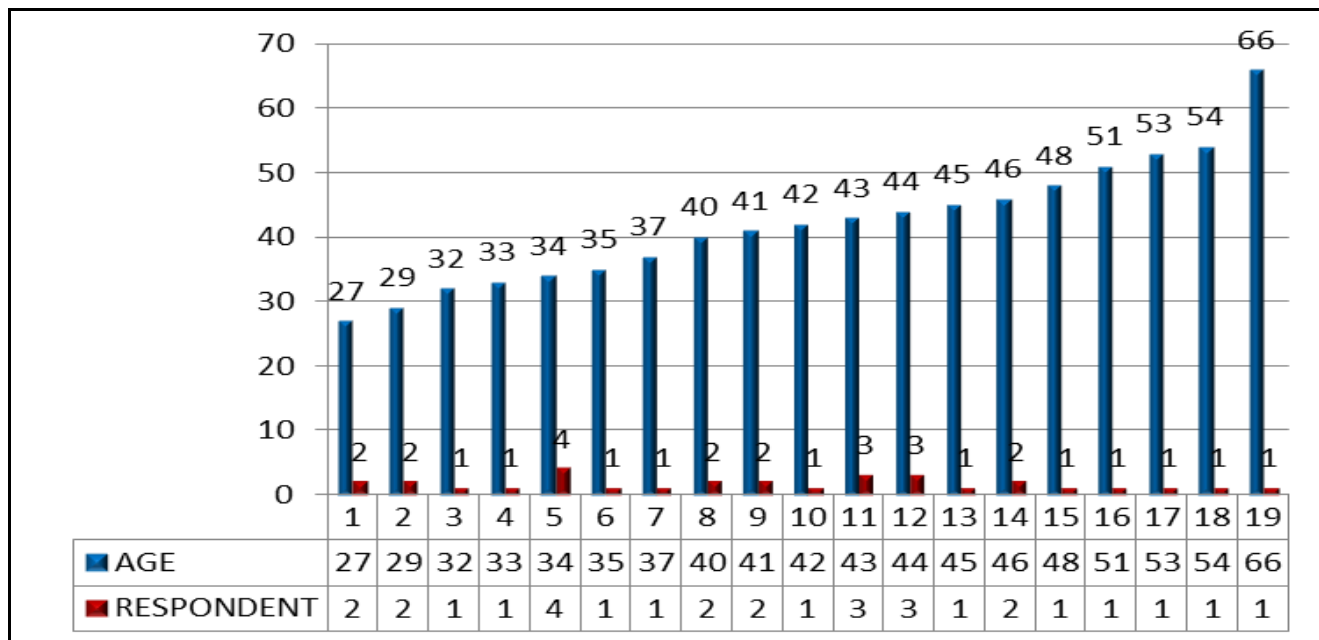
ANALYSIS, PRESENTATION AND INTERPRETATION OF FINDINGS FROM IN-DEPTH INTERVIEWS

7.1 Introduction

All data techniques involve summarising data, regardless of whether the researcher applied qualitative or quantitative research methodology. This study applied both research methodologies. The aim of this chapter is to analyse and interpret data collected during in-depth interviews.

The findings of the study will therefore be clearly outlined. Purposive sampling was used to select the respondents. In-depth interviews were conducted with thirty-one clients on antiretroviral therapy. Each interview took an hour and the entire data collection process lasted for two weeks. The researcher transcribed the data obtained during in-depth interviews. The data was then divided into meaningful analytical units and was coded. The researcher applied the grounded theory analysis method. Demographic data obtained from in-depth interviews were tabulated and analysed using database and spreadsheet software. Different types of graphs were also used to present the data. The data was also aligned with topics outlined in the literature review. Themes and sub-themes were identified and discussed with reference to verbatim accounts of respondents. The three theoretical frameworks applied in the study were aligned with the findings.

7.2 Demographic Data Presentation



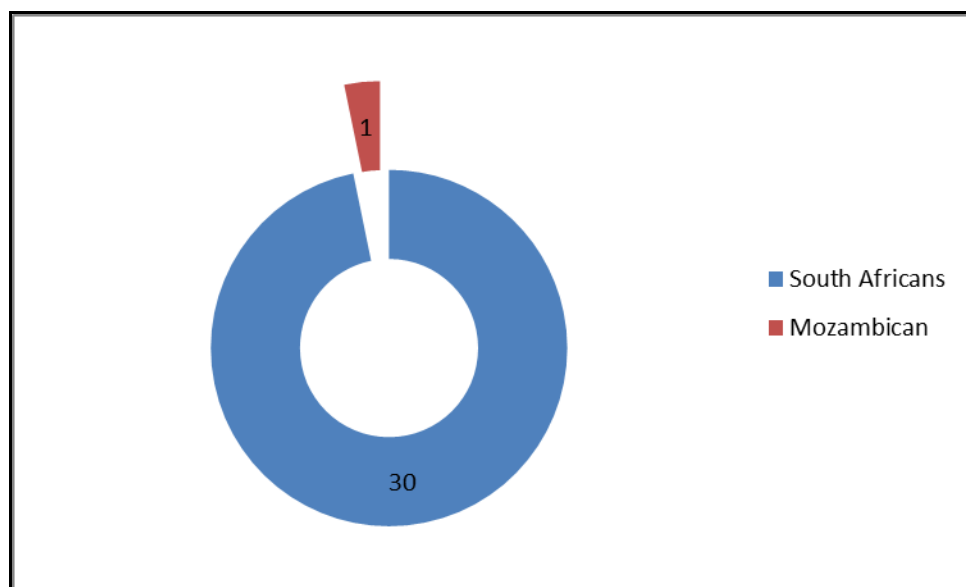
Bar Graph 3: Age of respondents on ART

In order to qualify for this particular study, respondents had to be above the age of 18. There were no respondents below the age of 27. Respondents between the age of 40 and 48 were the most dominant as the data indicates that (48%) were amongst this age group. The second most highest group were respondents aged between 32 and 37. Interestingly, only (13%) respondents between the age group of 27 and 29 participated in the study. Only (10%) respondents in their 50s were interviewed and only (3%) respondent in her 60s was interviewed. Research has shown that age may influence adherence and it was found that adherence tends to increase with age other than the most elderly (Wenger, Gifford, Liu, Chesney & Golin, 1999).

Table 1: Gender of the respondents on ART (N=31)

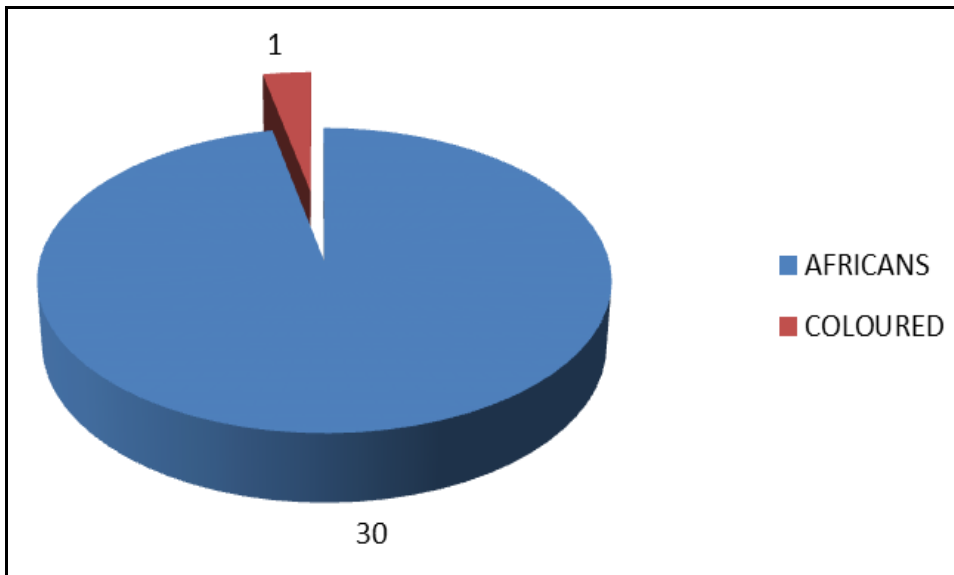
GENDER	FREQUENCY	PERCENTAGE
Female	22	71
Male	9	29
TOTAL	31	100

The data confirms reports that indicate that women are more vulnerable to HIV and AIDS compared to men. Women are not only vulnerable, but are also the ones who carry the responsibility of carrying for the sick in their families and in the community. Women are more likely to seek medical care than men, thus they are more prevalent at health facilities. Prevention and treatment programmes are female dominated. Many women have to come up with excuses for the reason to visit health care centres. There are those who even start treatment without informing their spouses and have to continuously hide their medication from them (Human Rights Watch, 2007). Women are also the ones that are blamed for bringing HIV within the family, hence the need to conceal the positive HIV status.



Doughnut 1: Nationality of respondents on ART (N=31)

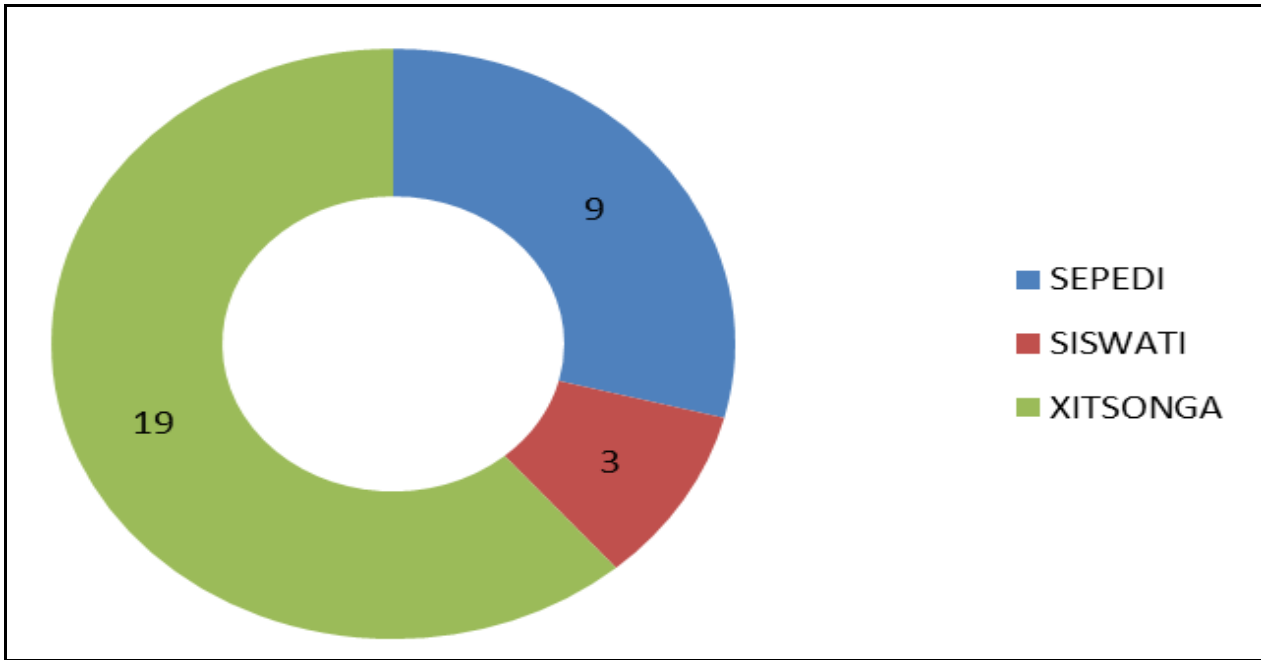
There was one foreign respondent amongst the participants and was receiving his treatment at a local clinic. “The National Strategic Plan on HIV and AIDS, STIs and TB is committed to challenging discrimination against groups of people who are marginalised, including people with disabilities, orphans, refugees, asylum seekers, foreign migrants, sex workers, men-who-have-sex-with-men, intravenous drug users, and older persons. All these groups have a right to equal access to interventions for HIV prevention, treatment and support” (Vearey & Nunez: 2010, 54). Foreign migrants should therefore also be afforded quality health care at public health facilities.



Pie Chart 2: Race of respondents (N=31)

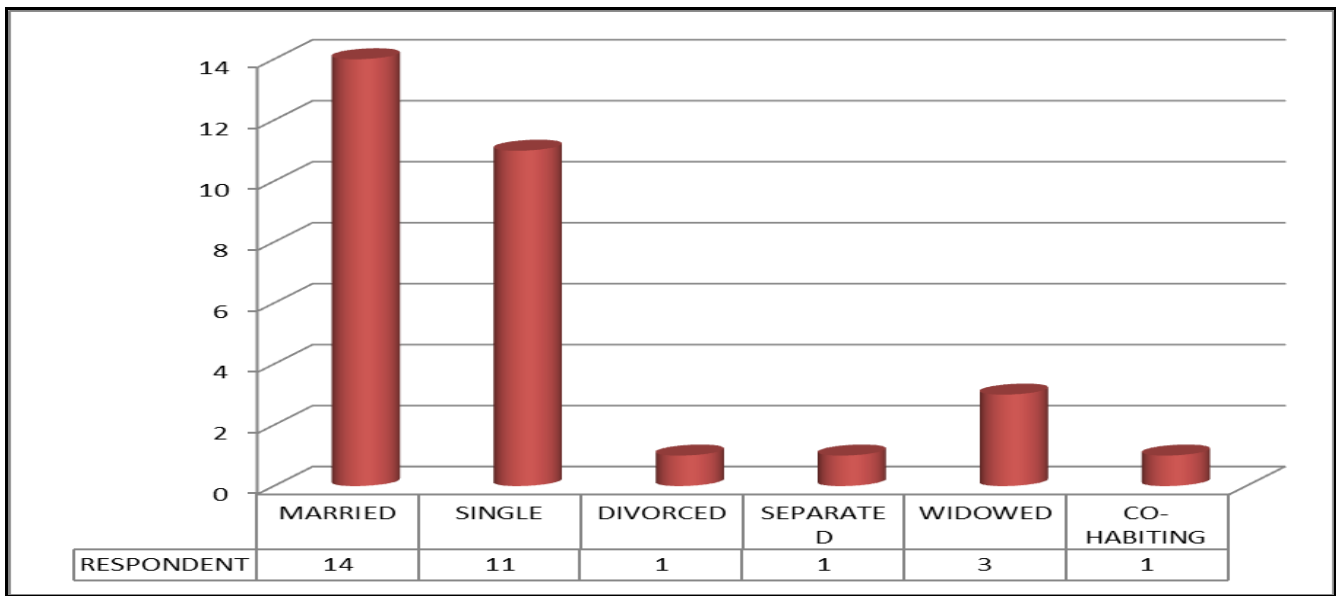
HIV is regarded as the disease of poverty, and there is a very strong correlation between HIV and poverty. According to the 2011 South African Antenatal Sentinel HIV and Syphilis Prevalence Survey the race group with the heaviest burden of HIV was the Africans at 31.4%, followed by the Asian population at 8.8%, then the Coloured population at 7.6% and last the White population at only 1.1%.

Poverty also fuels the spread of HIV and AIDS. International evidence implies that there is a close correlation between poverty and HIV and AIDS. The poor constitute the majority of the people who are living with HIV and AIDS. There are also a significant number of middle class people who are infected with HIV and it should be indicated that there are also poor people who are not infected with HIV.



Doughnut 2: Languages of respondents on ART (N=31)

The study was conducted in the Mopani district and the predominant languages are the Xitsonga, Sepedi, English and Afrikaans. Ethnic people's languages, philosophies and world views should be taken into consideration when conducting a sociological study, as it is through these constructs that people make sense of themselves and their world (Mkhize, 2004). Amongst the Shangaan people the HIV and AIDS epidemic is usually accompanied by a lot of secrecy, denial and suspicion (Sanders & West, 2003).



Bar Graph 4: Marital status of respondents on ART (N=31)

This data may be an indication that more couples are becoming more tolerant and understanding with regard to HIV and AIDS. Contracting HIV does not have to lead to separation or divorce as couples are choosing to be supportive of each other.

Marriage is a sacred and holy union that is established to enable two or more people to share their lives together. This contract is intended to be permanent and requires the parties to be faithful to one another (Akwun & Siraj, 2010). One of the objectives of this study was to determine the support networks available to people on antiretroviral therapy. This data confirms that spouses also provide the necessary support to their partners who may be HIV positive. According to Putnam (1995), moral obligations and norms, social values and social networks are critical for the social capital theory. These aspects are also crucial for the CCMT programme as those who are HIV positive have the responsibility to disclose their HIV status so as to protect their loved ones from infection and those who are identified as treatment supporters have the obligation to maintain confidentiality.

In Africa and in particular Nigeria, pregnancy is considered a means of saving a woman's relationship with her husband and of protecting her against the risk of rejection and abandonment by her in-laws and as a purpose of maintaining an accepted status as a wife and mother (Akwun & Siraj, 2010). As a result of this desperation, many women engage in unprotected sexual intercourse thereby risk contracting HIV. The South African government,

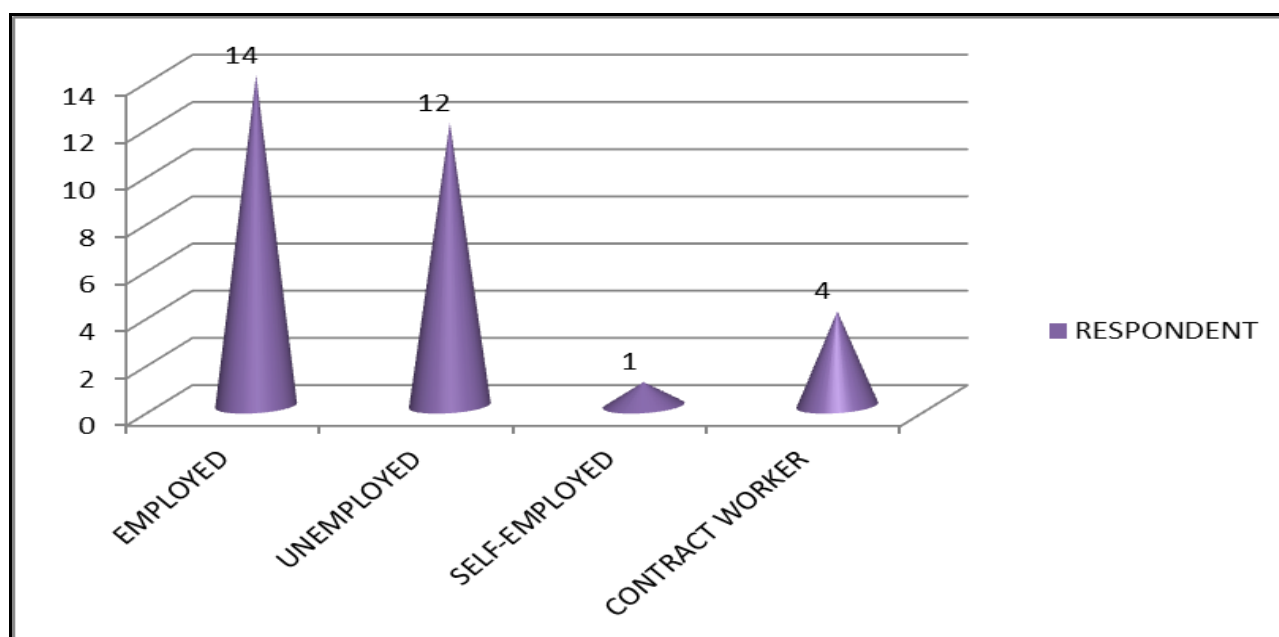
through the Department of Health place more emphasis on couples counselling to enable couples to support and care for one another regardless of the outcome. Those who are single are also encouraged to be adherent and to identify various sources of support networks that may available to them. A woman living with HIV or whose spouse has died of AIDS is often viewed as the “culprit” who brought the disease within the family and may also be accused of being promiscuous. This may lead to blame of infecting her husband and other children, even though it is widely known that men are the ones who are likely to cheat in a relationship (Muyinda, Seeley, Pickering & Barton, 1997).

Table 2: Highest educational level of respondents on ART

LEVEL	FREQUENCY	PERCENTAGE
Diploma after grade 12	1	3.2
Certificate after grade 12	2	6.5
Grade 12	5	16.1
Grade 7 and below	23	74.2
TOTAL	31	100

Literature reviewed show that there is a strong correlation between literacy and treatment adherence. However, this study disputes that notion as the data clearly indicates that out of the 31 sampled respondents, (74%) had obtained grade 7 and below. Only (16%) of the respondents indicated that they had received their grade 12 certificates. Two (6%) respondents said that they had acquired certificates after completing grade 12 and only 1 (3%) respondent had obtained a teachers’ diploma.

Research findings also suggest that there is a very strong relationship between levels of education, fertility and condom use. This evidence implies that those with higher levels of education are more able to prevent risk of HIV transmission. Income poverty forces people to engage in survival strategies that put them at risk of contracting HIV infection (Van Donk, 2004). Illiteracy has a negative effect on treatment adherence, whereas being knowledgeable and literate has been found to have a positive effect on adherence (Nakiyemba *et al*, 2004).



Cone 1: Employment status of respondents on ART (N=31)

Most of the respondents were employed. The data shows that (45%) of the respondents were employed, whereas (39%) were unemployed, (13%) were contract workers and only (3%) was self-employed. Antiretroviral therapy enables people who are infected with HIV to lead productive lives as they are also able to contribute positively to the economy of the country and to make a living. Some of the respondents who indicated that they were unemployed relied on social grants for a living. South Africa has a very high rate of unemployment and as a result, many families depend solely on social grants and in some instances, the entire family is forced to share a child support grant intended of one child. Disability grants are a major concern for people living with HIV and AIDS. Large numbers of people living with HIV and AIDS not eligible for grants have no other source of income. Using CD4 cell counts as eligibility criteria for accessing grants precludes many from receiving desperately needed funds and may have several negative effects on treatment and prevention efforts (Padarath, Ntuli, Sibiya, Searle, Pennings & Ntsike, 2006).

HIV and AIDS affect the economy on the micro as well as the macro-levels. From a macro-economic perspective, HIV and AIDS would affect labour supply and demand, capital investment and utilization, savings, investment, aggregate demand, GDP and the distribution of income. HIV positive workers whose condition has not yet deteriorated are as productive as their colleagues who may be HIV negative (Booyesen, Geldenhuys & Marinkov, 2003). It is

therefore critical that support should be provided to infected as well as affected employees, through the Employee Health and Wellness Programme (EHW). It has been suggested that social and economic factors may combine to yield poor adherence outcomes. Poverty in itself is likely to affect adherence, as financial resources may need to be directed elsewhere, funds for travel to the ART clinic may not be available, and child-care may not be readily accessible for parents who attend clinic visits. The competing demands of several responsibilities such as work and family life, along with the stresses associated with poverty and difficult life circumstances such as unemployment, may obviate an acknowledgement of the importance of complying with treatment regimens in general (Simoni, Frick, Lockhart & Liebovitz, 2002).

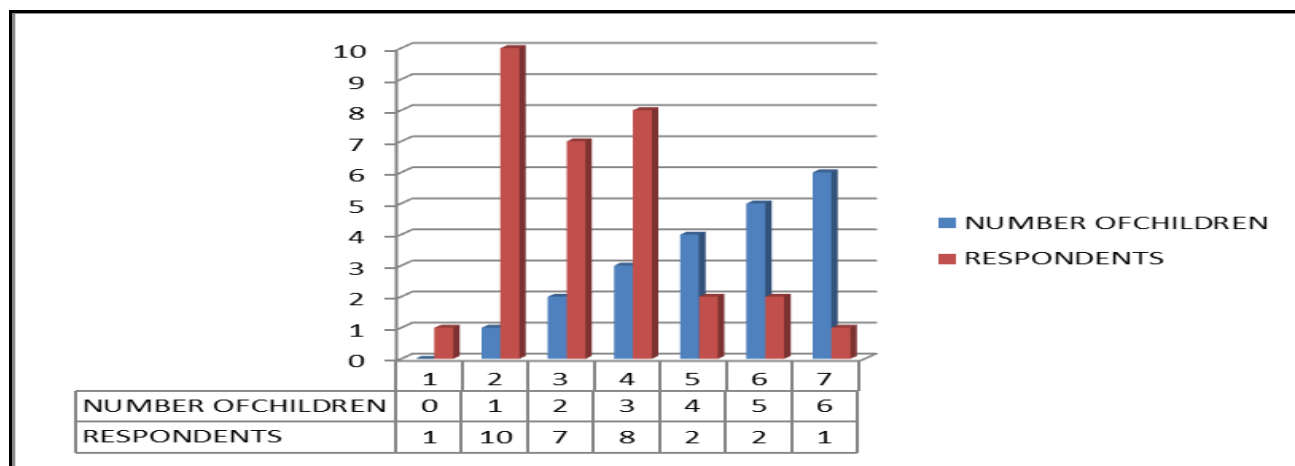
Table 3: Type of work done by the respondents on ART

TYPE OF WORK	FREQUENCY	PERCENTAGE
Domestic farm worker	2	7
Truck Driver	3	10
Farm worker	4	13
Educator	1	3
Contract worker	1	3
Lay counsellor	4	13
Security guard	1	3
Gardener	1	3
Hawker	1	3
Sales person	1	3
Unemployed	12	39
TOTAL	31	100

Farm workers are a highly mobile population who are constantly seeking employment. In most instances, farm workers are employed on seasonal basis. Due to the fact that in most cases the type of work they do is on a contract basis, most of them leave their partners and children at home. The risk here is that most of them as a result of loneliness and the need to belong they will establish sexual relationships with other people and this put them at risk of contracting HIV (Research Report, An ECAC and ECSECC Publication, 2010).

One of the key drivers of the HIV and AIDS epidemic is the truck drivers. Like farm workers, truck drivers are also highly mobile. As a result of the type of work they do, most of them also are forced to leave their families behind. Truck drivers usually seek sexual services of commercial sex workers near major transportation routes. This practice also exposes them to HIV and other sexually transmitted infections (Draft, 2004). Most of these truck drivers have wives and regular girlfriends back at home and are very likely to transmit the infection to their partners, who in turn spread the virus in their communities through promiscuous lifestyles (Hudson, 1996).

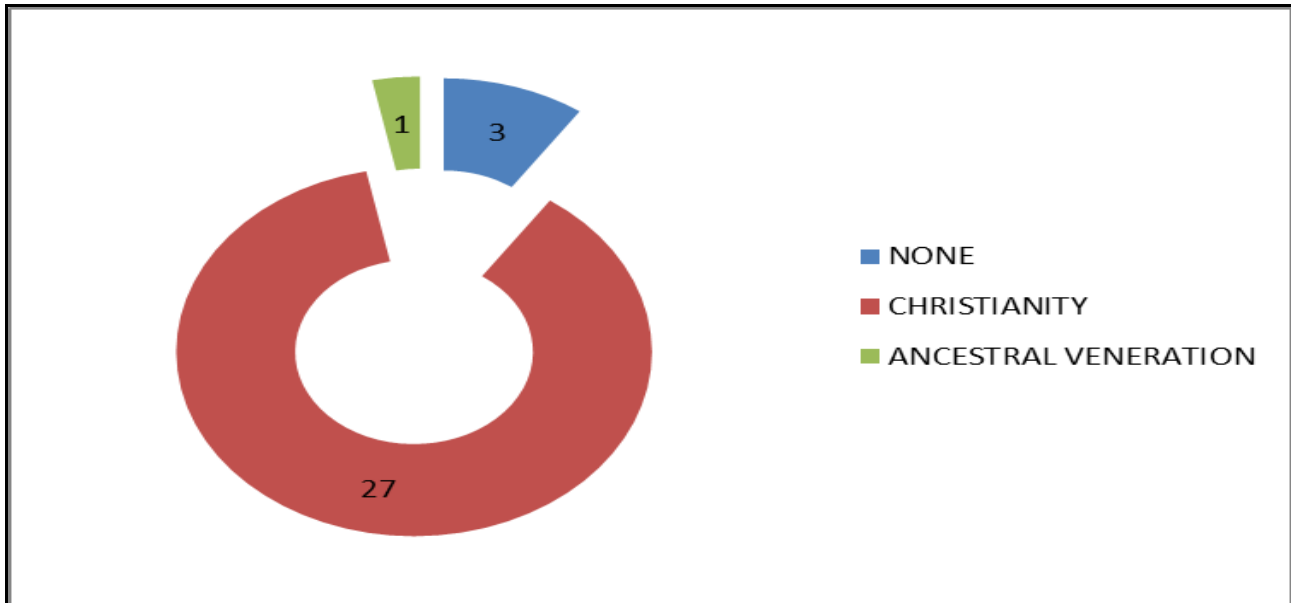
Lay counsellors living with HIV are deliberately selected to encourage other people to test HIV positive to live positively with HIV. Most lay counsellors who are also living with HIV are very open about their status and play a very important role in prevention and treatment of the epidemic. The role of lay counsellors within the CCMT programme is of utmost importance as they are able to motivate clients to live positively with HIV and to support those who are infected. In this regard stigma and discrimination against people living with HIV and AIDS is reduced.



Bar Graph 5: Number of biological children (N=31)

Children have been found to play a vital supportive role in ensuring that their HIV positive parents who are on antiretroviral therapy are adherent. Many people are choosing to have fewer children due to economic reasons. Even though parents thought children ought to know about illness within the family, they thought full disclosure was a challenge. Disclosure

was even challenging to parents who had already performed full disclosure to their older children (Gachanja, Burkholder & Ferraro, 2014).



Doughnut 3: Religious affiliation of respondents (N=31)

South Africa is predominantly a Christian community; as a result there are many different churches throughout the country. In certain instances there are those who practice Christianity and Ancestral Veneration at the same time. Ancestors are believed to play an important role in providing guidance, approval and support to family members who are still alive. It is therefore not surprising that there are still people who practice both religions as they find it difficult to divorce themselves from their ancestors as they believe that they are the once responsible for their success and prosperity.

Faith-Based Organizations (FBOs) have been faulted, for their delayed responses, for their failure to acknowledge the scope and implications of rising HIV infection rates, and for moralistic, judgmental and socially conservative stances towards HIV and AIDS which have contributed to silence and secrecy.

The association of HIV infection with immoral behaviour and the failure to openly discuss the root causes underpinning HIV transmission, particularly differentials of power have contributed to stigmatisation and discrimination of people living with HIV and AIDS within the church. Cochrane (2005: 2) notes how religion feeds into the problem of stigma through the

taboos, sanctions and silences about sexuality, much of it authorised by religious legitimations (Parker & Birdsall, 2005).

7.3 The Following Themes were Identified:

- The church’s message on HIV
- Stigma and discrimination in relation to ART adherence
- Social support networks and disclosure
- Sexual partner’s HIV status and safer sex practices
- Gender and ART adherence
- HIV counselling and testing and ART adherence
- Health management
- Traditional and alternative therapy
- Adherence counselling
- Challenges of treatment adherence
- Resistance to ART
- Positive living
- Effective strategies to improve adherence
- TB and HIV
- HIV stigma scale

7.3.1 Theme 1: The church’s messages on HIV

Table 4: The Church’s Messages on HIV

THEME	SUB-THEMES
The church’s messages on HIV	• How provision of information on HIV is done
	• The church’s position on HIV

7.3.2 Category: How provision of information on HIV is done

In the category “How talking about HIV is done” some respondents indicated that, as they were living openly and positively with HIV they found it easy to educate other church members about the disease and antiretroviral therapy.

Client 05 put it this way:

“My church teaches us about the usage of condoms and the importance of prevention”

Many churches’ responses to HIV and AIDS go undocumented, some of the responses are professionally run, coordinated at denominational level, reaching many people, both young and old. Many of those who choose to be involved are individual church members who share information and in some instances food with the destitute (Lutheran World Federation, 2007).

7.3.3 Category: The church’s position on HIV

With regard to the church’s position on HIV, many respondents indicated that their churches’ positions were positive, in that the pastors of the churches seemed concerned and were actively implementing programmes within the church so as to assist those who are afflicted.

Client 01 indicated:

“The church now understands more about HIV and AIDS and that people can live longer if they take good care of themselves”

Faith-Based Organizations (FBOs) promote values of compassion, tolerance and care for the needy, they are embedded within communities and understand local needs and conditions, and they have long histories of providing health care and other social services in poor and underdeveloped areas (Health Development Networks, 2001).

Client 16 had this to say:

“The church now acknowledges that there is HIV and we are allowed to bring medication to our church, which is Moria”

Table 5: Support offered by churches to members

THEME	SUB-THEMES
The way in which church members are supported by their churches	<ul style="list-style-type: none"> • Church members are educated on prevention of HIV and encouraged to support those who are HIV positive
	<ul style="list-style-type: none"> • Other women who are HIV positive take the initiative to educate other women within the church about HIV and antiretroviral therapy
	<ul style="list-style-type: none"> • Church members who are on treatment are encouraged to adhere to treatment
	<ul style="list-style-type: none"> • Their churches do not preach about HIV
	<ul style="list-style-type: none"> • HIV is treated as a taboo in their church

It is encouraging to learn that even amongst churches church leaders promote prevention amongst their followers. There is not yet a cure for HIV, therefore prevention is still the best option.

Faith Based Organizations (FBOs) promote values of compassion, tolerance and care for the needy, they are rooted within communities and understand local needs and conditions, and they have long histories of delivering health care and other social services in poor and underdeveloped areas. Yet some FBOs have been involved in denouncing or rejecting people living with HIV and AIDS (Parker & Birdsall, 2005).

Those who are already infected are encouraged to live positively HIV and to educate other people about the disease. Even though at some churches the leaders do not preach about HIV, some church members take the initiative to educate other fellow members about HIV and AIDS. It is disturbing to learn that some churches still consider HIV a taboo.

Many people contract HIV out of wedlock, and this may be regarded as a double-sin as the individual is assumed to have engaged in premarital sex and has been promiscuous (Duffy, 2005). There is a strong moral judgement associated with HIV, as a result contracting HIV may be viewed as punishment from God (Machyo, 2002). Thus, those who are infected and aware of their HIV status may not feel encouraged to disclose and if they are on treatment would rather take their treatment quietly without disclosing to fellow church members.

It has long been recognised that FBOs play a pivotal role in relation to the HIV and AIDS epidemic. Elements include doctrinal positions and religious teachings on the meaning of HIV infection, the degree of openness with which religious figures address HIV and AIDS, and HIV prevention and HIV and AIDS mitigation efforts undertaken by religious institutions in the communities and societies within which they work (Parker & Birdsall, 2005). Church leaders are usually very respectable people in their communities, and if such communities realise that they take HIV seriously, they are likely to gain interest in taking action about educating themselves about the disease, providing support to those who are infected by encouraging them to adhere to their treatment.

7.4 Theme 2: Questions about Stigma

Table 6: HIV stigma

THEME	SUB-THEMES
Stigma	Experiences of stigma
	How respondents dealt with stigma

7.5 Experienced stigma due to HIV Status

With regard to experiences of stigma, only seven respondents indicated that they had experienced stigma. The majority of the respondents pointed out that they had never experienced stigma. Few of such experiences were selected for analysis.

7.5.1 Explanations on experiences of stigma

In explaining his experience of stigma client 10 had this to say:

“Initially when I got diagnosed, my father was very supportive and was my treatment supporter. My father would accompany me to the health centre for my medication and consultation. The problem is that my father is a heavy drinker of alcohol and as a result he would be very insensitive and cruel to me and my child. He would refuse to give us food, he would find us watching TV and would just switch it off, saying that he does not understand why people with HIV need to watch TV. He would also lock us out of the house. I eventually moved out of my father’s house and went to stay in an RDP house.”

Stigma is the idea that individuals or groups who do not fit the social norm can be subject to negative discrimination or even violence. It is often based on misperceptions and it implies that those who are stigmatised threaten society (Panos, 2006).

Stigma can be described as a felt and as an ‘enacted stigma’ that refers to sanctions individually or collectively applied upon those with HIV whereas the felt stigma relates to feelings of shame and an oppressive fear of enacted stigma. The social consequences of both felt and enacted stigma are experienced by the individuals in terms of their rights, freedom, self-identity and social interactions that often influence the decisions to seek HIV testing and to access prevention services (Mawar, Sahay, Pondit & Mahajan, 2005).

Client 22 also outlined her experience as follows:

“One of my siblings developed a very negative attitude towards me. She would not share any cups, plates or cutlery with me. My friends also turned against me upon learning about my HIV positive status.”

Another client related her experience of being stigmatised by community members as follows:

“People in my community talked badly about me. My relatives were also insensitive and would ask me if I was taking AIDS medication.”

Social capital emphasizes the fact that relationships are of utmost importance (Field, 2003). Social relationships that people forge in their communities enable them to confront their challenges and offer one another the support that they need. Through co-operation they are able to cultivate trust and acceptance (David & Li, 2008).

Client 31 explained her experience this way:

“I used to be an HIV and AIDS ambassador in my community. One person then decided to confront my children about it. I then went to the police station to report the individual, the police simply asked me if I was not HIV positive, to which I responded that I was. The police then told me that there was nothing that they could do for me since I had no case as I admitted myself that I was indeed HIV positive.”

As may be seen from the incidents outlined above, most of the human rights abuses are committed by people who are very close to people living with HIV. Family members are supposed to show support and a caring attitude, but in some instances they are the ones responsible for displaying discriminatory attitudes.

Some community members are also very insensitive. This is an indication that education about HIV and AIDS can never reach saturation. There has to be continuous education amongst community members through various methods, such as in churches, women’s gatherings, workplaces etc. In a study that was conducted by Shisana *et al* (2005) they found that 29% of South Africans indicated that they would not buy food from a vendor who has HIV. This point to the fact that community members may not even be aware of how HIV is transmitted.

7.5.2 This is how respondents dealt with stigma

This is how client 10 dealt with the stigma:

“Staying with my father in the same house became unbearable and I decided to move out, so that my child and I could have a piece of mind.”

Client 22 indicated that:

“I went to a certain health care worker for counselling.”

People who are very close to the individual who is on antiretroviral therapy play a critical role, as they have the power to influence their behaviour. Therefore, if they are aware that the individual is on antiretroviral therapy, they will encourage him or her to adhere to their treatment (Roberts & Mann, 2000).

Some respondents took it upon themselves to educate their families and communities about HIV. Client 25 had this to say:

“I made it my responsibility to educate my family about HIV, as my mother would sometimes touch my vomit with bare hands. I decided to ignore my friends.”

Stigma, which still exists at both household and community levels, is a key barrier to HIV care, treatment and prevention programmes, and its impact on people living with HIV and AIDS is prevalent (Padarath, Ntuli, Sibiyi, Searle, Pennings & Ntsike, 2006). Empowerment of those who are HIV positive is crucial as it enables them to deal with challenges regarding stigma.

Client 31 related her experience this way:

“The community benefited a lot from the information that I shared with them, but the pain of being ridiculed was just too much to bear. I stopped being the ambassador of HIV and AIDS in my community.”

People who experience stigma take various measures to cope with the experience. In this regard the most common approach to stigma was to empower the culprits. Seeking further counselling was also regarded as a solution. Withdrawal from being an ambassador of HIV and AIDS was seen as an alternative by one respondent. One respondent felt that it was her responsibility to educate her family members about HIV and AIDS. This is a confirmation that people react differently to similar experiences.

The self-determination theory indicates that the concept of relatedness is very important, in that people are more likely to adopt values and behaviours that are advanced by those they trust and have close relationships with (Ryan, Patrick, Deci & Williams, 2008). Relatedness therefore, improves one's self-esteem and enables them to exercise their choices.

7.6 Theme 3: Questions about Discrimination

Table 7: HIV discrimination

THEME	SUB-THEMES
Discrimination	Experiences of discrimination
	How respondents dealt with discrimination

7.6.1 Experiences of discrimination

Similarly, respondents affected by discrimination were only six. Most of the respondents indicated that they had never experienced discrimination. Few of such experiences were selected for analysis.

7.6.2 The following are some explanations on experiences of discrimination

Client 4 had this to say:

“I was discriminated against by my colleagues as they would gossip behind my back. Some of them would also make sarcastic remarks as well.”

Many individuals who choose to be open about their HIV status within the workplace do so in order to obtain support from their employers, supervisors and colleagues. Access to appropriate treatment and care for people who are HIV positive is a basic right, discrimination prevent them from accessing HIV and AIDS programmes such as counselling and testing, treatment and adhering to such therapy once they initiate it (Tomaszewski, 2012). Therefore, even in instances where these programmes are offered at the workplace by the employer, employees may be reluctant to access such services for the fear of being discriminated against and being labelled as those who are HIV positive.

Client 10 related his experience this way:

“My father did not like my girlfriend (the mother of his child) who has since passed away and he would say hurtful words to her and would often talk badly about her.”

The family of the individual who is infected with HIV is the main source of care and support in many developing countries (Warwick *et al*, 1998). In many instances family members' reaction is very negative. People living with HIV are often stigmatized and discriminated against by their own family members and women with HIV usually face severe punishment than their male counterparts (Bharat & Aggleton, 1999). Family members and relatives may feel that the individual who is HIV positive has brought shame within the family and they also have to deal with secondary stigma and discrimination for being associated with the person who has HIV, hence the resentment in certain instances.

Client 31 who lives openly with HIV had this to say about her experience:

“I live openly with HIV and most of my fellow church members are aware of my HIV positive status. A church member discriminated against me and asked me to sit at the back during Holy Communion as other church members were not comfortable sharing the cup with me. I was then ordered to sit at the back so that I could be the last one to use the cup. The church then later decided to buy individual cups due to the complaints by other church members”

The incidents presented further confirm that family members in some instances are not as supportive as they are required to be. The workplace can also be a very hostile environment for those who are infected with HIV. It is inexplicable to learn that even church members were responsible for discriminating against fellow church members infected with HIV.

Coleman (1988) in his explanation of social capital indicates that the sociological approach is important as it views the individual in a social and cultural environment and he or she is guided by the values and norms of that particular society and the second intellectual stream that he considers important is the economic approach, which is re-occupied with self-interest and enables individuals to fulfil their goals. Discrimination is therefore, likely to deter people

on antiretroviral therapy from seeking the support that they need as they also would not like to be regarded as social outcasts.

7.6.3 Dealing with discrimination

People react differently to similar situations and likewise respondents in this instance dealt with discrimination in various ways.

Client 4 had this to say:

“I decided to ignore my colleagues and consoled myself by saying that at least I know my HIV status and I’m on treatment, unlike some of my colleagues who do not even know their HIV status and still sleep around and have multiple sexual partners”

Ignoring their abusers was seen as the best option by most people who suffered discrimination. Sharing the painful experiences with loved ones and disclosure of HIV status were also regarded as alternatives.

Client 10 dealt with discrimination in this way:

“My mother and my siblings were not aware of the ill-treatment that I was receiving from my father. I decided to inform my mother and siblings of what had transpired. I think my father is taking advantage of the situation because I used to be employed and when I became very sick I stopped working. I was not fired; I just decided to stop working as I could not cope anymore. I have now moved on with my life and have forgiven my father and still visit him.”

Illich (1995) was of the view that people were capable of taking control of their social environment and this would ensure that they claim back their independence. Therefore, the power that one has to influence their surroundings enables them to behave in ways that are favourable to their health.

This is how the church member who was discriminated by fellow church members dealt with discrimination:

“I ignored the church member who was very cruel to me and made a decision that I will continue going to church and no amount of hatred will separate me from the love of God”

Discrimination constitutes acts or omissions in which the content of the stigma applied, either at an individual or social/community level. Stigma and discrimination have a shameful history internationally. In South Africa they took a horrendous form in the apartheid system. Discrimination arises out of any point of difference that can be consistently labelled (Skinner & Mfecane, 2004). The attachment of discrimination to illness has a long history, with it impacting on people with mental illness and physical disorders such as cancer, TB, STDs and leprosy (Sontag, 1988). Stigma and discrimination are cruel social processes that offer some feeling of protection to the powerful, while increasing the load on the individual or group who is victimised in the process (Skinner & Mfecane, 2004).

7.7 Theme 4: Disclosure and Support Systems Available

Table 8: Disclosure of HIV status

THEME	SUB-THEMES
Disclosure	Relationship with the first person disclosed to
	Reaction of the first person disclosed to
	Feelings after disclosure
	Support from the first person disclosed to
Treatment	Reasons for having or not having a treatment supporter
	Relationship with the treatment supporter
Support group membership	Reasons for membership
Disclosure to colleagues	Reasons for disclosure to colleagues
Disclosure to sexual partners	Sexual partner’s reaction after disclosure
	Duration of disclosure

7.7.1 The First Person That They Disclosed Their HIV Status To

Female family members are very popular and the most preferred with regard to disclosure of HIV status. Their male counterparts are the least preferred more especially fathers, as no one amongst the respondents indicated that they had disclosed to their fathers. Mothers were found to be the most popular regarding disclosure of HIV status. Generally, respondents preferred close family members to disclose to. Some respondents also disclosed to their sexual partners.

Disclosure of HIV status is often linked to advanced stages of HIV-related illnesses, with some people disclosing their status just before death. Uptake and adherence to treatment is often compromised due to fear of discrimination (Padarath, Ntuli, Sibiyi, Searle, Pennings & Ntsike, 2006). Effective counselling assists clients to accept their condition.

With the advent of antiretroviral therapy however, many people do no longer wait until it is too late to disclose. In the Limpopo province, Health care workers and lay counsellors encourage and prepare people who test HIV positive to disclose their HIV status to their significant others to ensure that they receive the necessary support. As a result, many people choose to disclose immediately after being diagnosed HIV positive.

In South Africa, at the present time the requirement is that in order to be eligible for ART, clients must have disclosed their HIV status to at least one other person (Coetzee, Hilderbrand, Goemaere, Matthys & Boelaert, 2004). This requirement signals that not only that the client has accepted his or her HIV status but also minimises the likelihood that lapses in adherence will occur (Kagee, 2006).

7.7.2 Reaction of the first person disclosed to

The emotions displayed by those who were preferred with regard to disclosing one's HIV status ranged from being extremely negative to being positive. The negative emotions included shock, fear, blaming and rejection. The positive reactions included being supportive, encouraging and acceptance.

Client 01 had this to say:

“My husband was shocked and did not believe me, he also works here at the game lodge. I was pregnant and later gave birth to an HIV negative baby”

The reason behind the disbelief could be as the result of the misconceptions that people still hold regarding HIV and AIDS. The belief that it will never happen to them or that it is a myth could also be contributory factors to such reactions.

Client 04 said:

“I disclosed to my sister, she encouraged me to live positively with HIV, she understands many things about HIV and is very supportive as she is a professional nurse”

With regard to some clients on antiretroviral therapy, health care providers may be the only people with whom they discuss their treatment (Mehta, Moore & Graham, 1997). Therefore, if the family member is also a health care provider, it makes adhering to treatment easier.

Continuous education of community members and more especially family members about HIV and AIDS and antiretroviral therapy is crucial. It is evident that those who are empowered with information are more likely to offer their support to those who are infected with HIV. However, some respondents were not as fortunate as their counterparts. As client 22 indicated:

“I disclosed to my boyfriend over the telephone. He is the father of my baby. He dumped me on the phone and sounded very angry. I then later decided to go to the Magistrate to report him to force him to support his child”

Fears of verbal and physical abuse, fear of rejection and other forms of negative response after disclosure may prevent people with HIV from disclosing (Greeff, Phetlhu & Makoae, 2008).

Immediate family members are also very supportive. Client 12 pointed out that:

“I disclosed to my mother who was very supportive, she even volunteered to accompany me to the clinic for treatment”

Disclosure of HIV status to family members is higher compared to friends in Asia (Mawar, Sahay, Pandit & Mahajan, 2005). This study also found that many people who are HIV positive find it easy to disclose to very close family members. Perceptions of social support are also positively associated with the percentage of friends, family and sexual partners to whom the diagnosis has been disclosed (Derlega, Winstead, Greene, Serovich & Elwood, 2004)

Many people who are diagnosed with HIV are concerned about the reaction of their family members. Rejection is one of the negative reactions feared by many, therefore if family members are supportive, this is encouraging to those who need their support.

7.7.3 Feelings after disclosing

Living with HIV secretly is not easy as a result many people who are infected eventually disclose their HIV status to someone that they trust to maintain confidentiality. Most respondents pointed out that they felt relieved after disclosing their HIV status. This may be due to the fact that living with HIV secretly may have been a heavy burden for them.

Client 03 said:

“I felt good as I regard HIV like any other disease”

Disclosure of HIV status may lead to crucial social support to alleviate the damaging effects of stress associated with HIV and AIDS (Mawar *et al*, 2005). Hence, disclosure needs to be encouraged amongst those who are infected with HIV.

The normalization of HIV is crucial so as to encourage people to test for HIV and seek treatment if they are diagnosed HIV positive. Organizations implementing HIV and AIDS programmes also play a critical role in encouraging those who are infected with HIV to accept their condition and cope better with it.

Client 05 described her experience as follows:

“I felt good after disclosing and I was encouraged by the HIV ambassador at our clinic since she is also living openly with HIV”

Learning about other people’s testimonies of living with HIV plays a crucial role in motivating other people who may also be living with HIV. When they observe other people coping well with the disease and leading normal lives, this can be very encouraging.

It is however, important to indicate that there are those people who even after disclosure are left with even more negative emotions.

Client 11 explained how she felt after disclosure:

“I thought it was the end of the world”

Disclosure of HIV status is very challenging as it exposes one to stigma and discrimination (Praxton, 2002). Disclosure of HIV status is not always met with a positive reaction. Some people are rejected by family member after disclosing and yet there are some who are showered with affection and tremendous support.

To demonstrate this, client 26 explained it this way:

“I felt relieved after disclosing because of the support that I received from my family”

Consistently, family members were the most supportive group in terms of accessing both material services and emotional support. This has important implications as it enables the individual to be adherent to their treatment (Simoni *et al*, 1995). Furthermore, people with HIV who are integrated into social networks have higher levels of psychological well-being than those who are not (Simoni, Mason, Marks, Ruiz, Reed & Richardson, 1995).

According to Pierre Bourdieu (1986), social capital is a trait of an individual in a social environment. Through establishing meaningful social networks one can benefit not only socially, but economically as well. Disclosure enables the individual to lead a normal productive life.

7.7.4 Support from the first person they disclosed to

Most of the respondents indicated that they received support after disclosing their HIV status. Only a minimal number of individuals pointed out that they never received any support after disclosure. It is important for people who are infected with HIV to choose people that they will disclose to very carefully. The main aim of disclosure should be to obtain support. Disclosing to people who are negative and not supportive may even cause the infected person depression. Hence, HIV counsellors discuss the importance of disclosure with clients during pre-test counselling in HIV Counselling and Testing.

Social support for adherence is defined as encouragement from family and friends for the patient to co-operate with recommendations and prescription of a health professional (DiMatteo, 2004). The expression of concern and encouragement from others to engage in health promoting behaviours, including medication adherence, may combine with social desirability needs on the part of the patient to yield higher rates of medical co-operation. There is strong evidence that positive social support, including being married, is associated with adherence to ART (Kagee, 2006).

7.7.5 Availability of a treatment supporter

With regard to whether they had treatment supporters, the majority of the respondents indicated that they had treatment supporters, whereas a minimal number pointed out that they did not have them.

Support is very critical in the management of the HIV and AIDS epidemic. In South Africa, one of the criteria for a client to be enrolled in the Comprehensive Care Management and Treatment of HIV and AIDS programme is having a treatment supporter and to have disclosed to the individual. Some health care facilities, such as one of the public health facilities indicated that they do not insist that a client on ART should have a treatment supporter, as clients would randomly bring in strangers from the streets claiming that they were related to them.

Clients on ART are required to attend treatment adherence counselling together with their treatment supporters, who are usually family members. From a facility perspective, adherence support consists of training people living with HIV and AIDS and their supporters, issuing medication in monthly or bi-monthly quantities requiring repeat visits to collect medication and counting dosages dispensed. People living with HIV and AIDS may receive assistance from treatment supporters or use alarms as reminders to take daily doses (Padarath *et al*, 2006).

This encourages them to be independent and not depend on their health care facilities. Medicalization is a form of social degradation through which dependence on service consumption is induced (Illich, 1982). Empowerment of clients on ART to identify methods that can assist them to adhere is crucial.

7.7.6 Reasons for having or not having a treatment supporter

There are many factors that motivate people on ART to have treatment supporters, some need to be reminded about taking medication. For most of the respondents it was mainly to get support and to have someone to share their problems with. The majority of the respondents had treatment supporters. Only five indicated that they did not need assistance with taking their medication as they were able to do it on their own.

Client 01 pointed out that she had a treatment supporter and laid out the reason as follows:

“I feel it is important for me to have a treatment supporter, so that I do not skip my doses”

In order to complement facility treatment services, resources in the community are needed to make sure care is continuous, those on treatment are not lost to care and people on treatment can be supported by and integrated into the community to live long and healthier lives (Hope, 2007).

There are those respondents who felt that by disclosing, it enabled them to be free and they were afforded a companion to share their challenges with. Client 12 voiced out her opinion as follows:

“I am able to share my problems with the supporter and it also enables me to be free”

People living with HIV can be an imperative part of prevention efforts for the broader community by increasing HIV counselling and testing services and putting a human face on AIDS (Hope & Israel, 2007).

There are however, those who felt that they did not need to have treatment supporters as they were able to take their medication on their own without seeking assistance.

In his attempt to explain the situation, client 10 said:

“I am able to take my medication on my own, without assistance”

Another respondent referred to the information that they were given by HIV and AIDS counsellors. She pointed out that:

“I do not need a treatment supporter, I understood all that I was taught during treatment adherence counselling by the counsellors”

With regard to some respondents, they were forced by their circumstances and working conditions. For instance, client 16 said:

“I need my wife’s support, because I work at night and need her to remind me”

It is also the prerogative of the client on antiretroviral therapy to comply with clinic appointments, and some are unable to do so due to work commitments. Client 26 said:

“I am at work most of the time and need someone to fetch my medication on my behalf, so my family members collect the medication for me”

Disclosing to family members consistently allowed HIV-positive people and their families to maintain their livelihoods. Some were able to be productive at their workplaces, whilst their family members ensured that they complied with their clinic appointments, by fetching their treatment on their behalf. This finding was very interesting in that it is not all health facilities that allow other people other than the client who is on treatment to fetch the treatment due to the misuse of antiretroviral therapy. A health care provider at one of the sampled health

facilities strongly felt that other family members should be allowed to collect the client's medication if the client is not able to do so himself or herself.

7.7.7 Relationship with the treatment supporter

Most respondents indicated that their treatment supporters were very close family members. Female treatment supporters were preferred more than males. This points to the fact that families need to be capacitated to be able to provide the necessary support to other family members who are on antiretroviral therapy.

Some respondents relied on their parents for support, particularly mothers. Astonishingly, none of the respondents indicated that their fathers were their treatment supporters. On the other hand, some respondents chose their spouses as their treatment supporters. Other respondents had their own children as their treatment supporters.

There are however, those few respondents who pointed out that they did not have treatment supporters as they were able to take their medication on their own. This is in sharp contrast to the findings of other researchers, for instance, (Hope & Israel, 2007) in their study found that, "many people are fearful of disclosing that they are HIV positive to their spouse, others at home, or close friends". This study indicates that disclosure rate of HIV infected individuals to family members is higher than to friends for illness management and treatment for HIV. (See pages 148,149 and 150).

7.8 Membership to a Support Group

For a health facility to qualify to be a Comprehensive Care Treatment of HIV and AIDS site (CCMT) it is required to have a support group of people living with HIV and AIDS. Remarkably, the majority of the respondents did not belong to a support group and only a limited number of the respondents indicated that they belonged to a support group.

Some respondents indicated that they did not even know what a support group was. At one public health facility, health care workers reported that they were not welcome to support group meetings by HIV positive lay counsellors as they accused them of being unable to maintain confidentiality.

A 66 year old woman likewise pointed out that she was rejected at support group meetings and the support group members said she was too old to be a support group member. They feared that she would make them feel uncomfortable to talk freely about various personal and intimate issues.

This is how she related her dilemma:

“I would love to attend support group meetings, but I am not welcome by other support group members, because they say I am too old to belong to their support group”

Support groups need to be categorised according to the number of years or months one has been living with HIV and according to age groups to ensure that support group members are free to share their experiences with the other members.

In order to complement health facility services, there is a need to provide social support services in the community. Continuous care and support as well as integration of services are essential so as to ensure that those on treatment are not lost to follow-up (Hope & Israel, 2007).

People living with HIV and AIDS and the social groups to which they belong have been stigmatized worldwide since the beginning of the epidemic. The epidemiological need to conceptualize risky groups has alienated the marginalized groups. People living with HIV and AIDS have been distanced by strangers and family members, discriminated against in employment and health care, driven from their homes, and subjected to physical abuse. Such fears of stigma have deterred individuals from being tested for HIV and from disclosing their sero-positivity status to sexual partners, family and friends (Mawar, Sahay, Pandit & Mahajan, 2005).

7.8.1 Reasons of membership to support groups

Support structures are crucial in the effective provision of antiretroviral therapy. Support groups in particular provide people living with HIV and AIDS an opportunity to share their experiences and challenges with other people who are also HIV positive. Being in a support group also affords the group members the prospect of being empowered with HIV and AIDS

information and other valuable information by professionals. It was appalling to discover that there were people on ART who did not even know about any existence of a support group.

A Mozambican national who was receiving his treatment at a local clinic in Giyani described his experience this way:

“No one has ever explained to me about a support group, I am Mozambican who came to South Africa in 2001”

Health Care Workers and lay counsellors need to revive or establish support groups of people living with HIV and AIDS and inform those who are infected with HIV of the existence of such groups so that people may get the support that they need. People who are diagnosed as HIV positive need lifelong care, support and treatment (Hope & Israel, 2007). Adherence is the integral part of their therapy, hence support is very important.

Some respondents pointed out that they were unable to attend support group meetings due to work commitments. It would therefore, be ideal for employers to encourage the establishment of support groups within the workplace so as to enable those employees who are infected and on antiretroviral therapy to obtain the support they need. Client 15 explained her situation this way:

“I am no longer able to attend the support group meeting due to heavy work load”

Interestingly, there are those respondents who pointed out that they did have support groups at their own workplaces, but were not able to attend the meetings due to work commitments. It is a futile exercise for an organization to establish a support group for employees without making provisions for such employees to attend such meetings. Client 02 had this to say:

“We do have a support group at my workplace, but I am not able to attend the meetings because I am always busy”

Some respondents were motivated by personal motivations. Client 09 had this to say about her decision:

“I do not see the need of belonging to a support group, as I would like to keep my HIV status confidential”

Respondents who were members of support groups indicated that they found the experience valuable. This is how client 03 explained his experience:

“The support group empowers me”

“A support group is a structure/meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning – emotional, spiritual, physical and psychological – and to share information, knowledge, ideas and experiences. Members of the group are bound by group norms, goals and objectives as agreed upon by the group” (Department of Health, 2000).

Client 05 said:

“We are taught valuable lessons during the support group meetings, we also get to share our experiences and ideas with other people”

Clients who have been on antiretroviral therapy for a longer period are a valuable asset to their counterparts as they are able to impart their knowledge. Client 22 had this to say:

“I am able to share my experiences and challenges with other people who are infected with HIV. I emphasise the importance of disclosure, I am able to disclose to other people who are HIV positive at the clinic and educate them about antiretroviral therapy and HIV”

By involving more experienced clients in the care of other clients, health care workers are able to reduce the burden of their work. Some clients also feel more comfortable to relate to other people who are also HIV positive other than professional nurses.

Client 14 also had this to say:

“I no longer have time to attend the support group meetings, as I now have a granddaughter and have to babysit her. During the times that I used to attend, I benefitted

a lot as I got to interact and share experiences with other people who are also HIV positive and on antiretroviral treatment like me”

In a study conducted by Weatherburn, Anderson, Reid and Henderson (2002), it was found that there was generally a lack of social support in practical areas such as performing household chores, travelling to health facilities and having sufficient funds to live on. It was also found in the study that many of the people who lived with children had difficulties regarding looking after them (Green & Smith, 2004).

7.8.2 Disclosure of HIV status to colleagues

Most of the respondents who were employed indicated that they had disclosed their HIV status to their colleagues, and others had not disclosed. In a study by Issiaka, Cartoux, Zerbo *et al* (2001) they found that women who were well educated were more likely to disclose their HIV status to their partner.

Disclosure of HIV status is an emotionally charged exercise for any individual who is faced with taking the action. Disclosure is highly influenced by fear of being an emotional burden, discrimination and disrupting relationships (Yoshioka & Schustack, 2001). Thus, some people who are HIV positive may decide to withhold information regarding their HIV status as they fear being discriminated.

Other respondents had indicated that they were not employed. Disclosure of one's HIV status to colleagues is not always met with the cordial attitude that many employees living with HIV would envisage. It is thus of utmost importance to identify a colleague to disclose to very carefully, as rejection or any other negative reaction is likely to cause depression.

7.8.3 The following recommendations are made that would create a conducive environment for disclosure in the workplace:

- Ongoing participative workplace programmes should be promoted
- Disclosure procedures must be clearly set out
- There is a need to amend and update existing legislation to promote confidentiality and protections against involuntary disclosure in workplaces.

(Open Society Foundation for South Africa, 2009).

7.8.4 Reasons for disclosing or not disclosing

The Labour Relations Act No 66 of 1995 protects employees against unfair labour practices such as pre-employment HIV counselling and testing. Employees who disclose their HIV status in the workplace should do so out of their own volition. The most popular employees to disclose to were the supervisors so that they could allow them to comply with their clinic appointments, some were forced by ill health to disclose, some needed support and some just wanted to be free.

Client 01 explained her reasons this way:

“I disclosed to my supervisor at work, so that I can be able to attend my clinic appointments”

Disclosure is also vital in managing HIV, especially in terms of adhering to complex treatment regimens. HIV-positive people have reported that they sometimes skipped doses because they could not take a prescribed medication without being observed doing so (Chesney and Smith, 1999). Disclosure of HIV status has become an entry criteria for many treatment programmes in resource constrained settings. In this study it was found that disclosure to the employer or colleagues within the workplace was of utmost importance as it allowed the individual to have time to consult at health facilities. The employees on antiretroviral therapy did not have to hide their HIV status from their employer, as they received support.

There was a general consensus amongst the respondents that if supervisors and employers to a certain extent are aware of the HIV status of employees they are more supportive and understanding.

Client 03 had also disclosed to his employer and outlined the reasons for doing so as follows:

“I disclosed to my employer, my employer encouraged me to take my medication. I used to be sickly and would visit the clinic quite often and my employer wanted to know the reason for this, so I had to disclose to him.”

Some respondents were motivated by the need to educate other employees about HIV and AIDS and treatment. Client 06 indicated that:

“I disclosed my HIV status at work, because I wanted to educate other people about HIV and AIDS so as to curb the spread of the epidemic.”

In some instances employers rely heavily on the employees who are living openly with HIV to educate other employees and encourage them to go for HIV counselling and testing, access treatment and use protection to prevent HIV infection. On the contrary, there were those who indicated that they had not disclosed as they did not feel free to do so.

Client 07 explained his decision this way:

“I have not disclosed, I am afraid that if I disclose I will get fired. I think that if I disclose to my colleagues, they will inform my employer and get me fired.”

Fear of rejection seems to be almost universal amongst people living with HIV and AIDS and often leads to internal stigma (Laryea & Gien, 1993). There is obviously trust issues involved regarding disclosure of HIV status to colleagues. Some respondents feel that their colleagues might not be able to maintain confidentiality.

7.9 Disclosure to Sexual Partners

Disclosure of one's HIV status to a sexual partner is critical as it plays a major role in curbing the spread of HIV. When asked this question the majority of the respondents pointed out that they had disclosed to their sexual partners, only few respondents indicated that they had not disclosed and one indicated that this question did not apply to her since she did not have a sexual partner.

There is increasing recognition that disclosing one's HIV status is an essential part of behaviour modification required to reduce the incidence of HIV. HIV counselling and testing is widely promoted as an important first step in behaviour modification. However, without disclosure, few of the benefits can be realized (Norman, Chopra & Kadiyala, 2005). Those who are sexually active and are HIV positive risk transmitting HIV to their partners.

Fear of being abandoned and loss of economic support were the primary factors that were mentioned quite often by respondents from studies both in developed and developing world. Other studies also found that, isolation and discrimination were other barriers to disclosure of HIV status. Many women also mentioned fear of violence as a deterrent in disclosing their HIV status (Maman & Medley, 2004).

The reasons for disclosing differed depending on the individual to whom the person was disclosing. Seeking social support was the primary reason for disclosure to friends and family (Maman & Medley, 2004).

There are many reasons for non-disclosure such as finding a new partner, male refusal to share results, male partner not willing to be tested for HIV, no steady partner, not being ready to disclose, fear of rejection and not knowing how to disclose (Mlambo & Peltzer, 2011). Social relationships are very important and many people who are HIV positive and on antiretroviral therapy choose to withhold their HIV status from their partners as they fear being rejected. The risk of skipping doses also becomes high as they try very hard to conceal their medication.

7.9.1 Sexual partner's reaction

The partners' reactions after disclosure varied, from being shocked, anger towards the partner, blame, fear of being counselled and tested to being encouraging and supportive.

In certain instances both partners would be HIV positive, without knowing that the other partner is also HIV positive. Client 03 put her experience this way:

"I accepted him, he disclosed his HIV status before we became involved in a relationship."

HIV disclosure patterns were different amongst individuals and motivation to disclose or not to disclose depended on the HIV status of their partners (Mlambo & Peltzer, 2011). Some clients disclose their HIV status as a result of a sense of responsibility towards their partners (Klitzman & Bayer, 2003).

And client 04 pointed out that:

"I knew before we were involved in a relationship that she was HIV positive. I also disclosed to her that I was HIV positive."

It seems that people who are HIV positive feel comfortable to date other people who are also HIV positive. This may be motivated by the need to feel accepted and the fear of rejection. So if they are both HIV positive, the chances of them being rejected become limited.

There are however, those respondents who were taken aback by the disclosure as they never suspected that their partners were HIV positive. The reaction of client 10 is more expressive:

"I wanted to know why he kept his HIV status confidential."

In some instances the partners were very supportive and accepted their partners' conditions. Some even took the initiative of accompanying their partners to the clinic for counselling and testing. Being accepted by their sexual partners was important to the respondents. One respondent indicated that she had not disclosed to her sexual partner as she was afraid that he would react violently. Client 26 explained her predicament this way:

“I have not disclosed, and I think it is going to be hard now because I kept it for too long. If I disclose now I don’t know how he is going to react. I am really scared, what if he thinks that I infected him with HIV deliberately and reacts violently.”

The social hierarchy and the differential power relations that exist, blame women for bringing the infection in the family, especially seen when the woman has been tested for HIV before the husband. Coping with her HIV status and looking after her child or a sick family member is a burden that she has to manage along with her own health and social vulnerabilities. Social norms, subservience in marriage, often reinforced by violence, can compromise women’s ability to protect themselves, while a husband even though HIV-positive gets an opportunity to leave his wife with AIDS and his children to find another wife. Furthermore, women are often blamed for spreading both STDs and HIV (Mawar *et al*, 2005).

Client 28 had not disclosed to her husband and this is how she explained her situation:

“I have not disclosed to my husband, I think he is also HIV positive because he is on treatment but does not tell me what the treatment is for.”

Empowerment of couples regarding disclosure of HIV status is critical. Health care professionals need to strengthen support of couples in this regard. Self-determination Theory (SDT) has always maintained that the development of incorporated, independent functioning depends on awareness. Recently SDT researchers have begun to incorporate that idea through studies of mindfulness, defined as an open awareness and interested attention to what is happening within and around oneself (Brown & Ryan, 2003). If people on antiretroviral therapy are aware of their environments and how those around them are likely to react to their positive HIV status, they will be encouraged to disclose their HIV status.

7.9.2 Duration of disclosure of HIV status

Most respondents indicated that they disclosed immediately after being diagnosed HIV positive. Only a few took a bit longer to disclose. Some respondents pointed out that this question did not apply to them as they had not disclosed or did not have a sexual partner. The individual’s ability to disclose to a sexual partner is influenced by many factors.

Disclosure is a process and not an event, requires sufficient preparation. Studies on HIV status disclosure conducted on men indicate that they did not disclose directly but rather would hint to their partners about their condition (Canadian HIV/AIDS Legal Network, 2012). Some men even go to the extent of initiating antiretroviral therapy without disclosing to their partners and in some instances would even lie that they tested HIV negative.

Waiting for a longer period before one discloses also poses challenges when they decide to disclose at a later stage as they do not know how their partner will receive the news. Those who decide to disclose immediately after being diagnosed HIV positive are also able to encourage their partners to go for counselling and testing. Thorough HIV counselling also assists clients to cope easier with HIV and also empowers them on how and to whom to disclose.

7.9.3 Theme 5: Safer Sex Practices

Table 9: Safer sex practices

THEME	SUB-THEME
Safer sex practices	Reasons for adopting safer sex practices

When asked about their sexual partners' HIV status the majority indicated that their sexual partners were HIV positive, and only a few said that their sexual partners were HIV negative, and the others said they did not know and the rest pointed out that this question did not apply to them as they did not have sexual partners.

Disclosing one's HIV status may limit the risk of transmitting HIV to sexual partners and may lessen the stressful burden of hiding one's condition, increase material and emotional support and facilitates both shared responsibility for safer sex practices as well as providing assistance with regard to treatment adherence (Bouillon *et al*, 2007).

It is evident from this data that someone's HIV status does not necessarily reflect their partner's HIV status. Owing to the fact that some people still chose to remain with their partners even after an HIV positive diagnosis is an indication that more people are becoming

more tolerant and accepting of people infected with HIV. The majority of the studies reported positive outcomes related to disclosure. Women reported receiving support, their partners being kind, understanding and caring after they had disclosed (Medley *et al*, 2004). Only few respondents indicated that the relationship broke up after disclosure in this study. The majority of the respondents chose to stay and be supportive of their HIV positive partners.

However on the contrary, there are those who even after their partners were diagnosed HIV positive and offered their support still refused to go for counselling and testing. Women with HIV and AIDS are hesitant to access health care for fear of breach of confidentiality, perceive stigma from provider, and are reluctant to take medications that identify them as being ill. Women are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism or their property being seized after their partner died. The denial of these rights increases women and girls' vulnerability to sexual exploitation, abuse and HIV. The impact of the epidemic on women and girls is especially marked as they face heavy economic, legal, cultural and social disadvantages. According to the Centres for Disease Control and Prevention (CDC), the number of women with HIV and AIDS continues to increase (Mawar, Sahay, Pandit & Mahajan, 2005).

7.9.4 Safer sex practices

Safer sex practices are not only essential for those who are not infected with HIV, but also to those who may be infected. Most of the respondents said that they practiced safer sex, a few indicated that they did not practice safer sex and the others pointed out that the question did not apply to them. Mlambo and Peltzer (2011) in a study that they conducted in Mpumalanga found that some clients who were on antiretroviral therapy persisted with engaging in unsafe sexual intercourse and did not disclose to their partners even though they knew they were HIV positive. Disclosure strategies are critical and need to be given priority so as to prevent more HIV infections or even the transmission of the resistant strain of HIV.

Gender based violence (GBV) contributes significantly to the transmission of HIV and many women who are HIV positive are subjected to this inhumane practice. Violence or being threatened with abuse prevents women from negotiating for safer sex and often these women do not even have a choice to abstain. Women and men who are vulnerable and scared of

their violent partners may not be in a position to demand condom use. As a result of abusive behaviour of their partners many women may be afraid to go for counselling and testing, disclosing after a positive diagnosis and will not even seek treatment even when they know they are HIV positive (VSO, 2012). The South African government provides condoms that are distributed to the wider public free of charge. Some studies have reported inconsistent condom use.

Gender inequality suggests that women have a lack of negotiating power in sexual relations. Many South African women find it very hard to negotiate for safer sex practices with either their husbands or sexual partners. This exposes them to sexually transmitted infections such as HIV. One of the major factors that play a role in the dynamics of HIV infection, is the level of empowerment. The low level of education, especially in women and patriarchal systems puts women in a subservient position. Consequently, women have lesser control over their protection (Mawar, Shay, Pandit & Mahajan, 2005). A woman who is financially dependent on her partner will find it difficult to insist that her partner use condoms during sexual intercourse, thereby exposing herself to HIV infection or re-infection if she is already HIV positive. According to self-determination theory those who choose not to disclose their HIV status to people in their support network need to rely on internal motivation to adhere to treatment. Therefore, autonomous motivation becomes critical in this regard (Kennedy *et al*, 2004).

7.9.5 Reasons for not practising safer sex

Safer sex practices are very important in curbing the spread of HIV and AIDS. However, many people still find it difficult to practice safer sex. Some women indicated that their partners did not like condoms as they burst.

The difference between sexual behaviour of sero-concordant and sero-discordant partners is not evident. After diagnosis with HIV, many respondents indicated that their sexual behaviour changed in certain respects. Behavioural changes pointed out included abstaining from sexual intercourse and using condoms consistently (Mlambo & Petlzer, 2011).

Some couples were trying to conceive and had decided to engage in unprotected sexual intercourse.

Client 03 put it this way:

“My partner and I would like to conceive a baby, therefore we do not use any protection.”

Not using condoms also carries the risk of unwanted pregnancy and the subsequent transmission of HIV to the child (Sarna, Gupta, Pujari, Sengar, Garg & Weiss, 2006). The findings of this study contradict these findings, as respondents in this study consciously engaged in unprotected sexual intercourse to enable them to conceive. Many people who are HIV positive in South Africa are very poor and cannot afford advanced procedures such as invitro-fertilization or artificial insemination. Therefore, these people would often risk HIV transmission to their partners and to their unborn babies.

Some could not practice safer sex due to intoxication. Client 10 had this to say:

“I used to drink a lot and would often forget about using protection.”

Alcohol use may disproportionately impact antiretroviral therapy adherence in women. Alcohol use is very common among people living with HIV (Bonolo *et al*, 2003). The danger of abusing alcohol and other substances whilst on antiretroviral therapy is that one may forget taking the treatment.

The majority of the respondents had regular partners and most of the sexual activity was with a regular partner. Reported condom use with a regular partner was very high. Inconsistent condom use is a concern for sero-concordant partners because of the risk of re-infection with new viral strains, which in turn accelerate disease progression.

Incidents of unprotected sex were higher amongst married women than their male counterparts. Partners' refusal to be counselled and tested for HIV was one of the most crucial hindrances in prevention interventions. Condom use was much higher in sexual relationships in which both partners were aware of their HIV status (Bunnell, 2006). The need to protect one's partner was a motivation to use condoms.

Women need not accept unjustifiable excuses of the inability to use male condoms due to the fact that they burst or are too small, as there are female condoms that afford couples an alternative.

Client 27 voiced out her frustration by saying the following:

“My husband refuses to use condoms.”

The Prevention of Mother-to-Child Transmission (PMTCT) has given many couples hope of giving birth to healthy babies. HIV and AIDS counsellors need to reinforce the message regarding the dangers of engaging in sexual intercourse after consuming alcohol, as the chances of engaging in unprotected sexual intercourse are very high and one may also forget to take their treatment.

7.10 Theme 6: Gender Related Questions

Table 10: Gender and ART adherence

THEME	SUB-THEMES
Gender issues	History of caring for an HIV positive person
	Accessibility of health facilities

7.11 History of Caring for an HIV Positive Person

With regard to whether the respondents had ever taken care of an infected person, the majority of the respondents indicated that they had taken care of a close relative who was HIV positive, only a few indicated that they had never taken care of a person living with HIV.

Client 03 had this to say:

“Yes, I do have the experience of taking care of family members infected with HIV. My wife was very sick I was very caring and supportive until she died. I am now taking care of our 9 year old child who is also on antiretroviral therapy”

Within families, several routes of HIV infection need to be taken into account such as engaging in sexual activities with a partner who is negative, the risk of HIV transmission in the course of taking care of a person infected with HIV and HIV transmission from the mother to the unborn baby (WHO, 2005).

Client 13 explained his experience this way:

“I was married to two women, both of them became very sick because of HIV and I had to step up and take care of them. They have both passed away”

The fact that the majority of the respondents indicated that they had taken care of a person who was infected with HIV indicates that South Africa is the hardest hit country by this epidemic. Many families have one or more family members who are infected with HIV. Collaboration and networking remain critical if we are to combat the spread of HIV and half new infections by 2015 according to the Millennium Development Goals. The responsibility of caring for the sick is usually assigned to women, however, this study revealed that men also occupy this role if the need arises in their lives. The experiences of these respondents may also be an indication that South Africa is a caring society.

Client 23 had this to say about her experience:

“HIV hit our family very hard, my younger sister and her husband became ill, I don’t even know who came with the virus in their home. I did not focus on that, I took care of both of them. I showed them love, but unfortunately they both died eventually”

Family members may be burdened by caring for those who are HIV positive and may also be stigmatised by community members. Learning about the HIV status of a family member leads to concealed information about the individual’s sexual behaviour or unfaithfulness (WHO, 2005). Therefore, if family members are not careful they will waste valuable time and their limited resources trying to determine who brought HIV within the family and in some instances the assistance of a traditional healer is sought in order to catch the culprit responsible for the illness.

Client 31 explained her experience in this way:

“Yes, a few of my family members are infected with HIV. I am caring for my son, my husband and I also took care of my brother who has since passed away”

HIV diagnosis places a heavy burden on partners and family members of those who are infected with HIV. Seeking assistance from the available social networks becomes difficult and in some cases they cannot even disclose to other family members. In situations where the caregiver is the partner of the sick individual, he or she may become depressed and experience burn-out as a result of caring for the sick person. Counselling and other support services become crucial for families that are caring for a person living with HIV and a comprehensive package of services need to be provided (Chan & Chung, undated). In the course of providing support to the individual who is infected with HIV, the focus should also be on the family as they also go through a stressful period. The individual living with HIV cannot be treated in isolation from their family members, they need all the information on the disease so that they can be able to support the person who is sick.

7.12 Accessibility of Health Facilities

According to the Constitution of the country, Act 108 of 1996 section 27, sub-section 1 (a) the South African Government has an obligation to ensure that all health facilities are easily accessible to the people. This study found that most of the respondents did not find the health facilities accessible. Only a limited number indicated that the health facilities were accessible.

Stigma is strongly associated with visiting certain health facilities, including HIV Counselling and testing and antiretroviral therapy treatment sites. Fear of stigma and discrimination deter people from seeking these services, as a result this culminates into unnecessary delays in knowing one’s HIV status and the initiation of therapy (Padarath *et al*, 2006).

In South Africa, health facilities are given names, and as a result people can easily associate the name of the ART clinic with those who are infected with HIV. Having a low income may inhibit clinic attendance because of patients’ inability to pay for transport or childcare.

Accessibility of a health facility is mostly dependent on the management of that particular health facility. The first individuals that the client comes into contact with are usually the administration staff members, and many clients complain that they do not maintain confidentiality and in many instances divulge private information about people who are HIV positive. People lose trust in this kind of service and may even refrain from seeking medical care at such facilities (Jones, 2006). The implication in this regard is that all health facility staff members need to be educated on the importance of maintaining confidentiality so as encourage people to seek medical care.

In this study one respondent explained her ordeal this way:

“Yes, coming to the hospital for treatment is difficult, my village is very far from here so it is impossible to walk. Today I borrowed money from my neighbour who is supportive and understanding, but I do not know how I’m going to repay her as I am unemployed”

Poverty is also an environmental and political problem in the sense that appropriate transport infrastructure may not exist in many townships and rural areas (Kagee, 2006). Many clients are thus forced to borrow money from family members, friends or neighbours so that they can comply with their clinic appointments. Even clients who always comply, transport costs were of great concern as they often did not know whether they will have the funds or not the following months.

Some clients reported that they missed doses because they could not comply with their clinic appointments as they did not have funds before their medication was finished (Bangsberg, Ware & Weiser, 2009). The health facility management needs to take into consideration that most of the people on antiretroviral therapy are poor and unemployed and cannot afford frequent trips to the clinic. The Department of Health in South Africa has introduced the down referral system, which means that antiretroviral therapy is now even available at primary health facilities and clients do not have to travel to hospitals for their treatment anymore.

The shift from curative to preventive medicine, could be used as a rationale for more intense medical policing (Illich, 1982), The Minister of Health in South Africa is advocating for preventive health care as he believes that this approach is cost effective. There is a need to

modify the health care system from being centralized and expensive to being decentralized, accessible and affordable (Illich, 1982); a view shared by the South African Health Minister

A male respondent who is also a truck-driver had this to say about his experience

“I don’t have challenges with regard to accessing health facilities, my work involves a lot of travelling. I make it a point to inform health care workers wherever I go about my condition. For instance, nurses at one of the clinics in Durban know me. Whilst there, I just walk into the clinic and explain that I’m on transit and have run out of medication. They always provide me with treatment, so I can say being open is very helpful” Mobile populations are considered a high risk group, thus HIV and AIDS programmes and other intervention strategies should be geared towards them as well.

7.13 Theme 7: HIV Counselling and Testing

Table 11: HIV Counselling and Testing

THEME	SUB-THEMES
HIV Counselling and testing	Learning about their positive HIV status
	Period of diagnosis
	Consent to HIV counselling and testing
	Referral for CD 4 cell count and viral load tests
	Turn-around time for CD 4 cell count and viral load test results

7.14 Learning about Their HIV Positive Status

There is only one method of learning about one’s HIV status, which is through counselling and testing. However, even though there are those who were just self-motivated to go and seek counselling and testing; there are those women who were HIV positive and pregnant

and were motivated by the need to save the lives of their unborn babies and those who were very sick and just had to be counselled and tested for HIV.

The Self-determination theory (Deci & Ryan, 1985) draws a distinction between autonomous behaviours (those believed to be performed voluntarily and because of personal importance) and controlled behaviours (those that are performed due to pressure or coercion). Even in the context of HIV and AIDS, there may be self-motivated action and forced action.

Client 01 explained it this way:

“I was pregnant and agreed to be counselled and tested as I wanted to protect my baby”.

HIV transmission from the mother who is infected to her baby can take place at three levels, that is: during pregnancy, delivery or during breast-feeding (Woldesenbet, Goga & Jackson, 2012). HIV is a major cause of child morbidity and mortality in developing countries. The pregnant woman has to take responsibility of being counselled and tested so as to protect the health of her unborn baby. If the HIV expectant mother is counselled and tested during pregnancy, the chances of her transmitting the HI virus to her baby become significantly reduced.

The South African government is signatory to the Millennium Development Goals (MGDs) and in this instance three goals are of importance. That is, goal 4 which seeks to, reduce child mortality, goal 5 seeks to improve maternal health and goal 5 seeks to combat HIV and AIDS, malaria and other diseases (Country report, 2013). The level of childhood mortality is a reflection of a country's health status in general. It also reflects on the quality and efficiency of the health system of a particular country (Mckerrow & Mulaudzi, 2010). Childhood mortality is not only a global issue, but a national priority as well. Complications associated with pregnancy and childbirth is among the leading causes of mortality among women of reproductive age in many developing countries. The World Health Organization (WHO) defines a maternal death as “the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes” (WHO, 2008: 157). The use of antenatal care in South Africa is very high, and this is positive for both women and their babies.

South Africa has the highest number of people living with HIV and many of these people need antiretroviral therapy. The HIV epidemic severely hampers the country's ability to achieve several developmental goals, including the target of halting and reversing TB by 2015. South Africa has the third highest TB burden in the world. One of the greatest challenges facing the country is the control of the concomitant HIV and TB infections in the face of increasing drug-resistant forms of TB (UNAIDS Country Report, 2013). The risk of waiting until one is too sick before seeking help is that treatment may not be effective.

Client 07 put it this way:

"I was very sick and my wife encouraged me to go for HCT, I tested positive for both HIV and TB"

The co-infection rate is very high in South Africa. Clients at health facilities need to be counselled and tested for both HIV and TB. South Africa's national response continues to focus on controlling the HIV epidemic and TB, and the government has developed intervention strategies in this regard. The new strategic plan on HIV/AIDS, TB and STIs is comprehensive and outlines four strategic objectives, which are;

- To address social and structural barriers to HIV, STIs and TB prevention, care and impact;
- Prevent new HIV, STIs and TB infections;
- Sustain health and wellness;
- Increase protection of human rights and improve access to justice.

(UNAIDS Country Report, 2013).

It is highly envisaged that this new strategic plan will ensure effective collaboration with regard to treating HIV and TB.

Health care professionals work in collaboration with funded non-governmental organizations so as to provide health care services of good quality. Home based carers also encourage community members to go for counselling and testing.

Client 23 indicated that:

“My wife and I received couple counselling”

One of the most important principles in antiretroviral therapy adherence counselling is that clients need to be actively involved in making decisions about their own treatment. Highly Active Antiretroviral Therapy (HAART) should not be prescribed without the commitment of clients. Couples need to be educated on proper use of condoms and couple counselling on the importance of safer sex practices is also important (Chan & Chung, undated). If a couple is HIV positive they can be given information on how to care and support one another in adhering to their treatment. The counselling session also affords the couple the opportunity to ask questions that they might have on HIV and antiretroviral therapy.

Client 30 said:

“I had cancer of the cervix and HCT was done”.

Pap smear is also encouraged so as to screen for cancerous cells in the cervix. Many women who are HIV positive also suffer from cervical cancer.

7.14.1 Period of HIV diagnosis

The majority of the respondents learned about their HIV positive status between 2007 and 2008. Some discovered that they were HIV positive between 2009 and 2010 and the others found out between 2011 and 2012. There are those who learned about their status between 2003 and 2004 and yet others discovered it between 2005 and 2006. There is only one respondent who indicated that they found out about their status between 2003 and 2004.

At this point one needs to pause and ask whether South Africa will be able to meet the Millennium Development Goals (MDGs). The Millennium Development Goal 6 seeks to: Combat HIV and AIDS, malaria and other diseases. Target 7 seeks to, have halted by 2015 and begun to reverse the spread of HIV and AIDS (UN, The Millennium Development Goals

Report, 2007). This goal will be difficult to achieve if the country is still experiencing new infections.

7.14.2 Consent to HIV Counselling and testing

In HIV Counselling and Testing it is important for clients to give their informed consent in writing to indicate that they were not coerced into having the procedure done. Most of the respondents gave their consent and only one pointed out that she did not give consent as she was very sick. According to the AIDS Law Project and Lawyers for Human Rights (2005) there are exceptions to the rule of informed consent in that if the client being treated in a health facility is unable to give consent on their own for HIV counselling and testing their next of kin should give consent on their behalf.

The only times a health care worker does not need to obtain informed consent to conduct an HIV test are as follows:

Emergencies: if a patient needs emergency treatment, the doctor or hospital does not need to get consent before carrying out essential treatment that will save the patient's life.

Testing done on blood donations: the voluntary donation of blood at a blood transfusion service centre is controlled by the Human Tissue Act. This law indicates that all donations of blood must be voluntary, people cannot be forced to donate blood and they cannot be paid for donating blood.

- Mentally ill patients: the Mental Health Act says that, if a mentally ill person is unable to consent to treatment or testing, you can get consent from their:
 - Curator (person appointed by law to look after them)
 - Spouse (husband or wife)
 - Parent
 - Child (if the child is 21 or older)
 - Brother or sister

Anonymous, unlinked testing: testing is sometimes done for research purposes to find out how HIV is spreading in the population.

Testing when there is a needlestick injury: A person can be tested for HIV without informed consent if a health care worker has a needlestick injury and the person, whose blood sample is available, refuses to give informed consent to test the blood. The person must be told that the blood sample will be tested, but will not get the results of the test unless he/she asks for them. The person must be told that the results will be disclosed to the health care worker, otherwise it will remain confidential (AIDS Law Project & Lawyers for Human Rights, 2005).

If the law allows for testing without informed consent: if a statute law allows for testing without informed consent. There is currently compulsory HIV testing of people accused of sexual offences, such as rape.

7.15 Referral for CD4 Cell Count and Viral Load Tests

According to the ART policy guidelines, it is important for all clients who test HIV positive to be referred for CD4 cell count and viral load tests. If the CD4 cell count is below 350 the client is offered treatment adherence counselling together with their treatment supporter and thereafter initiated on ART. All respondents indicated that they were referred for CD 4 cell count and viral load tests.

Previous research has revealed that integrating STIs/HIV counselling and testing into family planning services is feasible and can improve the quality of care for both clients and health care providers. The challenge is that there is poor integration of services and family planning clients were not actively referred for further services such as antiretroviral therapy (APHIA II, 2010).

A referral system that is effective will enable clients to receive comprehensive treatment, care and support. Other research studies have discovered that there is growing evidence that people who test positive for HIV are not actively linked to HIV care programmes, which leads to late presentation for treatment and increased risks of HIV-related morbidity and mortality (Scalon & Vreeman, 2013). However, this study contradicts this finding in that all

respondents pointed out that they were referred for CD 4 cell count and viral load tests. This could imply that the policies that the South African government has developed in managing HIV and AIDS are being effectively implemented.

In a case study that was conducted in rural Tanzania, introducing simple referral forms, transportation stipends and community navigators showed success in increasing and monitoring linkages to care (Nsigaye, Wringe, Roura et al, 2009). A cross-sectional study in Kenya supported mobile testing and used the services of patient navigators to improve linkage (Hatcher, Turan, Leslie *et al*, 2012). This indicates that HIV management cannot be left to health care professionals alone, lay people also have a vital role to play in this regard.

7.15.1 The turn-around time for CD4 cell count and viral load test results

With regard to the amount of time it took for the respondents to receive their CD4 Cell count test results, this varied from three days in some cases to three weeks in others. Most respondents pointed out that it took two weeks for them to receive their results. The turn-around time is not supposed to last long as the health of the client may be compromised.

7.16 Theme 8: Health and Side-Effects Management

Table 12: Levels of CD4 Cell Count and Viral Load

CODE: CLIENT #	LEVEL OF CD 4 CELL COUNT AT ONSET OF THERAPY	LEVEL OF CD 4 CELL COUNT CURRENTLY	NUMBER OF YEARS ON ART	LEVEL OF VIRAL LOAD
01	147	420	5 years	Undetectable
02	51	552	6 years	Undetectable
03	72	431	7 years	Undetectable
04	146	533	3 years	Undetectable
05	150	539	4 years	Results unavailable
06	18	1100	8 years	Undetectable

07	120	577	3 years	Not known
08	162	490	4 years	Not known
09	195	400	4 years	Not known
10	50	162	2 years	Not known
11	7	984	6 years, ⁶ / ₁₂	Not known
12	266	266	10 months	Not known
13	304	507	6 years, ⁶ / ₁₂	Not known
14	170	274	2 years	Not known
15	118	645	8 years	Undetectable
16	157	566	4 years	Undetectable
17	31	31	2 years	Detectable
18	29	45	4 years	Detectable
19	37	37	9 years	Detectable
20	40	40	5 years	Detectable
21	80	146	3 years	Detectable
22	175	813	3 years	Undetectable
23	241	241	⁶ / ₁₂	Detectable
24	292	292	⁷ / ₁₂	Detectable
25	8	815	6 years, ⁷ / ₁₂	Undetectable
26	190	531	5 years	Undetectable
27	340	340	9 months	Not known
28	101	949	6 years	Undetectable
29	101	101	5 months	Detectable
30	181	573	2 years	Undetectable
31	114	619	12 years	Not known

The researcher was given permission to review the medical records of the respondents. Eleven (35%) respondents' medical results indicated that their CD 4 cell counts were below 100 at the onset of therapy. However, some of them improved to the extent where their viral loads were undetectable (the amount of virus in their blood was too low). The level of CD 4 cell count also improved as a result of being on ART. One respondent's CD 4 cell count was

only 18 at the onset of therapy, but at the time of the interview it was at 1100. Another respondent's CD 4 cell count was only 7 at the onset of therapy and 984 during the time of the interview and another remarkable case was a respondent whose CD 4 cell count was only 8 at the onset of therapy and 815 at the time of the interview. The longer one stays on treatment the more likely they are to have an increased CD 4 cell count and an undetectable viral load. There was very poor record keeping at the public health facility 08 and 02 health centre as most respondents' monitoring results were not available in their files, such as the viral load results.

Public health facility 06 also had challenges as their clients showed very little or no improvement at all even though some of them had been on treatment for 9 years. The viral loads of all respondents from public health facility 06 were detectable (there was a very high amount of virus in their blood). The health of all respondents from private health facility farm workers, improved tremendously and they all had undetectable viral loads. Interestingly, none of the respondents' CD 4 cell count was over 600, even though one had been on treatment for 7 years. Is there something that affects their immune systems? Could it be being exposed to the sun for many hours on a daily basis? Further research is recommended in this regard.

In more economically developed countries, the threshold for treatment is a CD4 cell count that has dropped below 350 cells per cubic millimetre (mm³) of blood, which is what has been recommended by the World Health Organization (WHO) for all countries since 2010. In less developed countries governments decide whether to follow old guidelines, which recommend treatment starts at 200 cells/mm³, or follow the WHO 2010 guidelines (ART in South Africa. Htm, 2011). The South African government initiates clients on treatment at a CD 4 cell count of 350 since 2010.

As the disability grant for people living with AIDS is an important source of income in communities where unemployment is high, a high viral load and low CD4 cell count may be seen as desirable as these represent access to grant and therefore a viable alternative to complete destitution (Nattrass, 2005).

7.17 Experience of Side Effects

Table 13: Side-effects

THEME	SUB-THEMES
Side-effects	Type of side-effects experienced
	Management of side-effects
	Treatment interruption

With regard to whether the respondents had experienced any side-effects, the majority indicated that they had experienced side effects and only a few pointed out that they never experienced any side effects.

According to Illich (1976) modern medicine has always been considered toxic and most of the medication is accompanied with side effects and these side effects are common as the medications are also widespread Illich (1976). It is therefore important for clients and their health care providers to engage in a collaborative relationship so as to manage the side effects effectively.

The most simple, effective and potent regimen will fail if patients experience side effects that they perceive as problematic and terminate their medications. At the time that the regimen is prescribed, health professionals should be proactive and provide strategies to help clients manage any side-effects that may occur (WHO, 2003).

7.17.1 The type of side effects that they experienced

During treatment adherence counselling, clients are alerted of the fact that they might experience side effects. Some people do not experience any side effects at all and yet there are those who suffer from severe and complicated side effects. The side effects vary from being minor and mild to being debilitating and severe. Rash, vomiting and hallucination were the most common side effects amongst the respondents.

Client 10 described her ordeal as follows:

“I had quite a few side-effects, hallucination, night sweats and hearing problems.”

Side effect refers to any result of a medication that is in addition to its desirable outcome, especially an effect that is damaging or unpleasant (Cocohoba, 2011). Many people in antiretroviral therapy are able to tolerate the treatment without major complications. Health care providers cannot predict who might be at risk of experiencing side effects while on ART. Factors such as gender, ethnic background, age and genetic make-up influence whether an individual will react poorly to medication or not. Research indicates that women are more at risk of experiencing side effects than men and this leads to treatment termination in some cases (Cocohoba, 2011). Strategies to assist women who experience severe side effects need to be developed and implemented in order to mitigate this challenge.

These are considered mild side effects in that they usually stop after a few weeks or in some cases with the aid of antibiotics. Lipodystrophy is a more severe side effect and can affect the client' self-esteem.

Client 16 had this to say:

“I started developing breasts like a woman, and the medication was changed.”

Fat accumulation, to the stomach or breasts or across the shoulders, has been more linked to protease inhibitors and non-nucleoside reverse transcriptase inhibitors (NNRTIs). Fat loss, from arms, legs, face and buttocks, has been linked mainly to d4T, and to a lesser extent to AZT. D4T and AZT are both drugs that are included in recommended first line therapy in the WHO guidelines (Collins, Clayden, Guarinieri *et al*, 2008). Continuous counselling and in some cases change of medication is recommended. Changes in body shape caused by ART are a concern for many women on ART.

Side-effects have been associated with decreased adherence and clients who experience more than two aversive reactions are less likely to continue their treatment. HAART regimens usually have temporary side-effects including transient reactions (diarrhoea and nausea) as well as longer-lasting effects (i.e. lipodystrophy and neuropathy). The extent to which side-

effects alter a patients' motivation to adhere to a treatment regimen depends greatly on the specific contextual issues surrounding the individual (WHO, 2003).

Client 04 pointed out that:

"I had Itching rash on my face and changes in body shape"

Lipodystrophy refers to changes in fat cells and the distribution of body fat. This can result in losing fat from your arms, legs and face or gaining fat in your abdomen, breasts or shoulders. It also includes changes in blood fat and blood sugar levels. Different drugs may be responsible for fat gain than those responsible for fat loss (Collins *et al*, 2008). Lipodystrophy is also another side-effect that is common amongst women.

Client 26:

"My body shape is changing, I also developed a buffalo hump and my legs were getting thinner"

The causes of lipodystrophy are not known. Some HIV-positive people who are not on treatment may also experience it. Lipodystrophy usually, but not always, develops slowly over many months or years. Early symptoms may reverse if the treatment regimen is changed. Exercise and dietary changes can also help (Collins *et al*, 2008). Treatment adherence counselling sessions also need to incorporate the adoption of a healthy life-style. Sensory neuropathy associated with HIV infection is the most common neurological complication of this disease. Distal sensory polyneuropathy (DSP) is the most common side-effect associated with (HAART) Highly Active Antiretroviral Therapy (Smith, 2011).

7.17.2 Management of side-effects

It is easier for people on ART to manage side effects if they are thoroughly prepared. As indicated earlier, side effects caused by ART usually stop on their own after a few weeks of being on treatment. In certain situations medication is even changed to enable the client to lead a normal life. It is interesting to realise that some respondents reported their side effects

to their church pastors who prescribed *ditaelo*, which could be water, salt, tea, Vaseline etc. (holy water and tea) usually prepared by the Zionist Christian Church (ZCC).

Client 25 indicated that she dealt with her condition this way:

“I went to my church, Moria to report to the pastor and he prepared “ditaelo” for me”

Most of the side-effects that many people experience are not life threatening, but can be very challenging to manage. Common side-effects are nausea, diarrhoea, rash and fatigue and may even cause some clients to terminate the treatment (Cocohoba, 2011). Clients on ART are encouraged to consult their health care providers as soon as they experience side-effects. It is interesting to observe that in this study some respondents indicated that they reported their side-effects to the churches and were given “holy water or tea” to manage the side-effects. Collaboration between health care facilities and churches is therefore important so as to care for the clients holistically.

However, most respondents reported to their clinics as soon as they experienced side-effects. Client 02 explained her situation this way:

“I received soap from the clinic for the rash and medication for my eyes.”

In certain instances where the side-effects are debilitating, it is imperative for health care workers to change the medication. Client 16 said:

“I went to the clinic to report about my side-effects and the medication was changed.”

Regular monitoring of clients on antiretroviral therapy is of utmost importance as it provides health care workers opportunities to detect serious challenges with the treatment and act promptly (Cocohoba, 2011). Clients who do not comply with their clinic appointments miss opportunities for serious problems to be detected earlier.

7.17.3 The Antiretroviral Therapy offered at Public Health Facilities

Table 14: ART offered at Public Health Facilities

TYPE OF ANTIRETROVIRAL THERAPY OFFERED IN PUBLIC HEALTH FACILITIES
Lamivudine, Tenofovir, Nevirapine
Lamivudine, Efavirenz, Stavudine
Lamivudine, Efavirenz, Tenofovir
Nevirapine, Lamivudine, Stavudine

Tenofovir and viread are nucleoside reverse transcriptase inhibitors (NRTIs). Common side-effects include fatigue, headaches, diarrhoea, nausea and gas. Other side effects may include kidney failure. Efavirenz is a non-nucleoside reverse transcriptase inhibitor (NNRTI) and the common side-effects are skin rash, dizziness, hallucinations and increases in cholesterol. Pregnant should not take this medication in the first trimester as it can have severe side-effects for the fetus, such as brain damage and spinal cord defects (Cocohoba, 2011). Health care providers need to be thoroughly trained on this medication so that they can provide clients with appropriate information.

7.17.4 The Antiretroviral Therapy offered at Private Health Facilities

Table 15: ART offered at Private Health Facilities

TYPE OF ANTI-RETROVIRAL THERAPY OFFERED IN PRIVATE HEALTH FACILITIES
Nevirapine, Lamivudine, Viread
Ritonovir, Lamivudine, Tenofovir

The type of ART provided at public health facilities differ from the type of ART provided at private health facilities. One of the reasons for the difference in the type of ART provided at public health facilities and ART provided at private health facilities is that the medication is supplied by different pharmaceutical companies and the issues of affordability are also taken into consideration.

The Minister of Health, Dr Aaron Motsoaledi has launched the new Fixed-dose Combination therapy in April 2013. Adults on ART will now only take one pill once a day, which will greatly improve adherence.

Most respondents indicated that they were on the government's ART programme, whereas a few indicated that they were not on the government's ART programme as they were receiving their medication from the private health facility. The facility is an NGO that receives their antiretroviral drugs privately and are funded by donors and the department of health.

All those who were on the government's ART programme indicated that they could not afford being on medical aids as these were too expensive. Most respondents did not have any medical aids and only two respondents had medical aids. The current health care system in South Africa is disproportionate in that only a privileged few are able to afford private health care. The national Minister of Health is currently piloting the National Health Insurance (NHI) project at selected public health facilities. It is envisaged that the NHI will enable many South Africans to enjoy quality health care services as it seeks to ensure universal coverage.

7.18 Monitoring of CD4 Cell and Viral Load Tests

One respondent indicated that they have CD 4 Cell count and viral load tests done every 3 months. Most respondents pointed out that they go for such tests every six months and the other fourteen indicated that they have tests once a year. It is very essential for CD 4 cell count and viral load tests to be done regularly so as to monitor the clients' progress and response to the medication. Many clients on ART usually improve after being on treatment for a few months.

Studies have demonstrated that suppressed infection of CD4 cells provides a mechanism for lifelong persistence of HIV-1, even in clients on effective antiretroviral therapy. Being able to suppress viral replication so that the viral load is below the level of detection with standard assays is one of the reasons to initiate antiretroviral therapy (Zhou *et al*, 2010).

The World Health Organization (WHO) now recommends that anyone with CD4 cell count that is below 350 should initiate antiretroviral therapy (<http://www.i-Base.info>: accessed on the

17th of June 2013). South Africa started implementing this policy in 2010, and many people's lives have improved as a result of this initiative. People infected with HIV no longer have to wait until their immune systems have severely deteriorated in order for them to start treatment. When an individual starts antiretroviral therapy, the CD4 cell count recovers to almost normal. Even after initiating ART and one's CD4 cell count has normalised, it is strongly recommended that treatment should continue ([Http://www.i-Base.info](http://www.i-Base.info): accessed on the 17th of June 2013).

During treatment adherence counselling, HIV and AIDS counsellors emphasize to clients that an undetectable viral load and improved CD4 cell count do not imply that they are cured and that it is imperative for them to continue taking treatment. Some clients on antiretroviral therapy are influenced by external forces such as faith healers, who claim to cure HIV and yet there are those who after a while develop treatment adherence fatigue. Medicalization is a form of social degradation through which dependence on service consumption is induced. Medicalization occurs whenever some aspect of ordinary, everyday life comes to be so defined that it requires input from an institutionalized medical system. Medicalization make people lose their personal ability to cope with reality as a result of their gain in health care (Illich, 1982). With regard to people on antiretroviral therapy it is imperative that their treatment regimen should be accompanied by a strict nutritious diet.

7.19 Treatment Interruption

It is encouraging to recognize that even though there are respondents who experienced side effects, they have never thought of discontinuing treatment. Antiretroviral therapy is a lifelong commitment and once treatment is initiated it should be taken for life, unless advised otherwise by doctors. In rare cases Structured Treatment Interruption (STI) is recommended by doctors for those clients who did not delay therapy and are responding well to treatment.

7.20 Theme 9: Alternative, Traditional Medicine And Antiretroviral Therapy

Table 16: Alternative, Traditional Medicine and ART

THEME	SUB-THEMES
Alternative, traditional medicine and antiretroviral therapy	Reasons for consulting traditional healers
	The effects of traditional medicine

When asked whether they have ever consulted traditional healers, only few respondents indicated that they have consulted traditional healers and the majority indicated that they had never consulted traditional healers. One respondent indicated that there was no need for consulting a traditional healer as she was one herself. Consultation with traditional healers features as a common recourse for relief in times of ill health, with many people seeking assistance from both traditional healers and allopathic medical practitioners although the order of consultation varies (Padarath *et al*, 2006). However, many clients who are counselled properly know that they are not to take traditional medicine and antiretroviral therapy concurrently as this may result in drug interaction.

The majority of South Africans consult traditional health practitioners on a regular basis for health problems and disease. These practitioners utilise traditional methodologies that stretch back thousands of years. Often the traditional health practitioner is the first port of call for someone sick with HIV or AIDS (Department of Health, 2003). Some clients are forced by their family members to consult traditional healers.

7.20.1 Reasons for consulting a traditional healer

Amongst African people witchcraft is often suspected when a family member suddenly becomes ill. Families spend a lot of money consulting traditional healers, mainly with the aim of “catching” the culprit. Usually traditional healers will identify someone very close to the family as the witch who is responsible for the illness that has befallen the family. Client 08 had this to say about his experience:

“I thought someone was bewitching me.”

In most cases with HIV many people start by consulting traditional healers before going to health facilities for counselling and testing. Witchcraft is often suspected when illness befall a family. Valuable time is wasted in these unfortunate cases, by the time the client starts taking ART it is usually too late to reverse the condition. Client 11 also articulated her experience as follows:

“My family and I thought I was being bewitched, that is the reason they took me to a traditional healer.”

Witchcraft has been a common interpretation of the symptoms of HIV and AIDS in many rural areas of the African continent. People use witchcraft in order to explain the cause a particular disease. Client beliefs of HIV and AIDS origins are important in influencing a treatment strategy (Mall, 2008). Family members play a critical role in supporting those who may be infected with HIV within the family. Empowering the family with information is of utmost importance so as to prevent some of the mistakes that they make in the endeavour to offer support. For some people consulting traditional healers is an individual choice that they make. Client 23 had this to say:

“I consulted traditional healers in Mozambique due to other problems I was experiencing, I thought I was being bewitched.”

The suspicion of witchcraft features very prominently amongst respondents that indicated that they have the experience of consulting traditional healers. Putnam (1993) indicated that social capital has characteristics of social organization, and these comprise trust, norms and social networks that have the ability to enhance the productivity of the society by aiding harmonized actions. Likewise, in order for people infected with HIV to lead normal and productive lives there is a need for them to develop trust with people that they interact with.

7.20.2 The effect that traditional medicine has had in their lives

It is apparent that many people who consult traditional healers have faith in them. The respondents in this particular case indicated that they were assisted by medication from traditional healers.

Client 08 explained his experience this way:

“The traditional healer just gave me herbs and did not reveal who was bewitching me, I was disappointed because I wanted to know who the culprit was”.

Traditional healers prescribe medication that are made up of animal products, herbs, water, alcohol, roots, leaves and bark of trees available in their communities. There are therefore two important critical aspects of traditional medicine, that is, the physical aspect and the spiritual aspect which consist of sacrificial offerings or rituals (Amzat & Abdullahi, 2008). Some people believe that HIV is caused by the anger of one's ancestors therefore, performing a sacrificial offering is a form of appeasing the gods.

There are two groups of traditional healers, those that are considered diviners and those that are seen as healers. The diviner employs divine means to make a diagnosis. The herbalist selects and implements relevant medicines. The continent and indeed the universe are changing rapidly due to modernization. The AIDS epidemic forms part of the modernization powers as it continuously defies and transforms traditional healers' roles and practices (Ritcher, 2003). According to Shilubane (2008) diviners within the worldview of the Tsonga-Shangaana are also referred to *sangoma* or *xingomantanda*. These are people who are spiritually possessed and thus possess mystical abilities to execute their vocations. There is thus a difference between a diviner and a medicine man. To be initiated into divinership (*ku thwasa vun'anga*) and to cut herbalism (*ku tsema vun'anga*).

The divining set according to the Tsonga-Shangaana when properly used by an efficiently trained person has no limits in its ability to divine or predict. It can presume whether a misfortune is as a result of witchcraft or dissatisfaction of the ancestral spirits. The witch will also be revealed as well as the ancestor who needs to be appeased. The cause of the disease, its nature as well as the steps that need be taken in curing or treating the illness may also be specified. There are also gender connotations in the difference, in that women are the ones that are most likely to become diviners, whilst men are more into herbalism (Shilubane, 2008). With regard to the HIV and AIDS epidemic, some diviners may also claim to know which ancestor needs to be appeased. It is thus imperative to ensure that diviners and healers are properly trained and capacitated with information on HIV and AIDS so as to ensure

that they do not mislead their communities. HIV does not discriminate and ancestral spirits and witchcraft cannot cause HIV. Those who are infected at some point will need antiretroviral therapy to prolong their lives and lead a normal life. Thus, adherence is of utmost importance.

There is only one respondent who indicated that the medication made her condition even worse than she was before taking it. This is how she described her ordeal:

“The medication from the traditional healer made me more ill”.

It would therefore appear that traditional medicine also has side-effects that may need attention. On the contrary, there are those individuals who indicated that they were assisted by traditional healers. For instance, client 23 had this to say about his own experience:

“The traditional healer assisted me as he was able to remove what I had eaten from my stomach”.

There is limited evidence for benefits of complementary and alternative medicine as part of HIV treatment, but many people still continue using this medicine. Some research findings indicate that traditional and alternative medicine can be useful in treating certain ailments. A study that was conducted in KwaZulu-Natal in South Africa, found that the use of traditional or alternative medicine had negative effects for treatment adherence (Campbell & Robertson, 2013). Another respondent pointed out that she used to have a terrible headache, which only stopped after the ritual was performed.

7.21 Theme 10: Treatment Adherence and Counselling

Table 17: Treatment Adherence

THEME	SUB-THEME
Treatment adherence	HIV Counselling and testing

7.21 Treatment Adherence and Adherence Counselling

Compliance and adherence are two different words with different meanings, and yet they are used interchangeably. Compliance means honouring health care workers appointments, whereas adherence refers to taking one's medication "religiously" without skipping doses. There was consensus regarding adherence as most respondents pointed out that it meant taking one's medication correctly and daily as instructed by health care workers. Defining compliance was difficult for most respondents as they thought it meant adhering to treatment. Most respondents indicated that they were adherent.

When asked what they understand by the word adherence client 01 defined it in this way:

"Adherence is when I do not skip doses and take my medication on time and comply with clinic appointments"

Adherence implies taking one's drugs exactly as they are prescribed. It further means taking them at the right time. Adherence also includes following a particular nutritional pattern (Steel *et al.* 2005).

This is how client 07 described adherence:

"It means taking one's medication 12 hourly"

Prior the introduction of the fixed-dose combination, many people on antiretroviral therapy had to consume their medication twice a day, 12 hours apart. There are those who had not yet been changed to the new drugs and have to still take their medication twice a day.

Effective adherence to antiretroviral therapy is required to achieve the best virological response it also limits the risk of developing resistance and reduces chances of having opportunistic infections and death (Tiyou, Belachew, Alemseged & Biadgilign, 2010). There are many benefits of adhering to treatment, it is the responsibility of each individual who is on antiretroviral therapy to fit the medication into their daily schedule.

Client 16 defined adherence this way:

“Adherence means taking medication on time daily, drinking enough water, setting an alarm, using protection and eating fruit and vegetables.”

Adherence to treatment has traditionally been viewed as an individual’s responsibility, adherence behaviour is rarely a client’s choice. External factors often conspire to prevent or make adherence difficult. At a macro-level in a country such as South Africa, structural factors are more prominent as many people live in abject poverty and are unemployed. Individual commitment, psychological well-being and behavioural change are necessary for adherence to be possible (Kagee, Remien, Berkman, Hoffman, Campos & Swart, 2011).

Some clients seemed to have difficulties differentiating adherence and compliance. Client 05 explained adherence this way:

“Not skipping doses, taking the medication on time and complying with appointments.”

Medication compliance is defined as the extent of conformity to the recommendations about daily treatment by the health care provider it involves the timing, dosage and frequency (Cramer *et al*, 2008). Compliance to medication also refers to honouring clinic appointments.

It was also indicated by some respondents that one indicator of adherence is an improved CD4 cell count and reduced viral load.

Prior to initiating antiretroviral therapy, it is crucial for clients to be thoroughly prepared. Almost all respondents indicated that they received treatment adherence counselling, only a few indicated that they did not receive any treatment adherence counselling. All public health facilities in South Africa that are providing antiretroviral therapy have treatment adherence counselling programmes, for both the clients and their treatment supporters. Treatment adherence counselling is usually provided by lay counsellors. Illich (1975) believed that lay people have a vital role to play in caring for the sick; he also pointed out however that as a result of the professional nature of health care, lay people’s role was limited. Even though they might have undergone comprehensive training, their professionalism is often questioned as most of them do not have formal training.

7.22 Theme 11: Challenges and Enablers of Treatment Adherence

Table 18: Challenges and Enablers of ART adherence

THEME	SUB-THEMES
Challenges and enablers of ARV treatment adherence	Challenges of antiretroviral therapy adherence
	Enablers of antiretroviral therapy adherence

The respondents offered their own opinions regarding the challenges of treatment adherence. Some were relating to their own personal experiences. The most common challenges revealed by respondents include, fear of being stigmatised, failure to disclose more especially to a sexual partner, fear of being ridiculed and alcohol consumption. There was a concern of “what people will think about me.”

Client 02 described her experience this way:

“Stigma and discrimination as well as being ridiculed that you are on medication.”

In a study conducted in Botswana, Tanzania and Uganda it was found that some clients on ARV’s reported that after disclosing their HIV-positive status they had lost their jobs, were abandoned or badly treated by their partners or were isolated by community members. Due to the fear of being stigmatized, clients on ARVs often decide to hide their HIV status, from colleagues, friends and other people (Hardon, 2006). Taking antiretroviral therapy secretly poses its own challenges as it implies that when there are people around the individual will not be able to take their medication. Social capital describes circumstances in which individuals can use membership in groups and networks to secure benefits. According to Pierre Bourdieu (1986), “Social capital is an attribute of an individual in a social context.” One can acquire social capital through purposeful actions and can transform social capital into conventional economic gains. Being accepted by people that one interacts with was seen as very important for some people on ART, to an extent that they would rather keep their HIV status to themselves than disclose and risk being isolated or even dismissed by their employers.

Disclosure of HIV status to sexual partners was viewed by some respondents as a challenge to treatment adherence. Client 05 said:

“Fear and failure to disclose to one’s sexual partner.”

Many people who are HIV positive are afraid of disclosing as they fear being abandoned, rejected and discriminated, upsetting family members and being accused of infidelity. Many women in poor societies are financially dependent on the male partners and choose to live with HIV secretly than risk disclosing and lose everything (Medley *et al*, 2004). Failure to disclose to one’s sexual partner poses many challenges such as HIV transmission if the couple is sero-discordant, re-infection in sero-concordant couples and unwanted pregnancies.

For some respondents the major challenges were economical, for instance client 21 had this to say:

“Lack of reliable transport, poverty and unemployment are major concerns for many people on antiretroviral therapy”

In a study conducted by Tuller, Bangsberg, Senkunga, Ware, Emenyou and Weiser (2009) they found that challenges in transportation costs was a main theme regardless of whether clients were adherent or not. Even with respondents that were compliant, transport costs caused anxiety as they wondered if they would be able to comply the following month. They also found that a widow who sold mats and baskets pointed out that she once missed almost a month supply of treatment as she did not have enough funds to go to the clinic to fetch her treatment.

Some respondents pointed to side-effects as some of the challenges to treatment adherence. Client 12 pointed out that:

“Lipodystrophy is a challenge as it changes one’s body shape.”

Lipodystrophy has been found to have negative effects on individuals. This side-effect can damage the individual’s self-esteem, one’s HIV status can also be unintentionally disclosed to other people as they will notice the changes in the body shape of the person and this can cause the person to be shunned by their peers and other people they associate with (Green &

Smith, 2004). Many women in this study complained about changes in their body shapes, and wanted to know if there was something that could be done to assist them.

Client 27 outlined the challenges as follows:

“Drinking alcohol and inconsistent condom-use is a challenge as the chances of engaging in unprotected sexual intercourse are higher when one is intoxicated”

Alcohol consumption is a strong and consistent risk factor for poor antiretroviral adherence, and some of this impact may be mediated by the alcohol-related amplification of ART toxicity. Clients who consume alcohol may choose to skip doses because they are scared of toxic symptoms or combined hepatotoxic effects (Braithwaite & Bryant, 2010). Some illiterate people may not even be aware of the dangers of mixing antiretroviral therapy and alcohol and may ignorantly indulge in alcohol whilst on ART.

Traditional healers and pastors who claim to cure HIV were seen by some respondents as challenges to treatment adherence because they lie to people. Unemployment and poverty were also considered challenges to adherence.

In a study conducted by Mall (2008) in KwaZulu-Natal, it was found that some respondents had negative attitudes towards traditional healers as they claimed that they had the cure of HIV. This finding concurs with the findings in this study as many respondents pointed out that they did not believe in traditional medicine as its efficacy was not credible.

Many people with HIV also have other complicating factors in their lives, including health concerns, economic worries and difficulties finding safe and affordable housing (Bamberger, 2000). Homelessness was not a concern in this particular study. Many respondents in this study pointed out that alcohol consumption, unemployment and poverty, traditional medicine and failure to disclose were the main challenges that faced many people on antiretroviral therapy.

7.23 The Enablers of Treatment Adherence

With regard to the enablers of treatment adherence, respondents also pointed out their own views. The most common enablers mentioned were, acceptance of one's condition, disclosure to sexual partners, support from family members and improved health condition and seeing other people who used to be sick getting better was seen as a motivation to stay on treatment.

Client 01 had this to say regarding enablers to treatment adherence:

“Knowing and accepting your HIV status is very important”

This implies that if the client has acknowledged the fact that they are living with HIV it becomes easier to adhere to antiretroviral therapy.

In a study conducted in Khayelitsha, South Africa it was found that some of the enablers to treatment adherence were that trained counsellors were available during clinic hours to assist and support clients who were having challenges regarding ART. All clients were required to identify treatment supporters, usually someone who lives with them. Peer support groups also provided clients an opportunity to be educated on enablers and barriers to treatment adherence. Clients were also supported by a local non-governmental organization (NGO), the Treatment Action Campaign (TAC) (Coetzee *et al*, 2004).

Client 06 outlined the enablers as follows:

“Support from family members, being active and looking after yourself.”

Support for adherence refers to the reinforcement from family members and friends for the client to co-operate with the prescribed instructions (DiMatteo, 2004). Although the respondent considered family support critical, she also felt that it was the individual's responsibility to keep themselves active and to take good care of themselves. There was a general consensus amongst the respondents that disclosure to significant others was of utmost importance.

Client 05 regarded disclosure as critical:

“Being able to disclose to one’s sexual partner is very important.”

Some respondents in this study even pointed out that their treatment supporters were their sexual partners as they felt comfortable to take their medication in their presence because they had disclosed.

Disclosure of HIV status may be a particularly sensitive issue for the youth. Non-disclosure was very common amongst HIV positive young people in Botswana (USAID, 2012). The pressure and the need of wanting to belong is very prevalent amongst young people. A significant proportion of young people living with HIV may have acquired HIV perinatally. This presents new challenges of having to develop strategies to deal with young people who were born with HIV when they reach teenage years (USAID, 2012).

Client 14 felt that health care workers also have a crucial role to play in enhancing adherence. This is how she explained her position:

“Receiving good counselling and knowing the importance of ARVs, as well as improvement in the CD 4 cell count and decrease in the viral load.”

In a study that was conducted by Coetzee *et al* (2004) it was established that most of their clients had just recently initiated treatment and the respondents were given strict adherence counselling sessions prior to initiating antiretroviral therapy.

Some respondents felt that the availability of food parcels also enhanced treatment adherence. Support groups were also viewed as essential in facilitating adherence. Support groups afford people infected with HIV an opportunity to interact with other people living with HIV and to share their experiences of being on antiretroviral therapy. Support groups of people who are ill play a crucial role in promoting adherence. These groups afford members a platform to share emotional state and experiences, they also share information on treatment resources and reduce feelings of being secluded (Chan & Chung, undated). Support can emanate from various sources, family members, friends and peers who are also going through a similar predicament can offer support.

7.24 Theme 12: Questions about Resistance

Table 19: Resistance to ART

THEME	SUB-THEMES
Resistance to antiretroviral therapy	Causes of resistance
	Prevention of resistance

7.25 Causes of Resistance in ART

7.25.1 Common themes

There are many factors that can cause resistance to ART amongst the respondents the most common ones were failure to take the medication correctly without skipping doses, believing that they are cured and failure to disclose one's HIV status. Notwithstanding the on-going introduction of effective ARV drugs, HIV resistance to all categories of existing drugs continues to develop, confining the successful treatment of many patients with HIV infection (WHO, 2001).

Virologic failure is caused by lack of adherence, which may be as a result of toxicity, poor admissibility or ill-timed dosing frequency or food interactions. There are many reasons for some clients to respond negatively to ART, and some might be because of toxicity and the inability to tolerate the medication. In cases such as these changing the treatment is usually recommended. Immunologic failure ensues when the CD 4 cell count deteriorates regardless of therapy (Del Rio, 2006). Many respondents in this study pointed out that their health improved soon after the treatment was changed to another regimen.

When asked about the causes of resistance, client 04 had this to say:

“Unprotected sex, alcohol abuse, drugs and traditional medicine are the causes of resistance to ARVs. Alcohol is bad for people on antiretroviral therapy, because if you are drunk you might even forget to take your medication.”

Alcohol and other ARV drugs are digested by the same enzymes that convert the ARVs into the associated toxic metabolites. The interaction of ART and alcohol may also lead to hostile reactions such as toxic epidermal necrolysis, hypersensitivity syndrome reaction and liver failure. There is a commonly held belief that alcohol should not be mixed with ART. This is due to the potential of developing adverse drug reactions as well as drug-drug interactions between HAART and alcohol. Many people who are HIV positive do not take their ARVs when they are drinking alcohol (Scheider, Neuman, Chersich & Parry, 2012). Some respondents indicated that the possibility of engaging in unprotected sexual intercourse when one is intoxicated is very high. They might even skip doses.

In a study conducted by Chopra, Kendall, Hill, Schaay and Nkonki (2006) it was observed that respondents who were on antiretroviral therapy had a tendency of using traditional medicine as well as dietary supplements, and they did not view ART as different from these products.

Poor adherence to prescribed antiretroviral therapy and the use of alternative therapies as well as the ability of the HI virus to mutate all facilitate the emergence of resistance (WHO, 2001). Most respondents also concurred that some clients on antiretroviral therapy stop taking the medication once their CD4 cell count starts improving and their viral load is undetectable.

Client 07 had this to say:

“Not taking the medication correctly and skipping doses also caused resistance.”

There are many factors that contribute to people on antiretroviral therapy skipping their doses, some are forgetfulness due to work commitments as well as the unconducive environment. More especially in instances where they are afraid or ashamed of taking their medication when there are other people close-by or in the same room.

Client 23 explained some of the causes as follows:

“Having a new lover that you do not want to disclose to and being uncomfortable with taking medication when there are other people.”

Health care providers need to develop strategies on disclosure so as to empower their clients. It is thus imperative to ensure that the environment is conducive and supportive of those who are on antiretroviral therapy to enable them to adhere to their treatment.

7.25.2 Prevention of resistance

From the responses that the researcher received regarding what they were personally doing in order to prevent resistance, it was evident that they were properly counselled and knew the consequences of non-compliance very well. Most of them emphasised that it was important to comply with clinic appointments, to adhere to medication and disclose one's HIV status.

Client 01 indicated that:

"I adhere to my treatment and comply with all clinic appointments. Being properly counselled helps, as it empowers you with information."

In a study by Johnson and Witt (2007) a number of different approaches were suggested to improve counselling. These included involving domestic partners in counselling and providing spiritual counselling, or offering strengthened counselling for specific clients. The use of peer counsellors was often recommended. Counselling and written information were recommended to be given in the client's home language. Some respondents emphasized the need to increase client literacy to increase understanding and willingness to adhere to the medicines. In South Africa, the Treatment Action Campaign (TAC) is involved in providing training workshops on treatment literacy to people living with HIV so as to prepare them to adhere to treatment.

Client 08 explained his experience in this way:

"I follow all the instructions and have disclosed to my colleagues as well"

HIV disclosure enables the person who is infected to receive the support that they need. It also helps to reduce the stigma that is associated with the disease as community involvement is also encouraged in fighting the epidemic. HIV positive individuals have remained a largely

unidentified and under-utilized resource on the HIV and AIDS prevention and alleviation endeavour (Norman *et al*, 2005).

There was a general consensus amongst the respondents that taking one’s medication as instructed by health care workers and complying with clinic appointments would prevent resistance. Some respondents believed that one’s lifestyle also determines whether one will adhere or not. This is how client 18 puts it:

“For me it is easy to adhere to treatment, because I don’t have extra-marital affairs, having to disclose to a lover is not easy and may even lead to resistance as you skip doses.”

Increased access to antiretroviral therapy may also positively affect sexual behaviour as the treatment improves health considerably as well as the quality of life. This may motivate them to engage in unsafe sexual intercourse (Kennedy, O’Reilly, Medley & Sweat, 2007).

Another respondent indicated that she took her medication wherever she went and did not care about what other people were saying about her. Not mixing antiretroviral therapy with traditional medicine also prevents resistance.

7.26 Theme 13: Positive Living

Table 20: Positive Living

THEME	SUB-THEMES
Positive living	The meaning of positive living
	The use of substances
	Sexual intercourse and the use of substances
	Nutrition and antiretroviral therapy adherence
	Stress and antiretroviral therapy adherence

7.27 The meaning of Positive Living

Once diagnosed HIV positive, it is very crucial for the individual to accept their condition and to develop a positive attitude towards the illness by living positively with HIV. Respondents understood positive living in various ways. They indicated that positive living meant having a balanced diet comprising of fruits and vegetables, having opportunistic infections (OIs) treated, following doctors' instructions without skipping doses, using condoms every time one has sexual intercourse, refraining from alcohol consumption and avoiding stress.

Client 01 had this to say:

“Positive living means taking treatment correctly and eating fruits and vegetables.”

The combination of adherence and having a balanced diet is seen as desirable.

Some respondents believed positive living was adhering and sticking to the times. Positive living also includes voiding drugs and alcohol, as one may forget to take treatment due to intoxication.

Client 05 said:

“Ensuring that I have opportunistic infections treated is very crucial.”

Opportunistic infections constitute a major cause of illness and death in many people living with HIV. The quality of life in many African societies is very low and there is a challenge regarding the access to antiretroviral therapy (Iroezindu, Ofondu, Hausler & Van Wyk, 2013). In these kinds of instances treatment for opportunistic infections might not even be available or easily accessible.

Another client indicated that:

“Positive living means taking medication correctly and not consulting traditional healers”

Research conducted on alternative medicine among people living with HIV in America found that St. Johns Wart, Cat's Claw, Vitamin C and garlic may reduce concentration of HAART in blood, which may cause ineffectiveness (Campbell & Robertson, 2013). Alternative medicine can negatively impact on the effectiveness of antiretroviral therapy.

Some clients pointed out that:

"It means protecting yourself from sexually transmitted infections by using condoms"

Moatti, Prudhomme, Traore *et al* (2003) found that condom use was significantly higher among antiretroviral therapy clients compared to those who were not on therapy. This finding is significant in that it suggests that people on antiretroviral therapy are serious about practicing safer sexual intercourse.

7.27.1 The use drugs, alcohol or cigarette smoking

Most respondents did not use drugs, alcohol or smoked cigarettes. Only a few of the respondents indicated that they drank alcohol and smoked. Substance abuse is a further threat to adherence (Gordillo, Del Amo & Soriano, 1999). In a study of 1889 HIV positive clients receiving ART, difficulties in obtaining medication was associated with non-adherence among heavy drinkers while poor fit of the regimen with the partner's lifestyle was associated with non-adherence among drug users who drank heavily (Tucker *et al*, 2004). Behavioural change in antiretroviral therapy is very important in that those who are on treatment need to adjust their lifestyle accordingly.

Among a sample of HIV positive persons whose ART use was electronically monitored, those with poor adherence had higher rates of substance abuse than those who adhered adequately (Levine *et al*, 2006). As ART adherence requires a high level of cognitive functioning, impairments in these domains are likely to seriously impact treatment outcomes as substance abuse affects concentration, memory, and motivation, leading to poor adherence. Furthermore, substance abusers may also experience more ruptured social and family relationships than non-substance abusers, making it difficult for them to receive social support (Kagee, 2006).

7.27.2 Sexual intercourse and the use of drugs or alcohol

Only one respondent indicated that he sometimes has sex after drinking alcohol and the other one said he does not as he is aware of the dangers of unprotected sex. Non-adherence to antiretroviral therapy has been linked to continued unsafe sexual practices among many people living with HIV. Clients who present with sexually transmitted infections have to be treated together with their partners. Having an STI increases one's chances of contracting HIV. Sexually transmitted infections increase viral load due to the high concentration of viruses in genital secretions (USAID, 2012). Condoms need to be consistently and correctly used.

One of the problems with alcohol is that it can cause liver damage. Excessive drinking can also damage other aspects of one's health. If someone is too much into alcohol, they are likely to engage in unprotected sex and might end up passing the virus on to other people (CHMT, 2006). Irresponsible and risky behaviour is very common amongst people who consume alcohol.

Even though most respondents indicated that they did not use drugs, drink alcohol or smoke cigarettes, they pointed out that their partners drank alcohol and smoked cigarettes and the others indicated that their partners did not use drugs, drink alcohol or smoked cigarettes.

7.27.3 Nutrition and antiretroviral therapy adherence

A balanced diet is very important for people living with HIV and AIDS; and counsellors emphasize the importance of this during counselling as it is part of positive living. It is therefore not surprising to realize that the majority of the respondents pointed out that they do eat fruit and vegetables. All respondents from the private health facility said their employers gave them fruit and vegetables and some respondents indicated that they had fruit trees and vegetable gardens in their homes. Only a few said they could not afford to buy fruit and vegetables.

Antiretroviral therapy saves lives of people who are infected with HIV. Food alone or food supplements cannot replace ART. Food and nutrition play a complex role in the absorption of ARV drugs (PEPFAR, 2006). Proper nutrition needs to be continuously promoted amongst

people living with HIV. In South Africa the former Minister of Health, Dr Manto Tshabalala Msimang used to advocate for the consumption of vegetables and fruit such as garlic, beetroot, African potato and lemon. This sole promotion of nutrition is one of the reasons for the delay in delivering antiretroviral therapy to the public. Civil society organizations such as the Treatment Action Campaign (TAC) challenged Dr Tshabalala-Msimang' stance and eventually won the case in the constitutional court.

7.27.4 Stress and HIV

When asked about their stress levels, most of the respondents indicated that they were not stressed at all and only a few indicated that they were stressed. It is very critical for people living with HIV and AIDS to be able to manage stress as being stressed can significantly harm their health and further compromise their already weak immune system.

Stress has negative effects on the immune system of an individual who is infected with HIV. Research has shown that chronic stress can lead to increased viral load and decreased CD 4 cell counts. Many people with HIV experience stress as they have to deal with compliance, adherence and behavioural change. Stigma and discrimination are some of the negative reactions that these people have to deal with. It is essential for people living with HIV to develop strategies to cope with stress (Toronto People with AIDS Foundation, 2010).

Stress is very dangerous for people living with HIV and AIDS as it can prevent them from seeking treatment. Respondents indicated that they did not feel inferior before other people, they talked about their challenges instead of keeping quiet about it and that they had accepted their condition. An individual's psychological state is crucial in determining whether one will adhere or not (Kennedy, Goggin & Nollen, 2004). Hence psychological problems are usually predictors of poor adherence.

Client 04 had this to say regarding how she copes with stress:

"I talk to my friends about my problems and if there is something that bothers me with my partner, I also talk to him"

Sharing one's challenges with significant others is seen by many people on antiretroviral therapy as contributing to stress reduction. Spiritual fulfilment was also viewed by some as therapy.

Client 11 had this to say about how she deals with stress:

"I talk about the challenges that I may be experiencing and also sing church songs."

Churches through Faith-based organizations play a vital role in educating various communities about HIV and AIDS as well as providing health care (PACANet, 2003). Hence, some respondents indicated that they go to their churches so as to receive spiritual healing.

"Churches' responses so far have focused largely on the pastoral and spiritual: care and support of poor and sick people has been a natural first step. Some churches are also starting to branch out into more complex areas of treatment and prevention. Many churches, have an AIDS desk at the denominational level, which provides trainers and counsellors to support local churches in developing their own HIV and AIDS response." (Nussbaum & Rachel, 2005: 14).

Client 19 had this to say about her experience:

"I talk with health care providers about my challenges"

Depression, anxiety and post-traumatic stress disorder, loss of faith in the health care system as well as experiences of stigma have all been found to be common among HIV positive people. Health care providers need to focus on the mental health of people living with HIV (USAID, 2012). If health care providers are supportive and encouraging, clients find it easy to trust them and easily confide in them. The South African public health sector has a challenge of attitudinal problems amongst health care providers.

For some respondents acceptance was very important and client 29 pointed out that:

"I have accepted my condition, because I know that anyone can acquire HIV"

Self-efficacy is very important in ART adherence. The role of the individual in their own health care is very essential. All respondents indicated that they were taking responsibility for their own health. HIV and AIDS is an individualistic disease and therefore taking responsibility for one's health is very important.

Perceived self-efficacy is concerned with people's beliefs that they can exert control over their motivation and behaviour and over their social environment. People's actions are influenced by their belief in themselves. Their determination to succeed can overcome any obstacle that they can confront (Bandura, 1990). When asked whether they exercised or not, most of the respondents said that they did and only a few indicated that they did not exercise. None of the respondents were member of any particular gym. Most of them indicated that they exercised by doing household chores and walking.

Most respondents were comfortable with taking their medication at home, some indicated that they were comfortable with taking their medication both at home and at work and only two pointed out that they were comfortable with taking their medication at work and did not mind about the stigma associated with taking antiretroviral therapy.

7.28 Theme 14: Effective Strategies to Improve Adherence

Table 21: Strategies to improve adherence

THEME	SUB-THEMES
Strategies to improve adherence	Recruitment of health care workers who care about people
	Respect of clients' confidentiality by health facility staff members
	Distribution of food parcels to people on antiretroviral therapy
	Establishment and sustainability of support groups of people on ART
	Efficient service at public health facilities
	Home based carers to implement DOTART

Respondents believed that there was a need to have continuous education on HIV and AIDS in communities. Adhering and complying with appointments were also prominent amongst the respondents. Normalising HIV was also viewed by some as an appropriate strategy. Two respondents felt that the involvement of Home Based Carers in the antiretroviral therapy programme would be useful as they have experience of managing clients on TB medication through the Directly Observed Treatment Short-Course (DOTS) strategy.

Client 03 felt that the following strategy could improve adherence:

“The government should appoint health care providers and lay counsellors who respect confidentiality and encourage lay counsellors living with HIV to disclose their HIV status so as to encourage other people who consult at health facilities”

The relationship between the doctor and the client helps to improve adherence (Ciechanowski, Katon, Russo & Walker, 2001). Medical health personnel understand the significance of adhering to treatment, hence the need to cultivate healthy relationships between themselves and their clients.

Appointing health care workers who cared about people as well as training and placing more health care workers at health facilities was seen by many as crucial. There was a general consensus that there was a shortage of medical doctors, the need to introduce the one pill a day, encouraging lay counsellors who are HIV positive to disclose their HIV status to clients as well as continuous education on the importance of condom use.

Client 06 pointed out her views as follows:

“If the government could continuously provide food parcels and employment to people it would help to alleviate poverty.”

The South African government provide food parcels and food supplements to people living with HIV, as many are unemployed and do not have access to quality food products. Food parcels and supplements are usually shared by the whole family due to the high levels of

poverty in many families. The provision of food parcels to those who are living with HIV and on antiretroviral therapy enables them to adhere to their treatment.

Client 11 felt that institutional support was important, this is what she said:

“We need to have support groups as they enable people to share their challenges.”

Musheke, Bond and Merten (2013) found that relationships that people living with HIV and AIDS had with their families, friends and health care providers motivated them to be adherent. Formation of and belonging to a support group enabled them to manage and cope much better with the illness. Support groups are a vital aspect in the promotion of ART adherence. Some people living with HIV can only discuss about their challenges and experiences at their health facilities and affording them the opportunity to do so in support groups could be beneficial for their health.

Challenges that have been identified within support groups need to be resolved. People on antiretroviral therapy may be receiving support from their families, but they also need to be supported by health care workers and other people who are also on antiretroviral therapy.

Client 13 felt that the strategies to improve adherence should include the following:

“I feel that people suffer a lot before they get treatment. There are always long queues and the waiting lists are very long as well. Health care workers need to respond to the clients promptly.”

In some instances, some people even pass away before they even access treatment. Human resources management is another challenge facing health care facilities. Health care providers are overburdened with many responsibilities. The HIV epidemic is depleting the resources as it demands more attention due to the devastation caused by the disease.

Client 16 had this to say:

“Home based carers play an important role, because they have experience of implementing treatment programmes. They should be more involved in antiretroviral therapy care and support.”

The psychosocial needs of people living with HIV are complicated, and a multidisciplinary approach is needed in managing HIV clients. Many people seeking assistance at primary health care facilities have various needs that can be addressed by a comprehensive team. This team typically comprise of medical doctors, nurses, midwives, psychologists, counsellors, dentists, pharmacists, social workers and people living with HIV (Green & Smith, 2004). Comprehensive care management and treatment of HIV sites in South Africa are also managed by a multi-disciplinary team. These people have different fields of specialization that complement one another.

However, there are conflicting beliefs about home-based carers, as some believe that they pose a challenge to the antiretroviral therapy programme as they do not maintain confidentiality.

7.29 Theme 15: History of TB infection

The co-infection rate in South Africa is very high and it is important for clients who are infected with HIV to be tested for TB and those who have TB to be tested for HIV. Only a few of the participants in this study indicated that they once had TB and the majority indicated that they had never had TB. In both epidemics treatment adherence is very essential so as to prevent resistance. Effective counselling is of paramount importance.

The co-infection rate is very high in South Africa. HIV's effect on TB is better understood as it is more straightforward than tuberculosis's effect on HIV disease progression. The immune system uses CD4 cells to defend the body against tuberculosis, a decline in CD4 cells lessens the immune system's ability to prevent the growth and spread of TB. Tuberculosis has a more technical interaction with HIV and is thought to increase HIV replication and viral load, thus worsening the course of HIV-related immunodeficiency.

The rate of HIV counselling and testing uptake at TB services is very low and more emphasis should be placed on identifying HIV infected persons when patients attend the consultation after 2 and 6 months of treatment. This study suggests that there may be benefits to integrating HIV and TB services (Coetzee, Hilderbrand, Goemaere, Matthys & Boelaert, 2004). In South African public health facilities, clients who come forward for HCT are also

counselled and tested for TB and those who come forward for TB tests are offered HIV counselling and testing services.

7.30 Theme 16: HIV Stigma Scale

An HIV stigma scale was administered amongst respondents and they were required to respond to 26 questions by indicating whether they strongly disagreed, disagreed, agreed or strongly agreed with the statements. With regard to the analysis of data, the researcher assessed the responses from respondents looking at each individual health facility. Only responses that stood out were analysed.

Private Health Facility 01

Only one respondent indicated that she/he strongly agrees that telling people she/he was HIV positive was risky. Four respondents indicated that they strongly agree that they never feel ashamed of having HIV. In a study that was conducted in the United States of America to determine the impact of internalized stigma, it was found that the majority of the respondents pointed out that they were embarrassed by their positive HIV status (Lee, Kochman & Sikkema, 2002). Three respondents indicated that they agreed that they never feel the need to hide that they have HIV. All five respondents indicated that they strongly agreed that when people learn about one's positive HIV status, they look for flaws in one's character.

Morality has been used to justify stigma and discrimination against those who are infected or affected by HIV (Das, 2002). Judgemental attitudes are displayed amongst those who are considered careless with their lives and sympathy is shown to those who are regarded as innocent victims, such as those who contract HIV through blood transfusion, babies who are born with it and women who are infected by their partners (Schellenberg, Keil & Bem, 1995). These findings confirm the statements of the respondents in this study, as they also felt that they were being judged by their communities.

Public Health Facility 02

Only one respondent indicated that he/she agreed that in many areas of their life no one knew they were HIV positive. The major impact of stigma and discrimination is that they ensure that the disease stays hidden. People who have contracted HIV are forced to conceal their status. As a result other people close to the infected person may be afraid to show their sympathy and support for the fear of being stigmatised and discriminated as well (Skinner, 2001). Many people who are infected would therefore, rather keep their HIV positive status to themselves, than risk being isolated.

All four respondents indicated that they strongly disagreed that they felt guilty because of having HIV. All four respondents indicated that they strongly disagreed that people's attitudes made them feel worse about themselves. Two indicated that they strongly agreed that telling someone they had HIV was risky.

South Africa has reported many incidents of HIV related stigma. Gugu Dlamini, an AIDS activist from KwaZulu-Natal was killed by her community members after publicly disclosing that she was living with HIV (Baleta, 1999). These kinds of reactions deter people from disclosing their HIV status, as they fear violent reactions from their communities.

Three indicated that they strongly agreed that they were careful whom they told they were HIV positive. Only two indicated that they strongly agreed that when people learn you have HIV that they look for flaws in your character. Blame for spreading the disease is often assigned to women and African people (Leclerc-Madlala, 1997). Even in instances where the woman was infected by her husband, blame will be apportioned to her as she will be viewed as the culprit.

Public Health Facility 03

All four indicated that they strongly disagreed that they felt guilty they had HIV. Only one indicated that they strongly agreed that telling someone you have HIV was risky. HIV disclosure is an essential aspect in the prevention, treatment, care and support for those who are infected. Even though positive effects of HIV disclosure have been identified, there are

also potential consequences associated with disclosure such as abuse, rejection and discrimination (Deribe *et al*, 2008).

Three respondents pointed out that they disagreed that most people think that a person with HIV is disgusting. Three indicated that they strongly agreed that they were careful whom they told they were HIV positive.

Temmerman *et al* (1995) found that violent reactions towards women who tested HIV positive were more prevalent than those who tested negative. This study also confirms that the main reason for women to conceal their positive HIV status is the fear of stigma, discrimination and violent reaction from their partners.

Three indicated that they strongly agreed that when people learn one has HIV they look for flaws in one's character. People who contract HIV are often considered responsible for their own misfortune as HIV is contracted from actions that are considered easy to avoid, such as engaging in unsafe sex (Herek, 1999). Some people may not have a choice on their sexual practices, as they may not have the power to negotiate for safer sex practices. In many relationships, men are the ones who make decisions about sexual matters. As they get to decide when, where and with whom to have sexual intercourse. This study revealed that their female partners may have little to say in this regard (See pages 167 and 168).

Public Health Facility 04

Two respondents pointed out that they agreed that people with HIV lose their jobs when their employers find out their positive HIV status. HIV stigma and discrimination negatively impact on every sphere of our society, more especially for those who are infected and their families. In many instances a positive diagnosis can be devastating in that it may lead to job loss, expulsion from school, violence, loss of property and withdrawal of financial support. People who constantly live in fear are less likely to adopt preventive measures, disclose their HIV status, access care and adhere to treatment (Cameron, 2007).

All three respondents indicated that they disagreed that since learning they have HIV they felt set apart and isolated from the rest of the world. All three also indicated that they disagreed that since learning they have HIV they worry about people discriminating against them.

Amongst individuals, the way in which HIV and AIDS related stigma and discrimination are expressed is influenced by family and social support and the extent to which people are able to be open about their HIV status and other private issues regarding their sexuality (Parker & Aggleton, 2002). In situations where the reception in accommodating people are more likely to open-up and be comfortable to discuss their most intimate issues.

Two respondents indicated that they strongly agreed that they have been hurt by how people reacted to learning they had HIV. HIV and AIDS related stigma and discrimination within families and communities are commonly manifested in the form of blame and punishment. Communities often react in very cruel ways towards people who are infected with HIV, and in some severe cases this has been accompanied by violence (Nardi & Bolton, 1991). Rejection by one's family members and the community to which one belongs may be ultimate abandonment and often this occurs after one has disclosed their positive HIV status.

Public Health Facility 05

All five respondents indicated that they disagreed that people with HIV lose their jobs when their employers find out they have HIV. Four indicated that they disagreed that people with HIV are treated like outcasts.

Even though HIV stigma is still prevalent, it seems to have declined in South Africa. The national HIV and AIDS household survey that was conducted in 2005 indicated that stigma had declined (Shisana *et al*, 2005). In this particular study only few respondents indicated that they had been stigmatized, but what was appalling about this finding was that those who experienced stigma, their experiences were very cruel and inhumane. Four pointed out that they strongly agreed that they were careful whom they told they were HIV positive. Four said that they strongly agreed that when people learn about one's positive HIV status they look for flaws in one's character.

Aportioning blame towards people who are infected, may be a way of dealing with the challenge. Even when intervention strategies are developed, they are designed in such a way as to discriminate against those who are infected and affected, the aim here would be to reinforce a sense of safety for those who are presumed negative (Skinner & Mfecane, 2004).

HIV and AIDS programmes may in a way exacerbate stigma and discrimination in the society, by drawing a distinction between those who are infected and those who are not infected.

Public Health Facility 06

Three respondents indicated that they disagreed that people's attitudes about HIV made them feel worse about themselves. Two said that they disagreed that people with HIV lose their jobs when their employers find out they have HIV. Certain governments have introduced legislations to protect the rights of people living with HIV and AIDS, and as a result their right to have access to education, health care including treatment, information and employment are upheld (Kirp & Bayer, 1992). The South African government has also established chapter 9 institutions in order to deal with discrimination against vulnerable groups such as women, children, homosexuals and people with disabilities.

Two indicated that they disagreed that it was easier to avoid new friendships than worry about telling someone they had HIV. Individuals who are already marginalized may be scared of negative or hostile reactions from others (Daniel & Parker, 1993). Therefore, even if people who are HIV positive establish new friendships they may not necessarily disclose their HIV status, as they may experience rejection.

All three indicated that they strongly agreed that when people learn about one's positive HIV status they look for flaws in one's character. Stigma is designed in order to assist the society to deal with HIV. Societies achieve conformity through drawing a distinction between those who are considered normal and those who are considered different. Cultures produce difference so as to attain social control (Parker & Aggleton, 2002). In this instance those who are viewed as different are labelled and shunned by their communities as outcasts.

Public Health Facility 07

All four respondents indicated that they agreed that in many areas of their lives no one knew they had HIV. The fear and experience of stigma and discrimination often deter people living with HIV and AIDS from disclosing their HIV status (Watt *et al*, 2009). In many instances those who are HIV positive disclose to only a few trusted people, usually close female family members.

Only one respondent pointed out that she/he strongly agreed that she/he never feel ashamed of having HIV. Stigma impacts on people infected with HIV as it is internalized into their self-perception and sense of identity, thereby negatively affecting how the individual relates with other people around him or her. Studies on HIV and stigma have shown that many people who are infected with HIV feel isolated, guilty, dirty and shameful (Kalichman, 2004). This is in sharp contrast to the findings in this study, as most respondents indicated that they do not feel ashamed that they have contracted HIV. (See pages 213 to 219).

Two respondents indicated that they strongly agree that they are careful who they tell they have HIV. One respondent indicated that she strongly agrees that some people who know she/he has HIV have grown more distant. Three respondents indicated that they agree that they never feel the need to hide that they have HIV.

In a study that was conducted in Ethiopia, respondents who had disclosed to family members and friends that they were on antiretroviral therapy indicated that they received support and these people ultimately became their treatment supporters (Mekonnen *et al*, 2010). This study also found that close family members were very supportive of the HIV positive individual and opted to be their treatment supporters.

One respondent indicated that she agrees that she has been hurt by how people reacted to learning that she/he had HIV. In a study that was conducted in Tanzania it was found that if a client thought his or her family members were not supportive, they would default on their treatment (Roura *et al*, 2009). Family support is thus, very important as it gives one a sense of belonging and the idea of being loved and cared for.

All four respondents pointed out that they strongly agreed that when people learn about one's positive HIV status, they look for flaws in one's character.

Public Health Facility 08

Three respondents indicated that they agreed that in many areas of their lives no one knew they had HIV. It is often very difficult to disclose to sexual partners, the clients may carefully select people to disclose to (Twehaze, 2009). The concept of relatedness is very significant within the self-determination theory as many people are likely to embrace values and

behaviours encouraged by those they trust. Therefore, with regard to antiretroviral therapy, clients are likely to identify close family members as their treatment supporters as they believe that they will maintain confidentiality. As it is the client's prerogative to decide whom to disclose to it is not always everyone who needs to know who will be disclosed to. If there is a slight sense of negativity, the client is likely to withhold the information.

All three indicated that they disagreed that people with HIV lose their jobs when their employers find out they have HIV. Two pointed out that they disagreed that people with HIV are treated like outcasts.

One indicated that he/she strongly agreed that some people act as if it is their fault they have HIV. HIV and AIDS-related stigma stems partly from the mistaken belief that the disease can be contracted casually and partly from the rejection of people associated with the disease. It fosters wrong assumptions, such as the idea that all women who are HIV-positive contracted the disease from having many sexual partners (Panos, 2006).

All three respondents indicated that they agreed that when people learn about one's positive HIV status, they look for flaws in one's character.

7.31 Summary

The demographic data of sampled people on antiretroviral therapy was outlined. The church has a very significant role to play in promoting ART treatment adherence and this was clearly articulated. Experiences of stigma and discrimination were very minimal, but serious. Social support networks available for people on ART were identified and discussed as well as the role of treatment supporters. The dynamics regarding HIV status disclosure were discussed as well as the importance of counselling. The role of traditional medicine and alternative therapy was outlined. Self-efficacy plays a major role in promoting treatment adherence and this was also discussed. Other challenges associated with ART adherence such as treatment failure were also discussed. Strategies that need to be adopted in dealing with ART treatment adherence were identified and discussed.

CHAPTER 8

ANALYSIS, PRESENTATION AND INTERPRETATION OF DATA FROM FOCUS GROUP DISCUSSIONS (FGDs)

8.1 Introduction

This chapter focuses on the findings from the focus group discussions (FGDs). Fourteen (14) individuals on antiretroviral therapy participated in the focus group discussions. Two focus group discussions (FGDs) of 7 people each were conducted at a private and public health facility. **Challenges experienced by people on antiretroviral therapy such as stigma and discrimination, disclosure, self-efficacy, social networks available to them, enablers and barriers to treatment adherence and strategies employed to enhance treatment adherence are therefore outlined.** Themes and sub-themes were identified. A narrative analysis is provided with verbatim statements of respondents. Grounded theory analysis was adopted.

8.2 Demographic Information

There were 9 females and 5 males in the focus group discussion. Their ages ranged from 25 to 60. With regard to the marital status, six were married, 3 were cohabiting, 4 were single and only 1 was widowed. Eight spoke Xitsonga and 6 spoke Sepedi. Nine were employed and 5 were unemployed, most of those who were employed worked as farm workers. All respondents were African. This data suggests that the respondents would provide meaningful input, as a variety of information could be obtained from all respondents.

8.3 Qualitative Data Analysis Framework

The following themes and sub-themes were identified during the focus group discussion analysis process

- Management of side-effects
- Barriers to treatment adherence
- Enablers to treatment adherence
- Acceptance of one's HIV status
- Disclosure of HIV status
- Treatment supporters
- Support Groups of people living with HIV
- Stigma and discrimination and ART adherence
- The use of technology in ART adherence
- Substance abuse
- Sexual partners and condom use

8.4 Management of Side Effects

8.4.1 Experiences of Side-Effects

Some antiretroviral therapy have side-effects. It is however comforting to learn that it is not all people on ART who will experience side-effects, as it became clear in this study. The most common side-effects were dizziness and diarrhoea. Other side-effects included, hallucination, nausea and vomiting and lipodystrophy. In some instances, medication had to be changed and most respondents pointed out that their conditions improved after the medication was changed.

Member 01 had this to say:

“I was also dizzy most of the time and it lasted for a few months. The side effects were caused by Efavirenz which I have since stopped taking. It was very surprising to me

because I was taking the correct dose. I also hallucinated and this lasted for 3 weeks. I have since changed my treatment from Efavirenz and Stavudine to Nevirapine and Viread”

Efavirenz affects the central nervous system, the symptoms include dizziness, insomnia, impaired concentration, vivid dreams or hallucinations, nightmares, and mania. Most of these side-effects stop on their own without medication, but research has shown that about 40% of people on this drug will experience these symptoms (Carr & Cooper, 2000). Other ARV drugs do not present the same side-effects.

When an ART client experiences severe side-effects it may make it difficult for them to adhere to their medication. It is therefore crucial for health care providers to counsel clients properly so as to prepare them for the challenges that they might experience.

Member 04 said:

“My stomach is getting bigger, my legs are getting thinner. I always have to tie my stomach so it does not show that it is big. My shape has changed as I don’t have buttocks anymore. I would not mind if the medication was just making me fat, but it is now completely changing my shape, even my clothes don’t fit me nicely anymore”

Side-effects such as lipodystrophy are not easy to treat in managing this condition many health care providers recommend a change in the regimen. The client has to work very closely with the health care professionals so as to enable them to develop an effective plan for adhering to treatment. It is important to deal with side-effects effectively to enable the client to lead a productive life (Heyer & Ogunbanjo, 2006). Lipodystrophy needs to be managed effectively as it has the potential of damaging the self-esteem of the client who experiences it. Changes in body shape can also require the client to alter their clothes, thereby inconveniencing them socially and financially. People who know the individual who suffers from lipodystrophy are likely to start noticing the changes in their body shape and this could inadvertently disclose their HIV status.

Women clients complain mostly about the changes in their body shapes. Fat redistribution or lipodystrophy causes changes in the body shape. Diarrhoea and dizziness are also some of the side effects that were experienced by some of the respondents.

Member 05 said:

“I also experienced side effects, such as dizziness and this lasted for a month. They also had to change my treatment, but would experience great pain when I went to the toilet and my anus was also swollen. My treatment has now been changed. I was given medication for the side effects and I am now much better”

Member 08 had this to say:

“I had diarrhoea for two weeks, but it then stopped on its own after that”

Side effects ranged from being severe and to being minor. There are a few respondents who indicated that they never experienced any side effects. It is however safe to point out that most people who initiate ART do experience side effects.

8.4.2 Dealing with side-effects

In order for clients on ART to adhere to their medication, it is crucial to manage side-effects effectively. In some cases health care workers recommend that medication be changed, in others clients are given treatment, whereas in some side-effects stop on their own after a few weeks on treatment. Clients are advised to consult their health care providers if side-effects persist or become severe.

Member 04 had this to say:

“I explained to the doctors and nurses and my medication was changed”

If there is a good working relationship between the client and the health care provider, the client will be encouraged to adhere. Effective communication thus plays a crucial role and a health professional who is perceived to be competent, reliable, empathetic and inclusive in their approach encouraged treatment adherence (Heyer & Ogunbanjo, 2006). People living with HIV need to be regarded as partners by their medical team and involved in decisions about their treatment.

Member 09 explained the experience in this way:

“I came here for consultation and was given medication by the nurse”

Medical practitioners and their clients interpret illnesses differently with medical personnel being more interested and concerned about the virological response and the client reoccupied with the social life and how they feel (Green & Smith, 2004). The consistency or equilibrium in the socialization process is considered very important amongst individuals on antiretroviral therapy. With regard to the clients whose medication was changed, the side-effects stopped soon thereafter.

8.4.3 The respondents were asked what they thought barriers to treatment adherence were, and the following responses were provided:

Patient Factors

Most respondents felt that disclosure of one’s HIV status was critical in order for them to adhere to their treatment. Disclosure to sexual partners or spouses was seen as very important, but most respondents indicated that this can be accompanied by many challenges. Forgetfulness, lack of reliable transport, false pastors and alcohol abuse were seen as some of the barriers to treatment adherence.

Member 01 said this:

“Being fearful and being afraid to disclose to one’s husband for the fear of being divorced. And you would find that the husband is the bread winner and the wife is unemployed, she would be concerned about the well-being of her children. So in some instances women feel that they would rather keep the positive HIV status to themselves and not disclose to their partners”

People living with HIV also have the right to confidentiality. Rights should however be accompanied by responsibilities, they are obligated to disclose to the people they have had unsafe sexual intercourse with. Disclosing one’s HIV status is very difficult and can be very

stressful. The fear of being rejected and the feeling of guilt that they might have infected their partners may hinder people living with HIV from disclosing (Chan & Chung, undated)

Inability to disclose to a sexual partner is a challenge because this may result in re-infection and in cases where the couple is sero-discordant, the partner who is HIV-negative might end up being infected. One respondent felt that there are pastors who claim to have a cure for HIV and encourage people on ART to stop taking their medication after being prayed for, she felt that this was a major barrier to ART adherence.

This is what member 11 had to say about this:

“Mhh...even some pastors also lie to people and say that if they pray for them they will be cured of HIV and it is a lie because there is not yet a cure for HIV”

Stigma and discrimination in the workplace was also a major barrier as those who are on ART and employed feel that disclosure of one's HIV status to their employers may lead to them being dismissed. Non-disclosure in the workplace may prevent the client on ART from adhering to treatment or even complying with clinic appointments. Unemployment is another barrier to treatment adherence, member 13 put it this way:

“Yes, and also lack of transport to go to health facilities. Some people have to borrow money to come here, so it is not easy”

In a study conducted by Tuller, Bangsberg, Senkungu, Ware, Emenyou and Weiser (2009), they found that unemployment was a barrier to accessing treatment, some clients pointed to loss of income as a result of HIV-related illnesses as the cause of their inability to pay for transport to take them to health facilities. In South Africa, the Employment Equity Act No 55 of 1998 expressly protects people against unfair discrimination on the basis of HIV status in the workplace. Section 6 (1) of the Act clearly points out that no person may unfairly discriminate, directly or indirectly, against an employee in any employment due to their positive HIV status. Furthermore, section 7 (1) of the Act prohibits employment related HIV testing unless authorised by the Labour Court (Open Society Foundation for South Africa, 2009). Therefore, if an employee contracts HIV they are not supposed to be dismissed from their job as it would be illegal to do so.

Some clients may think that if they become well after a few months on treatment then it means that they are cured.

As member 10 indicated by saying:

"Uuh...some people think that when they start feeling well and better they are cured of HIV".

It is thus essential for positive messages to be continuously conveyed to community members. There is not yet a cure for HIV and ART serves as treatment to improve the immune system of those infected and enable them to be economically productive in their communities.

8.4.4 The enablers to treatment adherence

Patient factors

With regard to the enablers to treatment adherence, most respondents indicated that acceptance of one's HIV status was pivotal. Support from family members and significant others was also viewed as critical, disclosure and being open about one's HIV status, more especially to people close to you was seen as important. Taking instructions that one was given by health care workers seriously and taking responsibility of one's health was regarded as essential. Three main themes emerged, and these are presented below, not in order of priority.

8.4.5 Acceptance of one's HIV status

Most respondents agreed that individual acceptance of HIV status was key to the necessary behavioural change that is required for good health outcomes. Member 08 said this:

"Accepting one's HIV condition and telling yourself that you did not contract HIV intentionally, it was a mistake"

The client's acceptance of their condition considerably impact on their adherence to highly active antiretroviral therapy (HAART). The client's belief in their ability to take and adhere to medication is referred to as self-efficacy and self-efficacy is related with enhanced adherence (Heyer & Ogunbanjo, 2006). The role of the individual on their own health care is more important than the role of family members or health care providers. The client on ART is the one who has to be enthusiastic about their treatment and should make a concerted effort not only to adhere but to comply with the treatment as well. Internal motivation is crucial in ART adherence because the individual on treatment is the one who needs to have the will and desire to adhere (Kennedy *et al*, 2004). Self-efficacy thus plays a critical role in treatment adherence. The client on ART also has to believe in their own ability to adhere. Self-motivation is thus crucial.

Member 01 said:

"Being able to communicate in the family and accepting one's HIV status"

8.4.6 Social Support Networks

Social support is based on the kind of relationships and interactions that provide individuals with assistance or feelings of attachment. Generally, most respondents agreed that the availability of social support was critical for good adherence to ART. Most respondents valued the support of family members, as member 06 pointed out that:

"Support from the family and disclosing to one's spouse, siblings or children and acceptance"

Social support is very important in ART adherence as it enables people through their social support networks to accept their condition, there is also a down side to social support in that it has the potential to undermine access to ART. Some family members may discourage the client to take ART and opt to encourage them to use herbs, traditional medicine or rely on faith healers to cure HIV (Musheke, Bond & Merten, 2013). On the contrary, this study found that most family members were very supportive and encouraged the respondents to take ART and adhere to the medication. (See pages 148 and 149).

Provision of support through support group members was considered by some clients as very crucial. Member 03 had this to say:

“Going to a support group as it enables one to share ideas and experiences with other people”

Clients on antiretroviral therapy are encouraged to identify treatment supporters who can assist them to adhere to their treatment. HIV and AIDS counsellors are also available to assist clients about ART. In order to follow-up on clients, home visits were conducted. Peer support groups for people on ART enable them to learn from other people on ART on techniques of disclosing one’s HIV status and shared their experiences as well (Coetzee *et al*, 2004). Some individuals only become comfortable to communicate about their illness when they are in the presence of other people who have something in common with them. Social capital exists as a set of enduring social relations, networks and contacts (O’Brien & O’Fathaigh, 2005: 5). Therefore, people on antiretroviral therapy need to be encouraged to associate with established support groups, so as to enable them to interact with other people who are also on antiretroviral therapy.

8.4.7 Disclosure

Being able to disclose to significant others was regarded as critical by some clients. Member 11 said:

“Not keeping your HIV status hidden from other people”

Another respondent felt that women were more likely to disclose their HIV status compared to men. He felt that men tend to keep their positive HIV status a secret from those close to them. Member 14 had this to say:

“Taking responsibility for your own health and not do what other people do. More especially men, we are not open about our HIV status, but I believe that if you need assistance you have to be open”

This statement suggests that women are more open with their HIV status than men, opening up would not only assist the individual to cope better, but would also encourage other men to disclose and live positively with HIV.

In a study that was conducted in Canada it was found that men were more adherent than women. Women were preoccupied with fulfilling their nurturing roles and would often be afraid to disclose their HIV status to their partners and this would severely compromise their adherence to ART (Heyer & Ogunbanjo, 2006). In South African health facilities, women are over represented than men and have a visible health seeking behaviour than their male counterparts.

One respondent also indicated that health care workers' attitudes towards their clients were very important as negative attitudes are likely to alienate people on ART. Showing respect for clients who attend health facilities is very important as this will give them confidence in the quality of service that is provided by the health care providers.

8.5 Social Systems Available

8.5.1 Respondents were asked who they disclosed to first, and the following answers were given:

It became apparent that respondents identified the first people to disclose their HIV status to carefully. Again, sexual partners and spouses featured more prominently than any other individuals. Mothers were very popular as well and some indicated that they disclosed to their children and siblings.

8.5.2 Disclosure of HIV status to children

Member 01 put it this way:

"I disclosed to my first born child who was at grade 12 then and he also accepted it. He also reminds me about taking medication on time"

Paxton (2002) found that disclosure to family members was far more complex and frightening than disclosure to peers, yet the majority of speakers found that a close relative, usually their mother, a sibling or their partner, was one of their prime sources of support. Paxton (2002) also found that African respondents were less likely to have strong support from family members than speakers from other regions were. In this study, some respondents also disclosed to their children. (See page 247). However, many faced a dilemma as they were not sure how to disclose and whether the children were old enough to deal with the news of their parents' positive HIV status.

8.5.3 Disclosure of HIV status to female family members

Female family members also featured more prominently as those who are trusted regarding the disclosure of HIV status.

Member 04 had this to say:

“I disclosed to my step mother, who said that she does not believe that I am HIV positive as I did not look like the other people who died of AIDS in my family. She further encouraged me to go and test for HIV at Hoedspruit clinic as they are more efficient than the Hluvukani clinic. I then indicated that I do believe that I am HIV positive and that there was no need for me to be re-tested for HIV. All I had to do was to accept my condition”

The myths and misconceptions about HIV and AIDS continue to exist in various communities, and as such some people do not believe that a person who looks healthy can be HIV positive. If there are a few people in the family who are infected with HIV, comparisons are often drawn and if one looks healthier than the others, it becomes difficult to convince other family members that he or she is indeed HIV positive. Constant educational programmes for family members and communities are therefore required.

Reliably, family members were the most supportive group in terms of accessing both material services and emotional support. This has important implications as satisfaction with social support has been found to shield the effect of HIV-related physical symptoms on depressive opportunistic infections (Simoni *et al*, 1995). Hays, McKusick, Pollack, Hilliard, Hoff and

Coates (1993) suggest that disclosure of one's HIV status to individuals who respond in a helpful manner contributes to improved psychological wellbeing.

8.5.4 Disclosure of HIV status to spouses

Spouses were also found to be very supportive. Member 14 indicated the following:

“I disclosed to my wife, it was difficult at first and I had to gather courage to tell her. And she was very supportive”

Following disclosure of HIV status, women were more likely to experience discrimination than men were, from the community and even their partner's family, yet more women are more supportive of their male partners. Many African women contracted the HIV from their spouse, they nevertheless, faced more discrimination than any other group, though they were the most strongly motivated to speak out about HIV (Paxton, 2002). In this study most men chose to disclose to their wives or partners, who were very supportive and encouraging. (See page 162).

8.6 The Consequences of Disclosure

The reaction of the first person that one discloses to is very critical. Most respondents pointed out that the first people that they disclosed to were supportive and accepted their HIV condition. Shock and disbelief were some of the reactions that respondents received.

8.6.1 Shock

Member 09 indicated that she disclosed to her mother and then to her children at a later stage and explained her experience in this way:

“My mother and my children accepted it, but they were shocked at first”

The shock may be as a result of the fact that HIV is associated with people who are careless with their lives and promiscuous. Therefore, if a close family member who is considered to be dignified, honest and respectful tests positive for HIV it becomes hard to contemplate.

8.6.2 Disbelief

Some people in the general population still believe that it is easy to tell if someone is infected with HIV. One woman had this to say about her family member:

“She did not believe me and told me that people with HIV did not look like me. We lost many family members to AIDS and they were very ill before they died and had lost a lot of weight”

It is imperative for HIV and AIDS counsellors to dispel all the myths that clients might be having regarding HIV. Dissemination of information on HIV and AIDS in the community needs to focus on dispelling the myths and misconceptions about HIV and AIDS. The reaction of those who are trusted to disclose HIV status to is very important, in that if the reaction is negative it is likely to affect the individual who has disclosed. In some instances, individuals on ART are very assertive and aware of the implications of their diagnosis and can play a significant role in dispelling the myths about the disease.

8.6.3 Hurt

Member 13 indicated that:

“I disclosed to my mother and she was very hurt about it”

HIV is incurable and some family members may find it unbearable to deal with this kind of news. Since the advent of ART it can be concluded that HIV has ceased to be a terminal illness to being a chronic illness that is easily manageable. Provision of counselling services for family members is important so as to assist them cope better with HIV status disclosure of a family member.

8.6.4 Anger

Some family members reacted angrily, member 14 had this to say about this:

“It was difficult at first, but I had to gather courage and disclosed to my wife who was very angry, but later accepted it”

A positive HIV diagnosis may be difficult to deal with for a partner who is faithful in the relationship and as such they are likely to respond angrily as they may feel that their partner exposed them to HIV and were unfaithful.

8.6.5 Acceptance

For some respondents those that they disclosed to also became their treatment supporters. Member 07 had this to say:

“My child accepted me as I had prepared him. He also reminds me about taking my medication on time. I am able to share anything with my child”

Spouses were also favourable to disclose to. Member 03 put it this way:

“My boyfriend accepted it and my child thought it was a joke”

Disclosure should not only be done to children but to other adult family members who can be responsible enough to provide the necessary support. Some young children may not even be able to comprehend the seriousness of their parent's condition, and instead of being supportive they will rather become confused and disillusioned.

8.6.6 Support

Support is very prevalent in HIV disclosure, member 11 indicated that:

“I disclosed to my lover who was very supportive”

In instances where the couple is sero-concordant, providing one another support becomes easy.

8.7 Feelings Following Disclosure

Most respondents indicated that they felt relieved after they had disclosed their HIV status.

8.7.1 Relief

Most respondents pointed out that they felt relieved after disclosure. Member 01 put it this way:

“I felt relieved after disclosing and learned to accept my condition” and member 02 pointed out that: *“After disclosing I felt like a heavy burden was lifted off my shoulders”*

Secretly living with HIV may be stressful for the individual as they have to constantly make an effort to hide their HIV status. Hence, many would feel relieved after disclosure. In a study conducted by Maman, Van Rooyen and Groves (2013) it was determined that participants who had shared their diagnosis with family members indicated that they were relieved after disclosing.

8.7.2 The ability to deal with stress

Member 03 said:

“I no longer had stress as I used to stress a lot about it”

Stress is a serious challenge for people who are infected with HIV. Some decide to keep the HIV positive status to themselves and do not disclose to anyone, thus resulting in stress. There are however, positive outcomes to disclosure.

8.7.3 Freedom and the unburdening effect of disclosure

Member 05 had this to say:

“It made me feel free to take my medication, I did not have to hide anymore. I was also able to educate other people in the community about HIV”

Many people feel free after disclosure as they are not compelled to hide their HIV positive status anymore. Educating their families about the disease was considered a positive action by some clients on ART. With regard to some respondents the action of disclosing their HIV status to family members did not only ensure them of their freedom, but they were also able to join various associations of people living with HIV within their communities to enable them to obtain support, thereby ensuring their right to freedom of association (Norman, Chopra and Kadiyala, 2007).

Member 09 said:

“For me, I had no choice I had to disclose because I wanted to be on treatment. I disclosed to my mother and later to my husband. I felt good after disclosing”

There are various reasons that motivate people to disclose their HIV status, the need to be healthy again is one of the critical motivators for those who are HIV positive to disclose their HIV status. Serovich, Craft and Yoon (2008) found that female family members may be viewed as more supportive than their male counterparts.

There can be benefits and disadvantages in disclosure of HIV status. Many people experience positive feelings after disclosure. Negative reactions from family members, friends, employers and community were very low. Immediate reactions to disclosure could be classified as, shock, fear, anger, violence, explicit or implicit advice, emotional support, acceptance or rejection (Law, Gogolishvili, Globerman & Rueda, 2013). In this particular study it became apparent that even though the reaction might have been negative after disclosure, family members eventually accepted the HIV status of their family member and offered their support.

8.7.4 Treatment Supporters

A significant number of respondents indicated that they did not have treatment supporters. Those who pointed out that they had treatment supporters said they thought having treatment supporters was crucial as they needed to be reminded about taking their medication. There are those who felt that having a treatment was not necessary for them as they were able to take their medication on their own.

There are also various reasons that motivate people to have treatment supporters. The need for support is a key motivator for many. There are however, those who did not have treatment supporters and felt that it was not necessary.

8.7.5 Self-Efficacy

One member indicated that:

“No, I don’t have a treatment supporter as I always remember to take my medication. But having a wife who is also on treatment helps as she reminds me”

“Cognitive perspective of health behaviour focuses on effective self-management behaviour of health habits that keep people healthy for the rest of their life” (Bandura: 2004, 151). This implies that if the individual understands their condition better they are likely to take the necessary steps to regain their health as they consider it as their responsibility. Remedicalization (Conrad, 1992) takes place in this regard and is often accompanied by self-care and self-efficacy as the client is empowered to adhere and comply with their treatment regimen and cope with associated challenges.

There are those who felt that it was not necessary for them to have treatment supporters as they were able to remember taking their medication without being assisted. Member 04 pointed out that:

“There is no need for me to have a treatment supporter because I never forget taking my medication”

Internal motivation is crucial for those who choose not to disclose their HIV status to their significant others. Perceived support for clients' autonomy predicted autonomous motivation, which in turn predicted adherence to medications. Therefore, autonomous motivation becomes critical in this regard (Kennedy et al, 2004). There are those clients who feel that they do not need treatment supporters as they can adhere on their own without assistance.

8.7.6 Disclosure to colleagues

Some clients who were employed felt that it was crucial for them to disclose to some of their colleagues as they needed to be reminded about taking their medication.

Member 05 said:

"I am employed, so it is important to have a treatment supporter who can remind me about taking my medication"

Disclosure of an individual's HIV positive status in the workplace is at present mostly a risky and potentially damaging act for the employee. However, there are also positive results in disclosing at the workplace if the environment is safe, confidential and supportive work environment. Disclosure of HIV status may enable the employee to gain the necessary support from colleagues and employers and to access medical care (Open Society Foundation for South Africa, 2009). Most employees in this study pointed out that they received support from their supervisors after disclosure. Those who choose to keep their positive HIV status confidential may thus miss crucial opportunities to be supported by their colleagues and employers.

According to Coleman (1988), social action can be classified according to the sociological approach, which sees the individual in a social and cultural environment and the economic approach, which is about self-interested, independent individuals seeking to fulfil their goals. As a social being, an individual will often determine whether their action or behaviour may expose him or her to certain undesirable reactions. The need to fit in in a particular environment usually prevents people to disclose as they fear being discriminated.

8.8 Reasons for Disclosing

8.8.1 Forgetfulness

Some clients indicated that their family members were very supportive, therefore it was crucial for them to have them as their supporters. Other respondents indicated that forgetfulness was a challenge for some clients on ART, thus it was crucial for them to have treatment supporters.

Member 09 had this to say:

“It is important for me to have a treatment supporter as it is not always easy for me to remember taking my medication, having a treatment supporter helps”

The use of reminders such as alarms, TV programmes, drug identification charts, daily schedules, diaries and educational materials are also provided to clients on ART to enable them to remember taking their medication. In a study conducted by Coetzee *et al* (2004) in Khayelitsha in South Africa they found that the Treatment Action Campaign (TAC) was very active in the promotion of treatment literary education.

8.9 Identification of Treatment Supporters

Respondents indicated that being trustworthy was important for them and this was evident in their choices of their treatment supporters. Having someone who was supportive and who could maintain confidentiality was critical.

8.9.1 Trust

Member 04 said:

“I knew that I would get support, I trusted my step mother and we lost many family members in my family to AIDS. Supporting one another is important”

Trust was very important for the respondents in identifying their treatment supporters. The act of disclosure requires the trust that the HIV positive individual will not be victimized, stigmatized or rejected after disclosure (Law *et al*, 2013). It is thus crucial for family members to talk positively about HIV as their negative statements may prevent family members who may be HIV positive from disclosing. Bourdieu (1977) is of the view that for social capital to thrive, it needs to enjoy the support of families. The family is a primary institution of socialization and has a very significant role to play in reinforcing values and norms.

8.9.2 Confidentiality

For respondents confidentiality was very important and they identified their treatment supporters based on whether they could maintain confidentiality or not. Member 05 said:

“I had faith that she would maintain confidentiality, this was very important to me as I was not ready for other people to know as I did not know how they were going to react”

HIV is not a notifiable disease in South Africa and those who are diagnosed HIV positive have the right to keep it confidential or to disclose to people who will keep their HIV status private as well. Relatedness as explained in the self-determination theory (Deci & Ryan, 1985) is very significant as many people are likely to share intimate information with those they trust. Consequently, with regard to antiretroviral therapy, clients are likely to identify close family members as their treatment supporters as they believe that they will maintain confidentiality.

8.9.3 Support Group Membership

Only a limited number of respondents indicated that they belonged to support groups. A large number of respondents said they did not belong to any support group. For some it was due to work commitments and yet with others they had never heard of the existence of any support group at the facilities where they were receiving their medication.

8.9.4 Reasons for support group membership

Others pointed out that being in a support group enabled them to share their experiences with other people living with HIV or on treatment and it also gave them an opportunity to motivate other people. Some were motivated by the need to support and encourage others who were HIV positive.

8.9.5 HIV and AIDS ambassador

Member 01 put it this way:

“I am the HIV and AIDS ambassador, so it is important for me to be a member of a support group and attend meetings regularly so as to motivate other people”

An HIV and AIDS ambassador is considered an “expert client/patient” in that they are live openly with HIV and talk openly about their experience of living with HIV. They also empower other clients on how to disclose and cope with the disease. They thus play a pivotal role in support groups. Many of them also exude confidence and have a very positive attitude, this can be very encouraging for newly diagnosed individuals as it gives them hope. Many programmes that provide care, support and treatment for people living with HIV and AIDS involve people living with HIV. In most instances people infected with HIV are directly linked to a treatment site. Many of these sites usually have support groups of people living with HIV and AIDS. One of the tasks that these people are involved in is providing support on treatment adherence to other members (Kober & Van Damme, 2006).

8.9.6 Empowerment

A support group is often one therapeutic intervention offered for people living with HIV and AIDS. Certain interventions are offered to group members by professionals and their peers (Spirig, 1998). Empowerment of support group members through providing them with education regarding their illness and treatment is one of the purposes of support groups.

Member 02 had this to say about her experience:

“I also go to a support group and it is very helpful. The support group gives me a chance to share my own experiences with other people who are on treatment. I was able to meet other people who were more ill than I was and it encouraged me to take my medication correctly”

Empowerment entails the client’s belief in the autonomy and their right to access information and to be responsibility enough to make informed choices. Clients who are empowered are able to cope with their disease as they interact with their health care professionals and comply as well as adhere to their treatment regimen (Van Uden-Kraan, Drossaert, Taal, Seydel & Van der Laar, 2009). Support groups therefore, promote self-care and self-efficacy amongst people living with HIV and/ or on antiretroviral therapy.

8.9.7 Employment as a barrier to attending support group meetings

In this study some respondents who were employed were unable to go to support groups due to work commitments.

Member 04 said:

“The work that I do is too demanding, and I am therefore not able to attend a support group meeting. I’m committed with work issues and there is no time for me to attend to other private activities”

Employers and managers need to be empowered with HIV and AIDS information. Establishing support groups in the workplace is critical so as to accommodate employees who are HIV positive and would like to attend support group meetings.

8.9.8 Online or internet support groups

The rise of computer technology and internet provide an opportunity to address the needs of individuals living with HIV and AIDS. Online support groups “open a door for people who would not ordinarily reach out for help” (Wellman & Gulia: 1999, 173). However, in rural

communities this remains a challenge as many people are illiterate and often only speak their local languages. It would be ideal more especially in the workplace to have such programmes for employees living with HIV and/or on antiretroviral therapy.

8.9.9 Lack of institutional support

It also became apparent that some health facilities initiated support groups but were not able to maintain them. Challenges regarding the inability to maintain support groups need to be identified so that appropriate interventions could be established.

Member 08 said:

“We used to come here at the clinic for the support group meeting, but we have since stopped coming, because we would come and they would tell us to come back another day”

Comprehensive care management and treatment (CCMT) of HIV sites in South Africa are manned by multi-disciplinary teams. Responsibilities of each member need to be clearly outlined as it became apparent during data collection in this study that it was not clear whether it was the responsibility of health care workers or lay counsellors to establish support groups of people living with HIV and/or on ART.

It was discouraging to learn that there are those who did not even know the existence of support groups. Initially when antiretroviral therapy was introduced having a well-functioning support group was one of the criteria for a health facility to be accredited to provide ART.

Member 12 said:

“The counsellor did not tell me about any support group”

Health care providers who do not inform their clients about the existence of support groups, deprive them of valuable information that they would gain by being a member of a support group. It is thus of utmost importance to ensure that health care professionals are also adequately trained and empowered to enable them to impart invaluable information to their clients.

Self-determination theory suggests that clients need to be given room to exercise their autonomy, competence and relatedness in health care facilities and that if instructions given by health care providers are clear they are likely to make an impact and thus result in behaviour change (Williams, Deci & Ryan, 1998). Services available for clients at health facilities need to be effectively communicated to them by their health care providers.

8.10 Challenges of Drug Adherence

8.10.1 Personal challenges of adhering to treatment

When asked about personal challenges of being on treatment most respondents pointed out that the side-effects that they experienced were a major challenge. One indicated that having to ask for permission from their employer was a challenge for them. This is an indication that many companies do not have HIV and AIDS policies in place.

8.10.2 HIV and TB Treatment

Member 08 said this:

“The side effects that I experienced were a problem more especially because I was also on TB medication”

There is a very high rate of co-infection in South Africa. Therefore, many clients have to consume TB and HIV medications simultaneously and this becomes difficult to manage. Some of the side-effects that the people on ART experience make it difficult for them to lead normal lives. Changes in body shape or lipodystrophy was a concern for many women.

8.10.3 Organization stigma and discrimination

One respondent indicated that she had not yet disclosed and having to constantly ask for permission to visit the health care facility was a challenge. This is how she put it:

“Having to ask for permission to come to the clinic is not easy as I have not disclosed to my employer”

Some employees who are HIV positive and on treatment face a dilemma as they have to comply with their clinic appointments and if they have not disclosed this becomes a challenge as they have to make up lies every time they have to go to the clinic.

8.10.4 Experiences of stigma and discrimination

With regard to stigma and discrimination only a few respondents indicated that they had such experiences. Amongst the few who had those experiences, it was pointed out that the abuses were perpetrated by close family members.

8.10.5 Stigma and discrimination by family members and colleagues of those on antiretroviral therapy

Member 01 had this to say:

“Yes, I experienced stigma and discrimination because I was ill. My family members are members of the Zionist Christian Church (ZCC) and they encouraged me to go to church with them and I refused indicating that I do not belong to a faith based church. They then kicked me out of the house and I had to go and erect a cardboard house for myself. They were scared because they thought I would infect them with HIV. What is funny is that the children of the family members who discriminated against me are now HIV positive and I guide them and offer advice on how to live positively with HIV”

The effects of HIV and AIDS-related stigma can be devastating. People have been attacked, some fatally, because they were open about the fact that they were living with the HIV. Women have lost their homes because their husbands had wrongfully accused them being unfaithful (Panos, 2006). Intolerance of a family member who is infected with HIV becomes a challenge as they have to deal with rejection by their own family members.

Member 04 said:

“I am being discriminated against by my own family members. My sisters are very cruel as they also torment my children about my HIV positive status. They tell them that I may die anytime as I have AIDS. My colleagues also discriminate against me and like passing sarcastic remarks to me”

Social capital according to Putnam’s view (1995) has three components. That is, moral obligations and norms, social values and social networks. These forms of social capital are central to the promotion of civil communities and civil society in general. Therefore, shared beliefs are important as they enhance social support networks in every society and help to deal with stigma and discrimination.

Educational programmes on HIV and AIDS and antiretroviral therapy need to be targeted towards employees within the workplace so that they can support their colleagues who may need the support.

8.10.6 Non-disclosure of HIV status to prevent stigma and discrimination

Certain respondents protected themselves by keeping their HIV status confidential. Member 09 indicated that:

“I’m not open about my HIV status, many people don’t know I live with HIV and I think it’s safer for me to keep it this way. People are unpredictable, you never know how they will react”

It was also evident that the South African government has made an enormous effort in educating the public about HIV and AIDS, as some respondents concurred that people were more accepting and tolerant of those living with HIV.

Member 11 indicated that:

“These days many people are educated about HIV and AIDS and they don’t treat people badly like they used to”

However, the fact that there are still people who experience stigma and discrimination, more especially from people that they have intimate relationships with is a great concern that needs attention.

8.11 Reminders for Taking Medication

Antiretroviral therapy is a life-long commitment, clients use various methods in order for them to remember taking their medication. Most respondents indicated that they used cell-phone alarms, some relied on family members to remind them and yet there are those who pointed out that they remembered on their own without anyone's assistance.

8.11.1 Cell-phone alarm

Member 02 explained her experience in this way:

"I use my cell-phone alarm to remind me to take my medication"

Many respondents indicated that they relied on their cell-phone alarms to remind them about taking their treatment. WHO (2009b) found that phone messages and reminders to take medication or for drug refill have been effective in promoting treatment adherence in a study conducted in Kenya. Implementing this strategy in underdeveloped countries would be a challenge as many people do not have access to telecommunication and cell-phones are usually too expensive for many poor people.

8.11.2 Family members as treatment supporters and reminders

Member 05 said:

"I never forget and my wife always reminds me and I remind her as well"

Couples who are both HIV positive remind each other to adhere to their medication. Openness and effective communication amongst couples ensures that they are both adherent.

Member 06 indicated that:

“My children remind me and I also do not forget”

Family members are the most reliable with regard to reminding those that are on treatment to take their medication. Each individual uses a method that works for them, it is therefore dependent on the individual to decide which method to choose. Some indicated that they do not rely on any devices as they are able to remember on their own.

8.11.3 Pillboxes

Some health facilities provide their clients with pillboxes that help to enhance adherence. Member 06 had this to say:

“I’m reminded by my children when it is time for me to take my medication and the nurse at the clinic has given me a pillbox, so I just put my medication in the pill box and consume it when the time is right”

The use of pillboxes and pill organizers has an enduring history as an effective strategy that promotes adherence (Simoni, Amico, Pearson & Malow, 2008). These kinds of devices act as prompts and also ensure that the client follows a particular routine that may be easy to follow.

8.11.4 Reliance on memory and following a particular routine

Some respondents pointed out that they relied on their own memory to adhere to their treatment. Member 08 said:

“I don’t have anyone to remind me, I take mine very early in the morning after eating, so it is easy to remember”

Relying on memory may not be an effective strategy due to competing priorities that the client may have to deal with. In instances where the client is preoccupied with certain activities they might forget taking their medication if they are not relying on any form of devices.

8.12 Condom Use

In order for ART to be effective it is critical for the client on treatment to live positively with HIV. They need to ensure that they have only one sexual partner that they are faithful to, they use they engage in safer sex practices and do not smoke cigarettes or drink alcohol. Most respondents said they only had one sexual partner that they were faithful to. However, many also indicated that they did not practice safer sex the last time they had sex. Most respondents indicated that they did not drink alcohol and did not smoke cigarettes.

8.12.1 Multiple sexual partners

Member 04 was very frank about her sexual relations, she had this to say:

“Yes, I do have other sexual partners besides the one I am staying with. I have to tell the truth as lying is not good. I am not married but have lovers, I don’t know how many they are but I have them”

Research has shown that people who are on antiretroviral therapy may engage in risky sexual behaviour. As soon as the health of the individual on ART improves they might be tempted to engage in sexual activities. Other studies have shown an increase in sexually transmitted infections (STIs) amongst heterosexual people on antiretroviral therapy (Scheer, Chu, Klausner, Katz & Schwarcz, 2001). Some respondents in this study indicated that ART drugs increase their sexual desire, hence they were very sexually active.

8.12.2 Faithfulness to one partner

Member 14 pointed out that:

“I have my spouse, so there is no need to have extra-marital affairs.”

Some respondents indicated they were faithful to their partners as they were aware of the dangers of having multiple sexual partners. Most people living with HIV do not want to infect their partners and would rather use condoms consistently or disclose their positive HIV status so as to protect their partners (Canadian HIV/AIDS Legal Network, 2012). Being faithful has

many benefits, not only for the individual but for the people that they engage in sexual activities with as well.

Most respondents indicated that they did not use condoms the last time they had sexual intercourse. In South Africa, male and female condoms are available for free and are distributed at public health centres and other institutions within the communities.

8.13 Smoking and Alcohol Consumption

Most respondents indicated that they did not drink alcohol and did not smoke cigarettes.

Member 02 said:

“No, I was told that alcohol is not good for my body. Both myself and my wife don’t drink or smoke”

Even though some respondents indicated that they did not smoke cigarettes or drink alcohol, they pointed out that their partners did. Having a sexual partner who drinks alcohol also places their partner at risk as they are more likely to behave irresponsibly, by not using condoms or insert it incorrectly.

Treating HIV infection in individuals who abuse alcohol can be very challenging. Research studies have indicated that viral suppression is slowed down by alcohol and treatment adherence also becomes difficult to manage (Braithwaite, 2010). Forgetfulness is very likely when someone is intoxicated and may also behave recklessly. Alcohol consumption is associated with non-adherence to ART which may lead to premature death (Scheider *et al*, 2012).

Member 04 indicated that:

“I don’t drink or smoke, and even my lovers don’t drink”

One respondent indicated that he smoked a lot and was not able to stop. Chain smoking amongst people living with HIV is a challenge as it affects their respiratory system. People infected with HIV are vulnerable to TB and chain smoking may cause TB infection as well.

8.14 Summary

Side-effects associated with antiretroviral therapy are some of the challenges that people on ART have to deal with. Types of side-effects experienced as well how they were managed was discussed. Barriers and enablers to treatment adherence were outlined. The chapter also dealt with disclosure of HIV status as the reaction after disclosure. Social support networks available to people on ART were outlined. It became evident that even though there might be other external social support networks, the most valuable support is from close family members. How the respondents dealt with stigma and discrimination was also discussed. Devices used by the respondents to assist them to remember taking their medication were also described. The dangers of substance abuse, multi-sexual partners as well as the risk of engaging in unprotected sex were discussed.

CHAPTER 9

ANALYSIS, PRESENTATION AND INTERPRETATION OF DATA ACQUIRED THROUGH THE QUESTIONNAIRE DISTRIBUTED AMONGST HEALTH CARE PROVIDERS AND LAY COUNSELLORS

9.1 Introduction

The purpose of this chapter is to present, analyse and interpret the data obtained from the health care workers and lay counsellors who completed the questionnaire. Seventeen (17) health care providers and lay counsellors responded to the questionnaire. Demographic data of respondents was discussed. The data was presented using tables and graphs. The Statistical Package of Social Sciences (SPSS) programme was used in the analysis of numerical data. Mathematical techniques that make data more understandable were used and they are referred to as descriptive statistics. Numerical counts or frequencies were used as well as percentages. Strategies identified by health facilities were presented in a narrative form.

Table 22: Name of the Sub-district (N=17)

SUB-DISTRICT	FREQUENCY	PERCENTAGE
Ba-Phalaborwa	3	18
Greater Giyani	4	24
Greater Letaba	2	12
Maruleng	6	35
Greater Tzaneen	2	12
TOTAL	17	100

As may be seen from the data presented on the above displayed table, all the five sub-districts of the Mopani district participated in the research study. The number of health care workers and lay counsellors who participated in the study varied. The reason for the variation is that at certain sub-districts only one health facility was sampled, whereas two sites were

sampled at some sub-districts. The level of co-operation was also different, with some health facilities being more open, keen and co-operative and others being non-receptive and uncooperative. The reason for including all the sub-districts is because they are unique and each one presents its own enablers and barriers regarding the implementation of the Comprehensive Care Management and Treatment of HIV (CCMT) programme and treatment adherence. Some of the challenges experienced by these sub-districts are similar. The Ba-Phalaborwa sub-district is a mining municipality. Miners are considered as one of the most vulnerable groups to HIV and AIDS due to the mobility involved in the nature of their work. According to the Medecins Sans Frontieres (2012) migrant populations are very vulnerable to HIV and TB and are at a higher risk of being infected. There are also challenges regarding access to health care services and once placed on treatment, they find it difficult to adhere. There are also many interruptions on their treatment and the rate of lost to follow-up is very high. The Greater Giyani sub-district is equally unique, in that it is resident to many refugees from Mozambique. This population is similarly vulnerable as they are often unemployed and poverty stricken. The South African government has made concerted efforts to ensure that refugees have quality access to health care. However, there are still challenges in this regard in that this group continues to be discriminated against regarding access to antiretroviral therapy (Randolph, 2010). Health care services need to be provided to informal settlements as well and health care workers need to be adequately trained on handling refugees.

The Greater Letaba, Tzaneen and Maruleng sub-districts have a very high rate of illiteracy and unemployment and many people in the municipalities rely on farm work to sustain their families. Factors such as poverty, poor social cohesion, sub-standard housing and limited access to health care also exacerbate the spread of HIV infection in farming communities. Other behaviours such as engaging in sexual intercourse with commercial sex workers, inconsistent condom use as well as the abuse of alcohol and drugs make this population more vulnerable (NCFH, 2012).

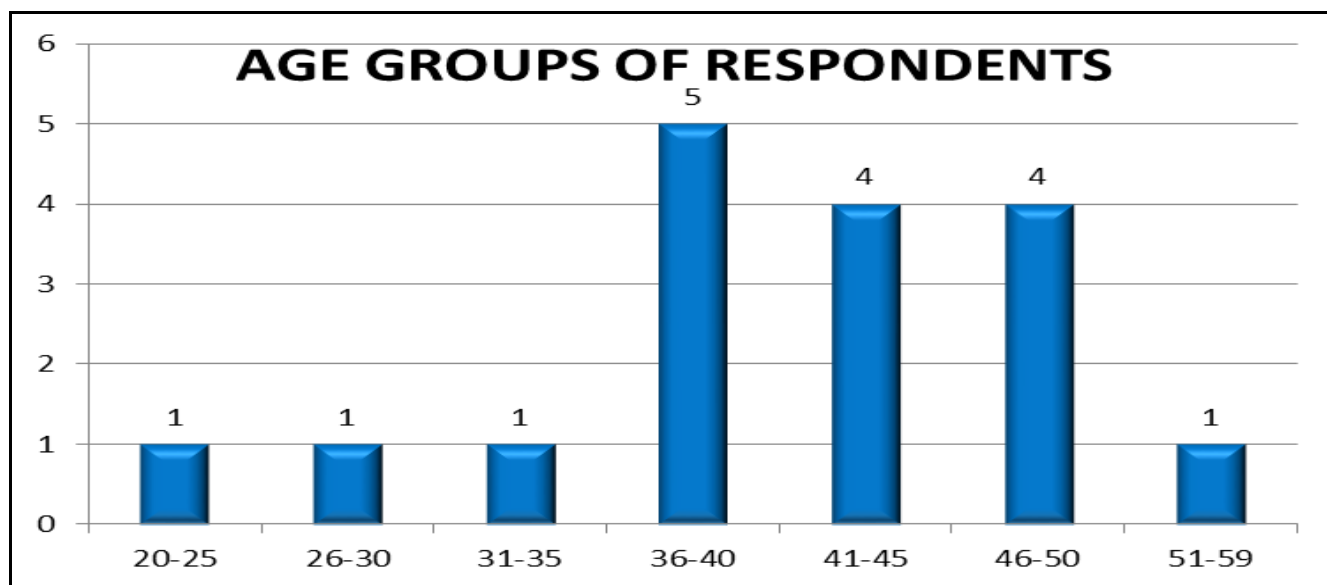
Table 23: Pseudonyms of Health Facilities (N=8)

NAME OF HEALTH FACILITY	NUMBER OF HEALTH CARE WORKERS	PERCENTAGE
Private Health Facility 01	3	17
Public Health Facility 02	2	12
Public Health Facility 03	2	12
Public Health Facility 04	2	12
Public Health Facility 05	2	12
Public Health Facility 06	2	12
Public Health Facility 07	2	12
Public Health Facility 08	2	12
TOTAL	17	100

The above table indicates that 17 respondents participated in the study. Three respondents were interviewed at private health facility, a health care worker, HIV and AIDS ambassador and a data capturer were interviewed. Two people comprising of the health care provider and lay counsellor were interviewed at all the public health facilities. The lay counsellor programme plays a pivotal role in the public health sector in South Africa.

An HIV and AIDS lay counsellor is an individual who usually undergoes anywhere between five days and three weeks of training on HIV and AIDS counselling and testing skills and agrees to offer time, attention and respect by providing pre and post-test counselling as well as other HIV related counselling such as treatment adherence counselling (DOH, 2000, Stewart, 2005).

There is a need for HIV and AIDS lay counsellors to have great interpersonal and communicational skills for building supportive relationships between themselves and their clients, because clients want the HIV and AIDS lay counsellors to relate psychologically, socially and emotionally (Van Dyk, 2005: 186).



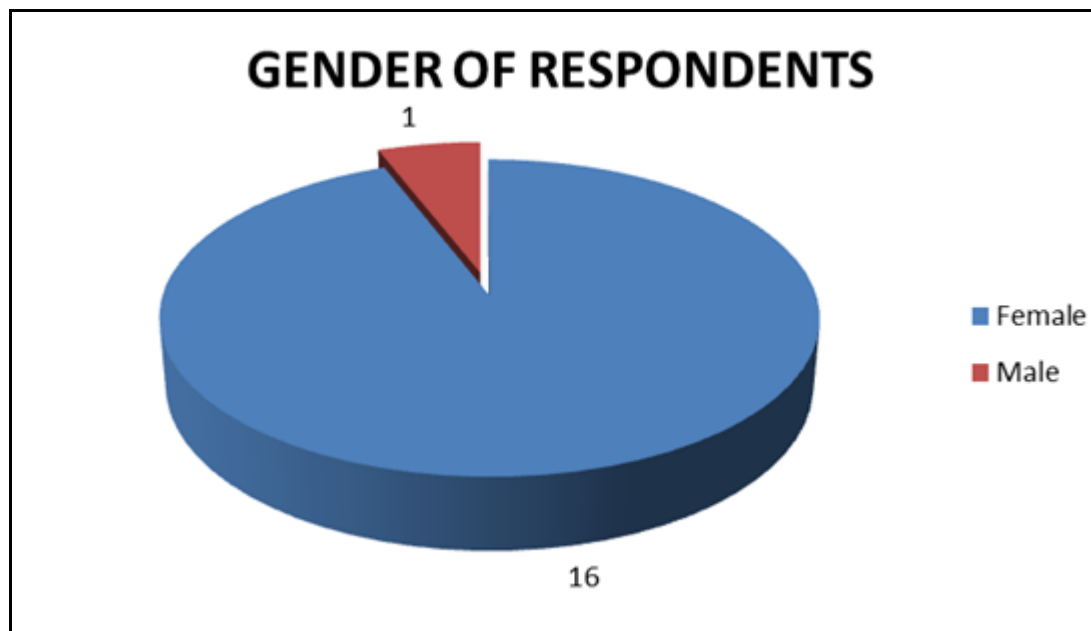
Bar Graph 6: Age of health care workers and lay counsellors (N=17)

With regard to the age groups, the respondents were between the age groups of 20 and 59. The most dominant age group was between 36 and 40, as 5 respondents were between this age group. Most lay counsellors are young people which is in correlation to the target group of people aged between 15 and 49 according to the 2010 National Antenatal Sentinel HIV and syphilis prevalence survey in South Africa. Young people are very critical in the provision of health care programmes as they are usually seen as more open and approachable by their peers. Young people who need access to sexual and reproductive health care often experience challenges regarding negative attitude of health care providers. It is also alleged that health care providers have judgemental attitudes towards young people who are sexually active. These young people are often treated rudely or denied services (WHO, 2009). This actions reveal that health care providers may not be adequately equipped to deal with young people (Oxfam, 2007). Usually clinics are designed for adult clients and staff members at those facilities are not trained on offering youth friendly services (Pathfinder, 2003). Therefore, recruitment, training and placement of young people at public health facilities is of utmost importance.

Table 24: Race of Health Care Workers and Lay Counsellors (N=17)

RACE	FREQUENCY	PERCENTAGE
African	16	94
White	1	6
TOTAL	17	100

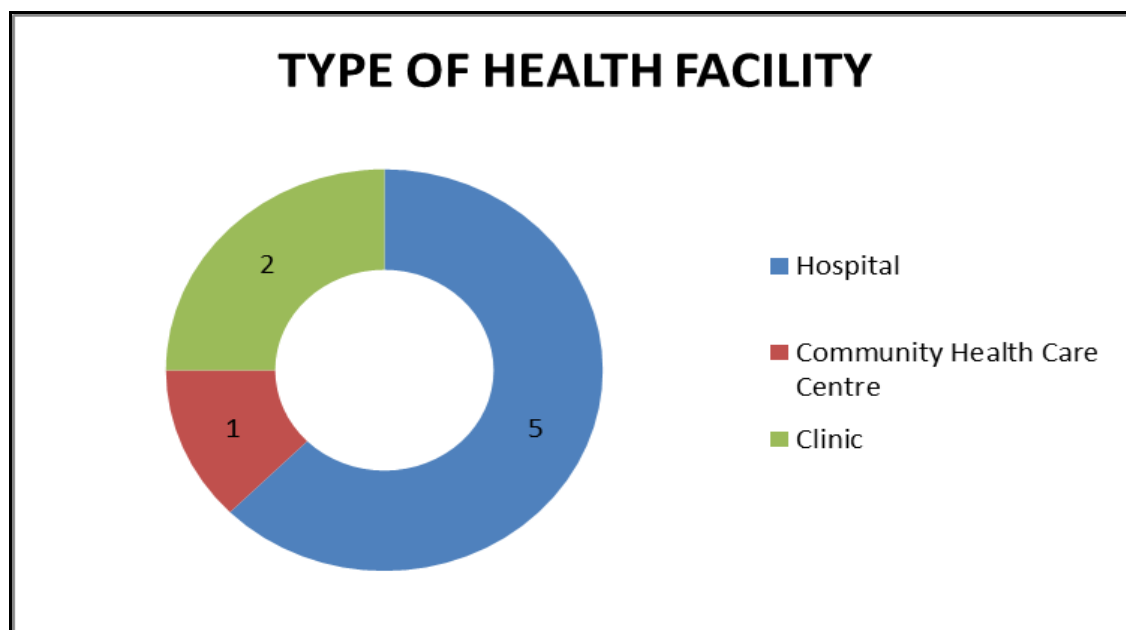
It is evident from the data presented on the table that most respondents who participated in the study were African, as 16 fell under this race group and only one respondent was white and was employed by the private health facility. The private health sector attracts an uneven number of professionals who are highly skilled and this challenge is likely to persist until such time that the public health sector develops effective strategies in retaining their health care providers (Wolvaardt, Niftrik, Beira, Mapham & Stander, 2008). In South Africa public health facilities are dominated by African professionals and seem to be less attractive to the other race groups due to the poor working conditions and unattractive remuneration packages.



Pie Chart 3: Gender of health care workers and lay counselors (N=17)

The gender inequality with regard to the respondents is quite evident, as the pie chart above shows that there were 16 female respondents and only 1 male respondent. The nursing

profession is traditionally viewed as a profession associated with nurturing and caring for other people, which is believed to be women's responsibility. The profession is therefore largely female dominated. There is a need however, to attract more males in the profession so that they can assist in cultivating health seeking behaviour in their male counterparts. There is a global shortage of nurses, thus strategies to attract, train and retain men in the nursing profession are crucial, the profession also lacks diversity in this regard (McLaughlin, Muldoon & Moutray, 2010). Male nurses could play a vital role in ensuring that other men in various communities develop health seeking behaviours and provide the necessary support to their partners. This could increase the rate of HIV counselling and testing and access to treatment amongst men.



Doughnut 4: Type of health facility (N=8)

Hospitals were the first ones to be accredited to provide antiretroviral therapy in South Africa, followed by the Community Health Care Centres and then the clinics. Human resources are still a major challenge with regard to the effective implementation of the CCMT programme. The reason for sampling more hospitals in the study is that they have more years of experience in the provision of antiretroviral therapy. Primary health care facilities such as community health care centres and clinics also provide antiretroviral therapy. The challenges and successes experienced by these facilities were outlined to ensure the sharing of best practices.

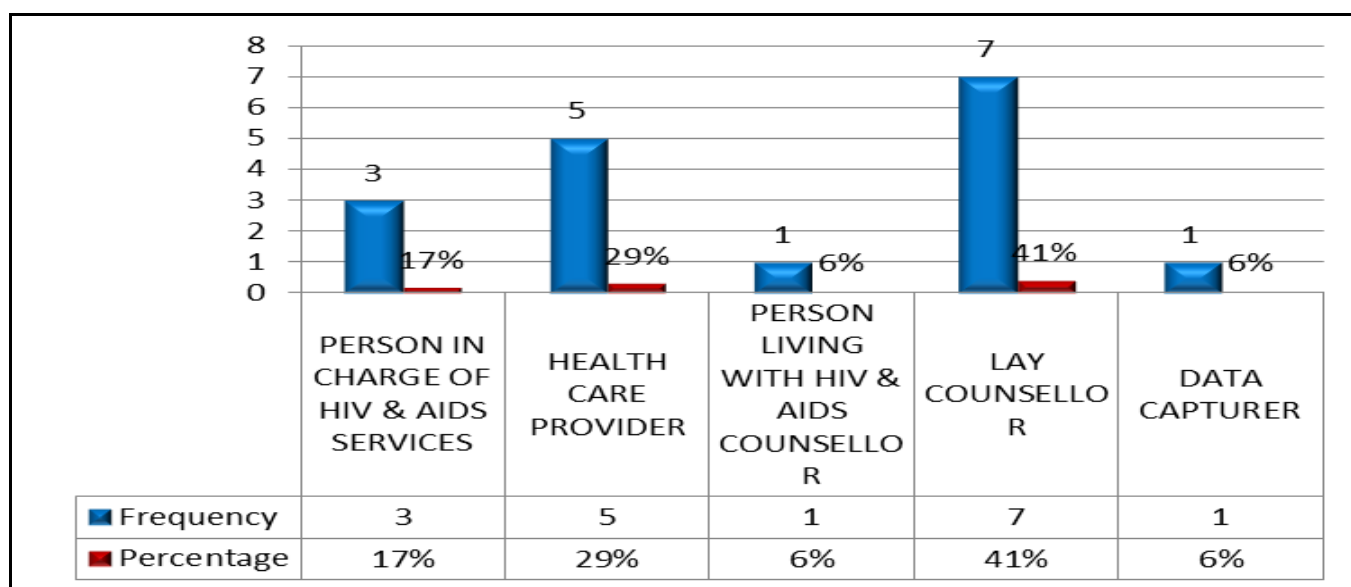
Provision of antiretroviral therapy in South Africa has been decentralised to primary health care facilities, however many of these facilities are not adequately resourced. Many clinics in Southern Africa have long patient waiting lists, inadequate infrastructure and facilities as well as a shortage of health care professionals (Medicines Sans Frontiers, 2007). It is thus imperative to ensure that all primary health facilities are sufficiently prepared to implement the ARV programme.

Table 25: Type of Health Facility (N=8)

FACILITY OPERATED BY	FREQUENCY	PERCENTAGE
The Government	7	88
Non-governmental organization	1	12
TOTAL	8	100

There are very few NGOs that are accredited to provide ART in the Limpopo Province. The Mopani district only has one such NGO. Capacitating NGOs in terms of provision of comprehensive health care services is crucial as they help to alleviate the burden of public health facilities.

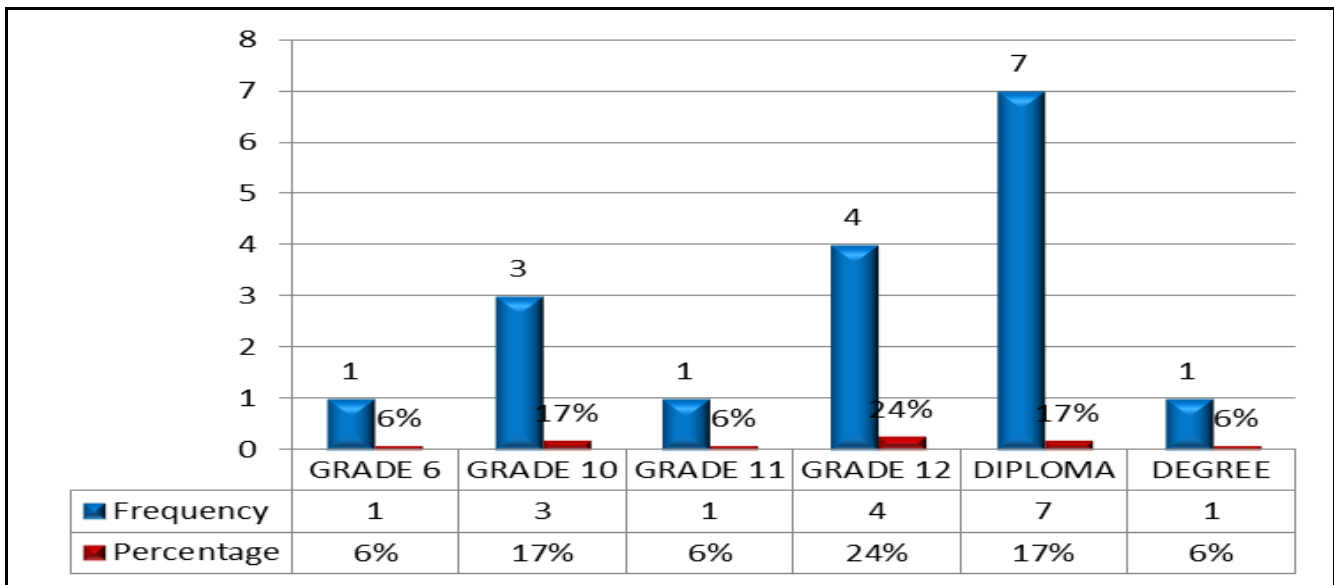
Non-governmental organizations (NGOs) play a significant role in implementing health programmes in South Africa. The private sector or non-profit organizations is involved in improving efforts to provide essential drugs at various levels. Many NGOs are able to deliver treatment through HIV and AIDS programmes that they implement at their private clinics (Wolvaardt *et al*, 2008). Many NGOs are funded by international donors and their governments. The department of health should identify and accredit more NGOs to implement the CCMT programme.



Bar Graph 7: Description of the nature of the respondent's position (N=17)

HIV and AIDS programmes that involve people living with HIV as service providers have an impact. According to the study that was conducted in Haiti, it was found that Directly Observed Treatment of Highly Active Antiretroviral Therapy (DOT-HAART) which is based on the experience of the TB programme could be effective in promoting adherence amongst HIV clients. In order to ensure that clients were adherent, each one was paired with an accompagnateur and they observe the individual on ART taking their treatment. They also conduct home visits so as to provide emotional support (WHO, 2003b).

In South Africa lay counsellors living with HIV are trained and placed at public health facilities, some NGOs that implement the ARV programme also recruit lay counsellors living with HIV. A major benefit of appointing people living with HIV to implement HIV programmes is that they always relate to their own experience of living positively with HIV and motivate newly diagnosed clients to accept their condition, thereby increasing their chances of adhering to antiretroviral therapy.



Bar Graph 8: Highest level of qualification (N=17)

The level of formal education is very low amongst lay counsellors. Health care workers implementing the CCMT programme were found to be better qualified. With regard to the training of health care workers and lay counsellors, there is a training package that they need to go through. The training workshops are usually organised by the Limpopo provincial department of health and district offices. Occasionally the national department of health also conducts workshops for health care workers and lay counsellors.

There is a very high burden of care placed on health care professionals and lay counsellors have been recruited to deal specifically with issues related to HIV and AIDS counselling. Their training is not adequate owing to insufficient resources and they are not properly supervised and usually have very little support. These lay counsellors are often relegated to the role of disseminating information other than engaging with clients at an emotional level so as to encourage treatment adherence (Rohleder & Swartz, 2005). Illiteracy is a major challenge in South Africa. The illegibility criteria for an individual to qualify as a lay counsellor should be at least grade 12, so that they can be able to comprehend the clinical information during training and also provide professional assistance to clients on antiretroviral therapy.

Table 26: The Mentorship programme (N=17)

MENTORSHIP	FREQUENCY	PERCENTAGE
Yes	12	71
No	5	29
TOTAL	17	100

Mentorship is the transmission of skills from a more experienced worker to a less trained and experienced worker (HIVCORE, 2004). Mentorship also prevents stress and burn-out in counsellors. There are various clinical mentorship models available to the mentees. With regard to the hospital-based clinical mentoring model, a group of mentees are placed in a referral hospital with an experienced clinical mentor. The frequency and scheduling of the clinical mentoring sessions need to be determined based on the availability of the clinical mentor and the mentees as well as the logistics that may be involved. There is also the Primary Health Care (PHC) clinical mentoring, mentors in this instance are allocated to provide mentorship to HIV and AIDS counsellors at their designated health facilities. In some instances mentors may not be able to visit respective health facilities, therefore telephone conversations and text messages (SMS) between mentors and mentees should be encouraged. Questions that mentees might have as well as difficult cases and referrals may be done telephonically (DoH, 2011).

The Limpopo province benefited from the Flemish Government donor funding from 2006 to 2010. One of the priority areas that were funded was the mentorship programme. Mentors comprising of experienced lay counsellors were trained and placed at funded NGOs to provide regular mentoring sessions to lay counsellors. The programme enhanced the quality of counselling provided by lay counsellors as difficult cases were discussed during mentoring sessions and counselling skills improved due to the quality of inputs given on handling such cases.

Table 27: Type of Mentorship (N=12)

MENTORSHIP	FREQUENCY
Individual	2
Group	2
Both	8
TOTAL	12

In order for HIV and AIDS counsellors to perform their duties optimally it is essential for them to receive both individual and group counselling. It is encouraging to realise that 8 respondents indicated that they receive both individual and group mentoring. Two respondents pointed out that they receive individual mentoring and the other two indicated that they receive group mentoring. It is important for mentors to attend to HIV and AIDS counsellors individually, because at times counsellors experience challenges and need someone to communicate with in private. Group mentoring enables counsellors to share experiences and learn from one another and it also enables them to improve on their counselling skills. De-briefing sessions are also conducted during mentoring sessions.

In the Limpopo province, all NGOs implementing the lay counsellor programme have trained mentors. These mentors were recruited and trained through the donor funded Flemish government VCT programme. Lay counsellors recruited by these NGOs enjoy professional and adequate mentorship as there are dedicated mentors to attend to their emotional well-being. Intrinsic motivation according to the self-determination theory is the inborn tendency to seek out challenging situations, to extend and exercise one's capacities, to explore and to learn (Deci & Ryan, 2000). In order for HIV and AIDS counsellors to perform their duties optimally, emotional support is crucial. The standard of care provided to their clients is dependent on their well-being.

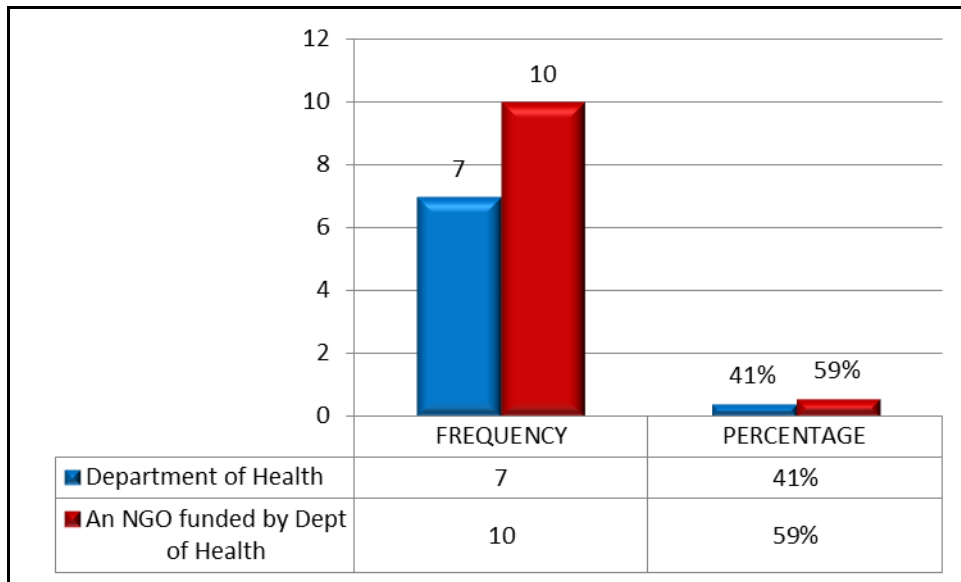
Table 28: Provider Client Ratio (N=16)

HEALTH CARE WORKER CODE	NUMBER OF CLIENTS
HCW/PRI-HF 01	30-40
HCW/PRI-HF 02	800
HCW/PUB-HF 03	100
HCW/PUB-HF 04	120
HCW/PUB-HF 05	230
HCW/PUB-HF 06	91-100
HCW/PUB-HF 07	30-40
HCW/PUB-HF 08	300
HCW/PUB-HF 09	61-70
HCW/PUB-HF 10	Data not provided
HCW/PUB-HF 11	30-40
HCW/PUB-HF 12	200
HCW/PUB-HF 13	61-70
HCW/PUB-HF 14	900
HCW/PUB-HF 15	800
HCW/PUB-HF 16	91-100

Health care worker 14 indicated that she attends to 900 clients in a month. Health care worker 15 pointed out that she attended to 800 clients a month as well as the health care worker from the private health facility. The number of clients seen by health care workers and HIV counsellors differ, in that health care workers attended to more clients than HIV counsellors. The shortage of health care workers at public health facilities is a major challenge. It is alarming to realise that the private health facility also had a similar experience with public health facilities. The data capturer from private health facility was not responsible for attending to clients.

The shortage of personnel at public health facilities is very serious even though the department of health receives a substantial amount of the budget from the national treasury. There is also a decrease in the nurse to client ratio, this reduction is due to the closure of

nursing colleges in the late 1990s, migration from public to private health sector and overseas as well as loss due to retirement and HIV and AIDS (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009). As the more experienced and knowledgeable health care professionals leave the health care system, strategies should be devised to replace them to ensure continuity of care.



Bar Graph 9: The name of the employer (N=17)

There are two NGOs responsible for implementing the HIV and AIDS lay counsellor programme in the Mopani District. These NGOs have the responsibility to recruit, train, place lay counsellors at health facilities and provide mentorship to lay counsellors. Lay counsellors work together with a team of health care professionals to provide comprehensive health care services to clients.

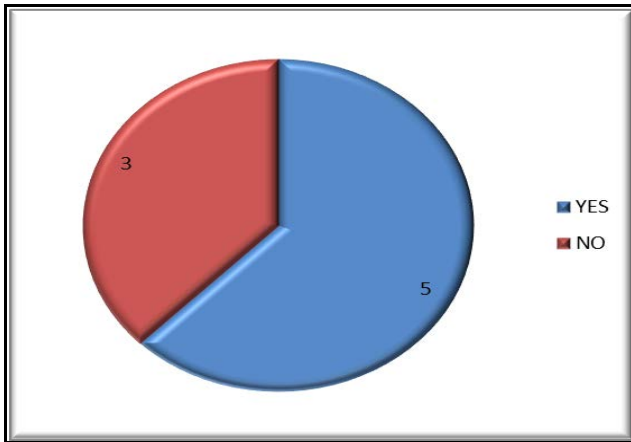
Provincial government departments in South Africa such as the department of health, social development and education are usually responsible for expending funding to various funded NGOs. Programmes that are frequently funded are the home-based care programme as well as the lay counsellor programme (Kelly, Birdsall, Tshose, Banati & Low-Beer, 2009).

Table 29: Experiences of delays in receiving salaries or stipends (N=17)

WHETHER THEY HAVE EXPERIENCED DELAYS IN THE RECEIVING THEIR SALARY IN THE PAST SIX MONTHS	FREQUENCY	PERCENTAGE
Yes	8	47
No	9	53
TOTAL	17	100

Non-governmental organization (NGO) funding experience delays annually due to bureaucracy in government. In some instances delays in transferring funds from the department of health to NGOs are due to the submission of incomplete applications by NGOs. Non-governmental Organizations (NGOs) are required to comply with the Public Finance Management Act (PFMA) and funds can only be transferred to NGOs on a quarterly basis. The National Government had placed 5 Limpopo Provincial departments under administration and the department of health was one such department. Officials within the department are required to explicate each transaction prior to approval by the administrator and this leads to further delays. The funding model of the department of health needs to be revised so as to ensure continuity in the services provided by counsellors from NGOs.

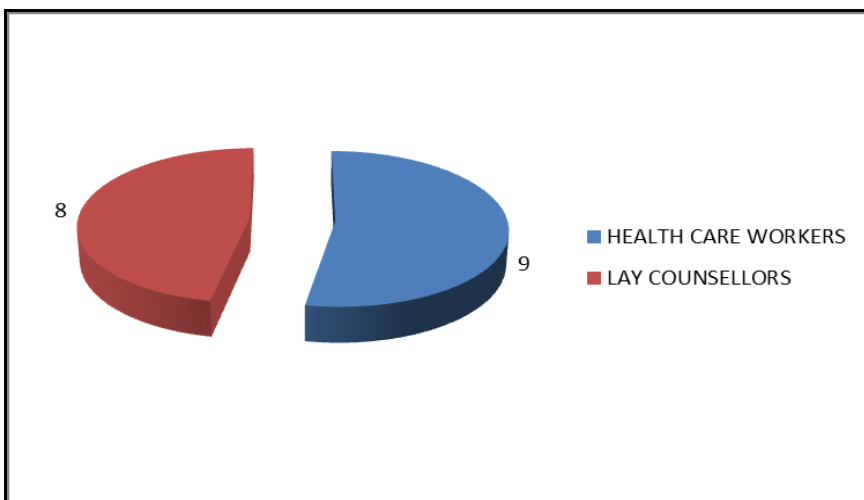
Lay counsellors receive their remuneration in a form of stipends. The department of health contracts NGOs to manage the administrative issues including payment of lay counsellors. Late payment and poor working conditions are very common (Black, Sprague & Chersich, 2011). It is important for NGOs to build-in sustainability plans within their programmes so that they can be able to function during the times that they experience delays in receiving their funds from their donors.



Pie Chart 4: Interruptions in receiving salary/stipend (N=8)

It is clear from the above displayed chart that delays in funding NGOs have a negative effect on service delivery. The inability of lay counsellors to go to work during times that they will not be receiving stipends impacts negatively on their counselling work. Clients receiving treatment adherence counselling and those who have complications such as side-effects may be turned away until such time that the lay counsellors responsible have returned to work.

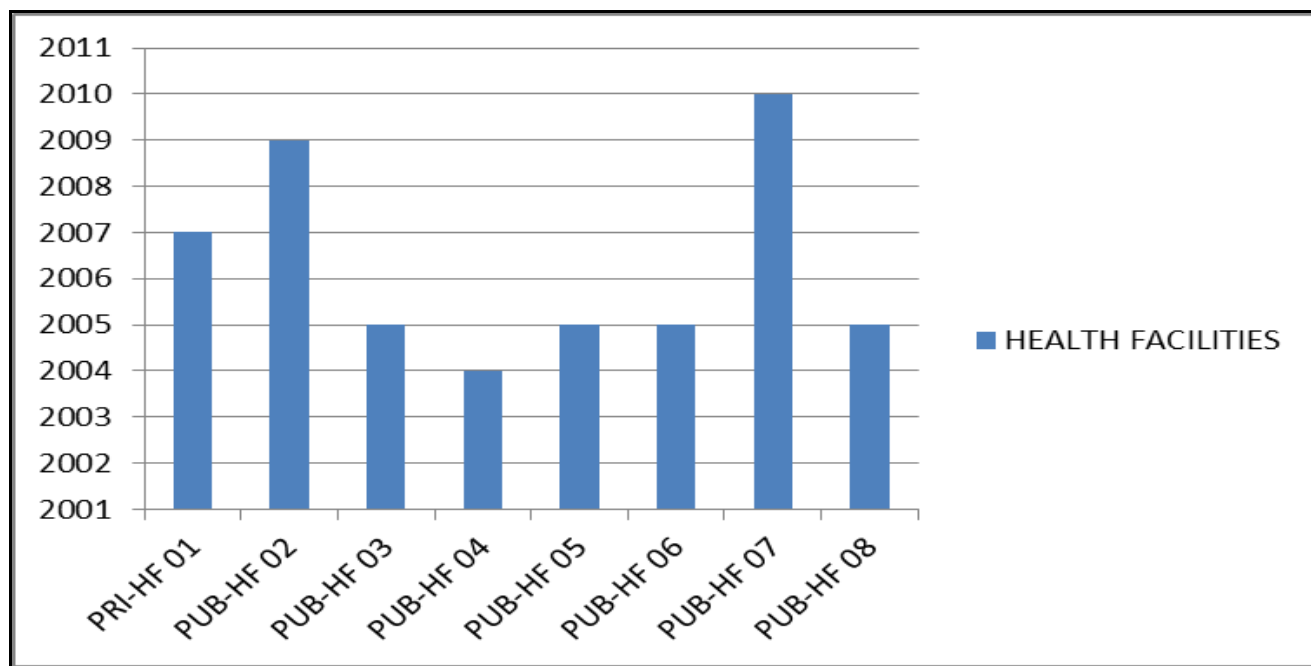
In a study conducted in Johannesburg by Black, Sprague and Chersich (2010) they found that delays in the payment of lay counsellors had a negative impact on the uptake of the Prevention of Mother to Child (PMTCT) services. Late payment also demotivates lay counsellors and some are unable to go to work as they would not have money for transport.



Pie Chart 5: Professional association (N=17)

There are several professional associations available to professional nurses in South Africa, such as the South African Nursing Council (SANC), the Democratic Nursing Organization of South Africa (DENOSA) and the Association of Nursing Agencies of South Africa (ANASA). It then becomes easier for these professionals to raise their concerns if they have a conflict with their employers. With regard to the lay counsellors, they however do not have such associations, which makes it very difficult for them to have a platform to raise their views when they are aggrieved.

Non-governmental organizations (NGOs) contracted to implement the lay counsellor programme hold monthly meetings with their lay counsellors so as to provide them a platform to discuss their issues and raise their concerns. It would however, be ideal to have a recognized body that could represent the lay counsellors. The fact that these lay counsellors are not formally employed exposes them to exploitation and their protection by labour laws becomes limited (Black *et al*, 2011).



Bar Graph 10: Initiation of ART provision for the health facility (N=17)

Public health facility 04 received accreditation for provision of antiretroviral therapy in 2004. It is one of the first seven hospitals in the province to be assessed and accredited by the National Department of Health. It was piloted as a project until it became a fully functional

programme and was rolled out to district hospitals and primary health care facilities. The regional and district hospitals have now down referred clients on ART to primary health care facilities as they are also accredited to provide ART to clients.

In accordance to the National Government's operational plan, the Limpopo provincial task team managed to ensure that ART service sites are integrated into existing health care systems at the primary health care level. The ART roll-out has endured many challenges, such as the lack of resources and human capacity as well as limited expertise in delivering this highly specialized programme (Department of Health and Welfare, 2003). There is a need to modify the health care system from being centralized and expensive to being decentralized, accessible and affordable (Illich, 1982).

Table 30: Number of adults on ART (N=8)

NAME OF HEALTH FACILITY	NUMBER OF ADULTS ON ART
Private Health Facility 01	466
Public Health Facility 02	± 1000
Public Health Facility 03	713
Public Health Facility 04	1,650
Public Health Facility 05	501
Public Health Facility 06	192
Public Health Facility 07	827
Public Health Facility 08	± 500
TOTAL	5, 849

It is apparent from the data displayed that Public Health facility 04 carries the heaviest burden with regard to the number of adults on ART. As a result it was anticipated that they should have a medical doctor on site. The medical doctor however, appeared to be stressed and burned-out, as he seemed irritable and was not even keen on being interviewed. The health facility with the least number of clients is Public health facility 06. Public health facility 06 and 07 are both situated in the Greater Giyani municipality, and it is ironic that a clinic would have more clients compared to a district hospital. It is perceptible that the down referral system is

not as efficient as it should be. District hospitals are usually adequately resourced compared to primary health care facilities. The down referral system needs to be carefully implemented so as to prevent unnecessary burden on the already heavily laden primary health facilities.

An estimated 2.3 million people were on antiretroviral therapy by mid-2013 (Simelela & Venter, 2014). South Africa has the largest ARV programme in the world and 500 000 new clients are put on treatment every year (Budget, 2014). Health facilities responsible for implementing the CCMT programme should be adequately resourced to enable them to meet the demand. When people's health is solely dependent on medicine, the implication is that their lives have become medicalized. Medicalization occurs whenever some aspect of ordinary, everyday life comes to be so defined that it requires input from an institutionalized medical system (Illich, 1982).

Table 31: Number of children on ART (N=8)

NAME OF HEALTH FACILITY	NUMBER OF CHILDREN ON ART
Private Health Facility 01	16
Public Health Facility 02	± 50
Public Health Facility 03	104
Public Health Facility 04	360
Public Health Facility 05	90
Public Health Facility 06	45
Public Health Facility 07	51
Public Health Facility 08	± 300
TOTAL	1,016

With regard to the number of children on ART, the displayed data shows that Public health facility 04 had the highest number of babies on ART, at 360 and the health facility with the lowest number of babies on ART was private health facility 01 at only 16. The Prevention of Mother-to-Child Transmission programme is being implemented at all health facilities in the province. There are also well trained counsellors who are responsible for providing counselling to expectant mothers. The data shows that there are still mothers who transmit

HIV to their babies, it is therefore crucial to assess the cause of these infections. Comprehensive strategies to deal with Mother-to-Child Transmission of HIV need to be developed and implemented.

Health care workers indicate that some of the reasons for the high rate of HIV transmission from mothers to children is that parents wait until it is too late for them to be counselled and tested as most of them suspect that they may be infected with HIV. The fear of stigma and discrimination by community members deter people from seeking medical assistance. For some it is just being ignorant as lay counsellors provide them with health education every morning during week days as they are waiting to consult.

Getting children enrolled in ARV programmes is challenging for a number of reasons. Paediatric treatment tends to be available only at tertiary hospitals and there is limited expertise in treating children at public health facilities (Padarath *et al*, 2006). The situation has since improved, in that all health facilities are now able to provide antiretroviral therapy to children who are infected with HIV.

Table 32: The individual authorized to collect treatment (N=8)

HEALTH FACILITY	PERSON AUTHORISED TO COLLECT TREATMENT FOR THE CLIENT
Private health Facility 01	Client
Public Health Facility 02	Client, any family member and treatment supporter
Public Health Facility 03	Client
Public Health Facility 04	Client, any family member and treatment supporter
Public Health Facility 05	Client, any family member, home based carer and treatment supporter
Public Health Facility 06	Client
Public Health Facility 07	Client
Public Health Facility 08	Client and treatment supporter

Only 4 health care facilities indicated that there were other people who were authorised to collect medication on behalf of the client. These health facilities indicated that this was important as sometimes clients are unable to go to health care facilities to collect their medication themselves. The other 4 health facilities indicated that only the client was authorised to collect their own medication. There have been reports of misuse of ART by the public in the media. The reports indicated that there are people who mix ART with other concoctions to make intoxicating drugs. It is therefore not startling to learn that there are health facilities that are very strict when it comes to dispensing ART.

South Africa has a very high HIV prevalence and the KwaZulu-Natal in particular has the highest HIV prevalence in the country at 40%. It is therefore disheartening to learn that the youth in this province abuse ARV drugs by smoking them. The Efavirenz drug has a very high black market value, as it induces hallucinations. Some HIV positive clients sell their life-saving ARV drugs for profit and others are stolen from clients or pharmacies (Sciutto, 2009).

9.2 Clinical Data and ART Monitoring

The following data is available in the records of ART clients at each facility:

Table 33: Clinical data of Private Health Facility 01

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects	✓				
Client self-report of recent adherence	✓				
Health Care Worker's written findings from client medication calendar	✓				
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence	✓				
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit	✓				
How close was actual visit to scheduled visit?	✓			✓	
Was the client referred for adherence counselling	✓				
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence	✓				
Does the client have Treatment Supporter?	✓			✓	
Did the Treatment Supporter receive adherence counselling?	✓				

The private health facility reported the highest rate of adherence amongst the 8 health facilities. The facility indicated that all vital data was always available except data on scheduled visits as well as information on whether the client had treatment supporter or not. The information on how close the actual visit was to the scheduled visit was only available sometimes as well as the information on whether the client had a treatment supporter or not.

Table 34: Clinical data of Public Health Facility 02

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects	✓				
Client self-report of recent adherence	✓				
Health Care Worker's written findings from client medication calendar	✓				
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence	✓				
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit	✓				
How close was actual visit to scheduled visit?	✓				
Was the client referred for adherence counselling?	✓				
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence	✓			✓	
Does the client have Treatment Supporter?				✓	
Did the Treatment Supporter receive adherence counselling?				✓	

Public health facility 02 reported that data on clients' self-report of recent adherence was usually available as well as data on scheduled visits. Reasons for non-adherence are critical to identify so as to prevent them as they can lead to resistance. This information was only usually available as well as information on treatment supporters.

Table 35: Clinical data of Public Health Facility 03

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects	✓				
Client self-report of recent adherence	✓				
Health Care Worker's written findings from client medication calendar	✓				
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence	✓				
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit	✓				
How close was actual visit to scheduled visit?	✓				
Was the client referred for adherence counselling	✓				
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence	✓				
Does the client have Treatment Supporter?	✓				
Did the Treatment Supporter receive adherence counselling?	✓				

Public Health facility 03 is the only health facility that reported that all the listed data was always available in clients' files. These points to the fact that there is no standardization with regard to data management at ARV clinics. Each health facility adopts an approach that is convenient for them.

Table 36: Clinical data of Public Health Facility 04

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects				✓	
Client self-report of recent adherence				✓	
Health Care Worker's written findings from client medication calendar				✓	
Pill counts of medicine in client's possession				✓	
Health Care Worker's assessment of recent client adherence	✓				
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit				✓	
How close was actual visit to scheduled visit?				✓	
Was the client referred for adherence counselling			✓		
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence	✓				
Does the client have Treatment Supporter?				✓	
Did the Treatment Supporter receive adherence counselling?				✓	

Public health facility 04 does not always have some of the most important information in clients' files. Side effects are very common amongst people on ART and yet the hospital did not always have this information. Pill count of client's medication is a method of monitoring adherence, it is therefore disturbing to learn that the regional hospital only has this information sometimes. The task of pill counting was assigned to lay counsellors and the NGO that is responsible for employing them objected and they have since stopped. Adherence counselling is very important in ensuring that clients adhere to medication, and again this information was only available sometimes. Information on treatment supporters was also only available sometimes.

Table 37: Clinical data of Public Health Facility 05

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects				✓	
Client self-report of recent adherence				✓	
Health Care Worker's written findings from client medication calendar					
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence					
Number of ART pills dispensed					
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit				✓	
How close was actual visit to scheduled visit?					
Was the client referred for adherence counselling			✓		
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence					
Does the client have Treatment Supporter?				✓	
Did the Treatment Supporter receive adherence counselling?				✓	

Information on reported side effects was only available sometimes. Client's self-report of recent adherence is essential but this data was also available sometimes. It is imperative that clients on antiretroviral therapy attend all their clinic appointments. It is therefore disheartening to discover that information on the date of next scheduled visit to the clinic was only available sometimes. Data on whether the client received adherence counselling was usually available. Data on treatment supporters was sometimes available. In order for health facilities to monitor clients on antiretroviral therapy thoroughly they need to ensure that vital data is always available in their files.

Table 38: Clinical data of Public Health Facility 06

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects	✓				
Client self-report of recent adherence	✓				
Health Care Worker's written findings from client medication calendar	✓				
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence	✓				
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit	✓				
How close was actual visit to scheduled visit?		✓			
Was the client referred for adherence counselling	✓				
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence	✓				
Does the client have Treatment Supporter?	✓				
Did the Treatment Supporter receive adherence counselling?	✓				

Public health facility 06 is the health facility with the most lowest adherence levels amongst the 8 health facilities profiled. Health care workers indicated that all vital data was always available in clients' files. The researcher struggled to find some of the crucial data in clients' files such as recent results of CD 4 cell count and viral load tests. The accuracy of the information provided to the researcher is questionable.

Table 39: Clinical data of Public Health Facility 07

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects	✓				
Client self-report of recent adherence	✓				
Health Care Worker's written findings from client medication calendar	✓				
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence					✓
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit	✓				
How close was actual visit to scheduled visit?	✓				
Was the client referred for adherence counselling	✓				
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence		✓			
Does the client have Treatment Supporter?	✓				
Did the Treatment Supporter receive adherence counselling?	✓				

Public health facility 07 has recently been accredited to provide ART, the facility has many clients on antiretroviral therapy, these clients were down-referred from a public Hospital. Information on health care workers' written findings from client medication calendar was never available as well as data on scheduled visits. Reported reasons for non-adherence were usually available. Reasons for non-adherence need to be recorded so as to identify strategies on how to deal with the challenges the client may be facing.

Table 40: Clinical data of Public Health Facility 08

	TYPE OF DATA	ALWAYS	USUALLY	SOME-TIMES	NEVER
Dosing schedule for ART	✓				
Names of other medications taken by clients	✓				
Reported side effects				✓	
Client self-report of recent adherence	✓				
Health Care Worker's written findings from client medication calendar	✓				
Pill counts of medicine in client's possession	✓				
Health Care Worker's assessment of recent client adherence	✓				
Number of ART pills dispensed	✓				
Expected day's supply of ART dispensed	✓				
Date of next scheduled clinic visit	✓				
How close was actual visit to scheduled visit?	✓				
Was the client referred for adherence counselling	✓				
Did the client receive adherence counselling?	✓				
Reported reasons for non-adherence	✓				
Does the client have Treatment Supporter?	✓				
Did the Treatment Supporter receive adherence counselling?	✓				

Public health facility 08 also pointed out that all vital data was always available except the one on side effects. Proper management of side effects is crucial as some clients discontinue taking their medication due to side effects. Regular monitoring of clients on ART is also crucial. During data collection it became apparent that clients dealt with side-effects in various ways. Most clients would consult their health care providers at their respective facilities, however there are those who would consult their church pastors to have the side-effects managed.

It is apparent from the responses given by the health facilities, that data management is a major challenge for most of the facilities. Data management within the CCMT programme is crucial as it helps to ensure that clients receive services of good quality. Reported reasons for non-adherence need to be determined to ensure that clients are assisted to adhere. Public health facilities 05, 02 and 07 indicated that they only usually have these data available in the clients' records

Table 41: Monitoring of individual client’s adherence

ADHERENCE MEASURE	PUB-HF 04	PUB-HF 05	PUB-HF 03	PUB-HF 06	PUB-HF 08	PRI-HF 01	PUB-HF 02	PUB-HF 07
Client self-report	✓	✓	✓	✓	✓	✓		✓
Client medication calendar				✓		✓		
Pill count	✓	✓	✓	✓	✓	✓	✓	✓
Clinicians subjective judgement	✓	✓	✓	✓	✓	✓	✓	
Client complying with regular appointments	✓	✓	✓	✓	✓	✓	✓	
Directly observed treatment at health facility		✓			✓	✓		
Directly observed treatment at home		✓			✓	✓		

Most Health Care facilities indicated that they monitor individual client’s adherence to ART by obtaining client self-report, conducting pill count, relying on the clinicians’ subjective judgement and by observing whether the client complies with regular appointments or not. The health care facilities do not rely on the client medication calendar and Directly Observed Treatment Short-course (DOTS). The Directly Observed Treatment Short-course programme has been successfully applied within the TB programme with the aid of Home Based Carers. The Home Based Carers observe TB clients taking their medication in the comfort of their homes. The DOTS programme could also be applied in the implementation of the CCMT programme, since it has been found that many people on ART receive support from their families. Family members could assist in ensuring that clients take their medication religiously by observing them taking their ARVs. Some NGOs do not allow their lay counsellors to perform some of the ART related tasks such as pill-counting as they believe it is the duty of the health care workers.

Table 42: Rate of adherence for an individual client

HEALTH FACILITY	RATE OF ADHERENCE FOR A CLIENT
Private Health Facility 01	95%
Public Health Facility 02	90%
Public Health Facility 03	Data not provided
Public Health Facility 04	80-90%
Public Health Facility 05	90%
Public Health Facility 06	85%
Public Health Facility 07	95-100%
Public Health Facility 08	90%

In order to achieve the desirable results such as durable suppression, it is crucial for most clients on ART to take 95% of their medication. In reality this level of adherence requires a client on a twice a day regimen not to miss or substantially delay more than 3 doses of ART medication per month (HIV InSite Knowledge Base Chapter, 2006). With regard to the data presented it is clear that only two health care facilities complied with this requirement, Hlokomela Training Trust and Kremetart Clinic.

Table 43: Rate of adherence for a health facility (N=8)

HEALTH FACILITY	RATE OF ADHERENCE FOR THE HEALTH FACILITY
Private Health Facility 01	95%
Public Health Facility 02	90%
Public Health Facility 03	Data not provided
Public Health Facility 04	80%-90%
Public Health Facility 05	100%
Public Health Facility 06	85%
Public Health Facility 07	95%-100%
Public Health Facility 08	100%

The rate of adherence considered to be satisfactory for health facilities was higher compared to the one considered to be satisfactory for the individual client. Public health facility 05, 07 and 08 are the only health facilities that indicated that 100% adherence for their facilities are required. Public health facility 04 and 06 indicated the lowest percentage of adherence, at between 80%-90% and 85% respectively. All health care facilities indicated that they relied on records from individual client's routine adherence monitoring to calculate ART adherence.

Table 44: The most recent rate of ART adherence for a health facility (N=8)

HEALTH FACILITY	THE MOST RECENT RATE OF ADHERENCE AT THE HEALTH FACILITY
Private health facility 01	80%
Public health facility 02	± 80%
Public health facility 03	Data not provided
Public health facility 04	80%
Public health facility 05	95%
Public health facility 06	80%
Public health facility 07	70%-80%
Public health facility 08	95%

Public health facility 05 and 08 are the only health facilities that reported the highest most recent rate of ART adherence. Public health facility 7 reported the lowest rate at between 70% - 80%. Public health facility 02 was not sure about the exact percentage of adherence as they only gave an estimation of ± 80%. Estimations are problematic as they do not give the true reflection of the situation.

Table 45: Monitoring and Evaluation of ART clients (N=8)

HEALTH FACILITY	SYSTEM USED TO MONITOR CLIENTS
Private health facility 01	Clients' files, ART attendance register, and the TIER.NET system are updated every time clients come to collect their medication.
Public health facility 02	Clients are booked using a diary system. The list is monitored to determine who failed to report for their medication according to their scheduled dates.
Public health facility 03	A book is used to record and the data capturer communicates with the social worker.
Public health facility 04	<ul style="list-style-type: none"> • Health care workers use a diary as well as client's records. • Health care workers phone the client or the treatment supporter.
Public health facility 05	<ul style="list-style-type: none"> • Clients are entered into a monthly register for ART. • The social worker helps in tracing the clients.
Public health facility 06	<ul style="list-style-type: none"> • Health care workers phone clients or treatment supporters. • An attendance register is used and clients are reprimanded for missing appointments.
Public health facility 07	Clients are given return date cards and if they failed to come it is easy to determine.
Public health facility 08	Clients are recorded and the social worker follows them up

In order to monitor whether clients receiving ART attend scheduled appointments or not most health care facilities phone either the client or the treatment supporter. Social workers also assist in tracing the clients. Some health facilities have devised very innovative strategies that need to be shared with other health care facilities as they are best practices. Public health facility 07 issues return date cards to clients on ART and it becomes easy to determine whether a client honoured the appointment or not. Private health facility 01 has the TIER.Net monitoring and evaluation system which is updated every time the client comes to collect their medication. Attendance registers are also used by most health care facilities. Accurate data collection by health care facilities is critical so as to properly inform decision makers and reflect progress. It is also crucial for health care facilities to use similar systems so as to ensure standardization and consistency.

Randomised controlled trials (RCTs) in Kenya investigated the use of mobile phone short message service (SMS) in improving treatment adherence. An intervention group that was receiving weekly messages to remind them to take their medication were more likely to achieve more than 90% rate of adherence and less likely to experience interruptions compared to their controls (Pop-Eleches, Thirumurthy, Habyarimana *et al*, 2011).

9.3 Data Management Systems

9.3.1 TIER.Net or HIV Electronic Register or eRegister

Owing to the scale-up of antiretroviral therapy in high burden countries, many treatment sites are no longer able to cope with monitoring large numbers of patients with paper based systems alone. These sites do not all have the necessary infrastructure and resources to implement full electronic medical record (EMR) systems. This awareness has led to the development of a 3-tier approach to monitoring, which includes a paper-based system making up tier 1, an electronic version of the paper register as the middle tier or tier 2 and full electronic medical record software as the 3rd tier. The 3 tier approach allows government departments, managers the department of health and NGOs providing antiretroviral therapy to strategically implement one of the three tiers in each of their facilities offering ART services. The TIER.Net software has been built to easily and effectively capture the minimum data

elements and resulting indicators (determined by systems based on the WHO paper-registers) required to monitor the HIV and ART services (Olser & Boulle, 2010).

9.3.2 The District Health Information System (DHIS)

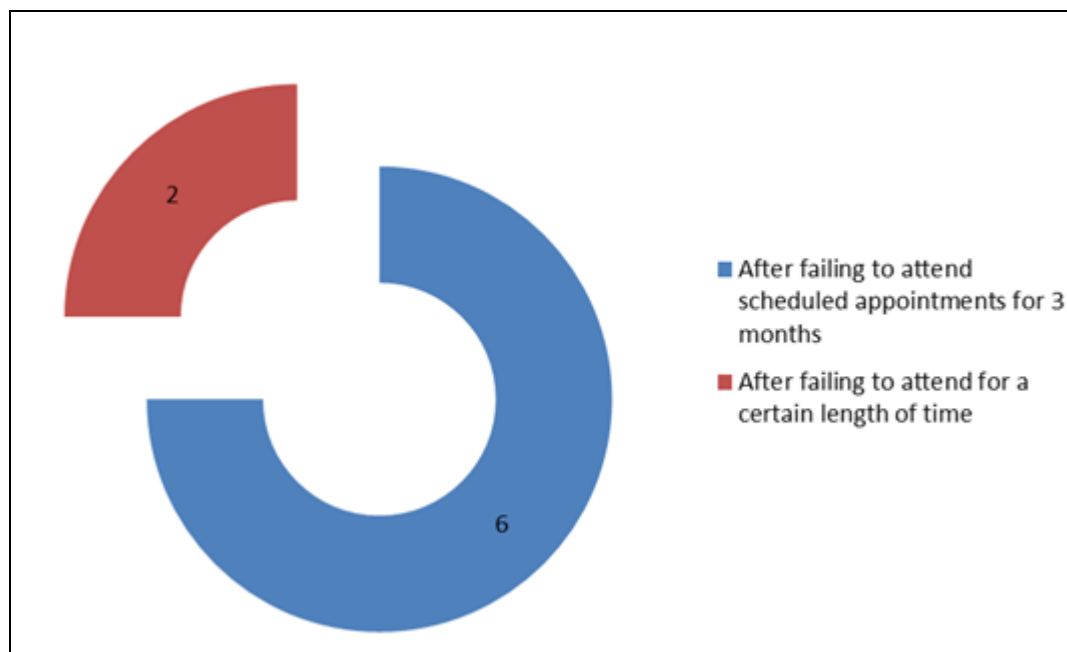
The District Health Information System (DHIS) is software designed for collecting, validating, analysing and presentation of statistical data. In South Africa, data is collected on a monthly basis from health facilities and NGOs to the sub-district office and then aggregated to district, provincial and national levels and wherever required to the donors as well. Information officers are responsible for data entry, validation, compiling reports, developing charts, pivot tables and reporting rates. There is a need to cascade this information to health facility managers so as to enable them to improve on their data management.

Table 46: The way of knowing about clients on ART (N=8)

HEALTH FACILITY	WAY OF KNOWING THE WHERE ABOUT OF THE CLIENT
Private Health Facility 01	<ul style="list-style-type: none"> • Clients are phoned to ask the reason they failed to collect their medication. • The family calls the clinic to inform them if the client is deceased or ill.
Public Health Facility 02	<ul style="list-style-type: none"> • Through other clients and enquiring in the community. • Clients are contacted telephonically and community tracers are also used to go for a home visit and compile a report.
Public Health Facility 03	The data capturer communicates with the social worker.
Public Health Facility 04	Health care workers call the clients to treatment supporters. They also go to the wards to check on the recorded deaths list. They also rely on other clients to inform them.
Public Health Facility 05	Social workers conduct home visits. The facility also used to rely on hone based carers but not anymore as they do not maintain confidentiality.
Public Health Facility 06	<ul style="list-style-type: none"> • Health care workers ask the group members that the client was supposed to have attended with. • Health care workers call the client or the treatment supporter and the social worker conducts home visits.
Public Health Facility 07	<ul style="list-style-type: none"> • The Health care workers would use a cell-phone, but it has since been taken by the district office. • They also rely on Home Based Carers.
Public Health Facility 08	The social worker conducts home visits.

If the client fails to attend a scheduled visit it could mean that they are either sick, have died or have dropped out. Health care facilities apply various methods in order to identify the reasons for non-compliance. Health care workers phone either the client or the treatment supporter. Public health facility 04 indicated that they go to the wards to check on the recorded deaths list. It is important to note at this point that 70 clients are lost to follow-up at the Letaba Regional Hospital every quarter.

Social workers also conduct home visits, counsellors and health care workers also rely on other clients for information on the whereabouts of their counterparts. The high rate of loss to follow-up is a clear indication that the facility needs to revise their monitoring strategies. At public health facility 02 tracers are used to go for home visits and compile reports. Public health facility 07 also relies on Home based carers, the clinic used to phone the clients and treatment supporters, but have stopped since the cell-phone was taken by the district office. Public health facility 05 used to rely on Home-based carers, but not anymore due to their inability to maintain confidentiality. Self-determination theory advocates that clients need to be given room to exercise their autonomy, competence and relatedness in health care facilities and that if instructions given by health care providers are clear they are likely to make an impact and thus result in behaviour change (Williams, Deci & Ryan, 1998).



Doughnut 5: The point at which an ART client is considered a drop-out or defaulter (N=8)

Many people on antiretroviral therapy usually improve after a few months of being on therapy. Transport costs, time needed for treatment as well as logistical challenges was barriers to treatment adherence. Unemployment and work commitments also prevent clients from complying with their clinic appointments (Miller, Ketlhapile, Rybasack-Smith & Rosen, 2010). If a client fails to attend clinic appointments for a period of three months, the implication is that such an individual would have missed a considerable amount of doses.

Table 47: Systems used to follow-up on clients (N=8)

HEALTH FACILITY	SYSTEM USED TO FOLLOW-UP CLIENTS
Private Health Facility 01	By checking the defaulter register book and by generating a defaulter report using the TIER.Net system.
Public Health Facility 02	<ul style="list-style-type: none"> • Health Care Workers link up with Home Based Carers to help trace the clients. • A team of HIV/TB tracers is used to race the clients.
Public Health Facility 03	The health care facility relies on social workers.
Public Health Facility 04	Health care workers used to phone clients, but are not able to do so anymore due to financial constraints.
Public Health Facility 05	<ul style="list-style-type: none"> • Clients are traced through a team of community tracers. Social workers and health care workers phones at times. • The facility also used to rely on Home Based Carers, but not anymore due to lack of confidentiality.
Public Health Facility 06	Health Care Workers use the attendance register. They call out the names of clients and tick next to their names as they respond.
Public Health Facility 07	Health Care Workers link up with Home Based Carers to help trace the clients.
Public Health Facility 08	The health care facility uses the services of social workers.

With regard to the systems that the health care facilities use for following up with clients who do not turn up for an appointment, approaches vary and are also similar in some instances. Most health care facilities rely on the services of social workers. Public health facility 05 relies on community tracers, they also used to work with Home Based Carers but have since stopped due to lack of confidentiality. Attendance registers are also used and the private health facility uses the TIER.Net monitoring and evaluation system. At public health facilities 02 and 07, health care workers link up with Home based carers, which is interesting to note since public health facility 05 has since suspended their services. A team of community HIV/TB tracers is used at health facility 02. Social capital according to Putnam's view has three components. That is, moral obligations and norms, social values and social networks (Putnam, 1995). Health care providers have an obligation to maintain confidentiality, promote social networking through support groups and to provide support to clients on ART and their families.

9.4 Interventions Used to Promote Client Adherence

9.4.1 Patient counselling before starting ART

Clients on antiretroviral therapy need to be thoroughly counselled prior to initiation of therapy. According to the CCMT guidelines a client being prepared for antiretroviral therapy is required to attend at least 3 treatment adherence counselling sessions together with their treatment supporter.

9.4.2 On-going counselling after starting antiretroviral therapy

The provision of on-going counselling services is imperative as clients on antiretroviral therapy usually experience difficulties in fitting in the medication into their lifestyles. On-going counselling helps to reassure them that support will always be provided to them if and when they need it.

9.4.3 Home/Community based carers

Home community based carers have a good history of monitoring TB clients effectively. It is widely acknowledged that the Directly Observed Treatment Short Course Strategy (DOTS) implemented within the TB programme can equally be entrenched within the CCMT programme. However, there is a need to have continuous training of these Home based carers and to reinforce the importance of maintaining confidentiality. Home based carers could work closely with treatment supporters in observing treatment amongst clients on antiretroviral therapy within the comfort of their homes.

9.4.4 Social Support (food parcels, food supplements, day care)

Social support is very critical in the CCMT programme. Some antiretroviral therapy drugs may only be taken after one has had a meal. Given the fact that there is a very high rate of unemployment in South Africa, many families are poverty stricken and cannot afford to meet some of the basic needs such as food. These families rely on the government and NGOs to provide them with decent meals. The South African Government has developed a system whereby unemployed people living with HIV and AIDS and their families are given food parcels to enable them to boost their immune systems. Food supplements are also distributed to supplement vital nutrients. Day care is arranged for HIV positive mothers who are unable to care for their children themselves wherever possible through Home based carers.

9.4.5 Fast track services at health facilities

Public health facilities are notorious for offering mediocre services and for having very long queues. Fast tracking services is crucial in that some clients only visit health facilities when their immune systems have severely deteriorated, therefore delays in assisting them could have dire consequences.

9.4.6 Use of devices to promote adherence

(Diary, pill box, alarm, reminder phone calls)

Antiretroviral therapy is a lifelong commitment and once a client start with the treatment they may not terminate without the proper advice of a medical doctor who specialises in HIV and AIDS. There are certain devices that clients on ART can use to enable them to remember taking their medication. The method that the client chooses is entirely dependent on their preferences. HIV and AIDS counsellors have the responsibility to enlighten them about the options available to them. Clients on ART are encouraged by Health care workers to associate taking their medication with a certain daily routine such as brushing of teeth. They are also encouraged to put their medication near their teeth brushes.

9.4.7 Support Groups of People living with HIV and AIDS

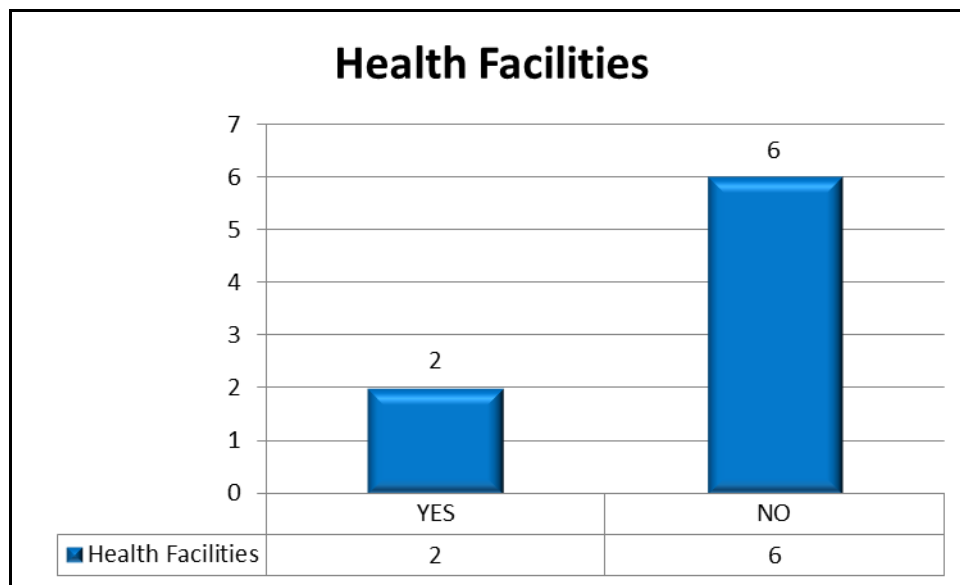
Support groups are very important in that they provide people living with HIV and AIDS an opportunity to interact with other people who are also HIV positive. In support groups members also share their challenges, successes as well as experiences of living with HIV and being on antiretroviral therapy. Professionals from different fields are also requested to address support group members about various topics that may be useful to them.

9.4.8 Promoting treatment adherence through media, such as TV and radio stations

The media is a very effective medium in disseminating information. Many families own TV sets and radios. More information regarding antiretroviral therapy need to be communicated to the public by the department of health official through the media, various South African Broad Casting Network (SABC) TV stations and public radio stations.

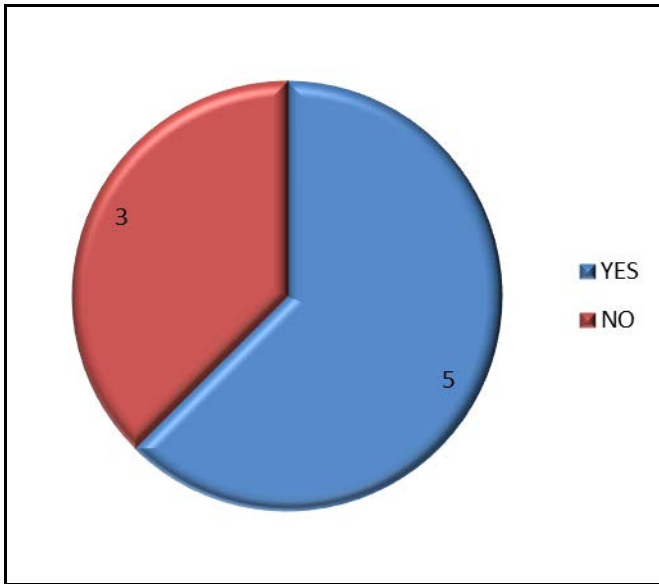
9.9 HIV/TB community tracers

HIV and TB are twin epidemics, in that many people who have HIV also have TB and those to have TB are infected with HIV as well. It is therefore, essential to treat and manage the two epidemics simultaneously. As proclaimed by some of the health facilities profiled in this study, HIV/TB tracers can be very effective in monitoring clients on antiretroviral therapy.



Bar Graph 11: Interventions to improve the health care providers' motivation to promote better client adherence (N=8)

HIV and AIDS counselling is too demanding and it is crucial for people providing the service to be kept interested in their job. Only public health facility 03 and private health facility 02 indicated that there were interventions at their facilities to improve health care workers' motivation to promote better client adherence. Public health facility 03 indicated that all staff members are sent notes of appreciation by the Deputy Nursing manager during excellence awards. At the private health facility 01 health care workers and counsellors are sent away for training workshops so as to keep them updated with new developments on HIV and AIDS.



Pie Chart 6: Support from the department of health and funded NGOs (N=8)

Monitoring and evaluation is very important in ensuring that HIV and AIDS programmes are properly implemented. Only 5 health facilities indicated that they were receiving sufficient support from the Department of Health. Public health facility 03 and 06 indicated that their HIV and AIDS counsellors also receive support from the contracted NGOs responsible for implementing the HIV and AIDS counselling programme in the Mopani District. However, 3 health facilities indicated that they were not receiving sufficient support from the Department of Health and the NGO. The Department of Health and NGOs provide health care workers and counsellors with support by conducting regular support visits.

9.5 Interventions to Improve ART Adherence at Health Facilities

9.5.1 Social support

Social support can take place at different levels, such as within the family by family members, within the health facility by Health care workers, at the workplace by employers and colleagues and in the community by community leaders.

9.5.2 Psychological support

People infected with HIV need psychological support because an HIV positive diagnoses unearths many negative emotions that need to deal with in a professional manner. The Department of Health utilizes the services of Psychologists and Social workers in this regard. Referral systems within health care facilities need to be efficient.

9.5.3 Health care facility location

The placement of a health facility needs to be carefully thought out by the authorities as it determines whether people will be able to access it or not. Accessibility of health facilities is critical, more especially in a country where the unemployment rate and poverty are very high. This mean that many people are not able to afford a taxi or bus fare. In situations where the health facility is very far, community members are forced to borrow money from relatives or neighbours. Some of the respondents in this study had borrowed money from their neighbours as they could not walk to health facilities due to their inaccessibility.

9.5.4 Health care workers' capacity and motivation

In order for health care workers to provide services of good quality they need to be supported emotionally through de-briefing and mentorship. The National Department of health has developed mentorship guidelines and commissioned a training workshop for masters trainers, who were responsible for training mentor trainers in their respective provinces. The Limpopo Province also took part in this initiative. Provincial mentor trainers were able to train mentors in all the districts. The role and responsibility of mentors is to provide regular mentoring sessions to HIV and AIDS counsellors. Mentorship is offered either in a group from or individual basis. Non-governmental organizations contracted by the Department of Health to provide the HIV counselling and testing programme through lay counsellors also have trained mentors who were trained by the Department of Health.

9.5.5 Use of reminders for client monitoring

Reminders have proven to be effective in ensuring that clients on antiretroviral therapy remain of their medication and do not skip doses. The private health facility has a very high rate of illiteracy as most of their clients are farm workers. The organization has developed a treatment adherence chart with symbols of the sun and the moon to assist their clients in adhering to treatment. They also distribute pillboxes amongst their clients, marked each day of the week to make dosing easier. These strategies can be copied by other health facilities in the province.

9.5.6 Improved adherence monitoring

Monitoring of clients on antiretroviral should be done holistically focussing on various critical aspects. Regular CD 4 cell count and viral load tests should be followed by regular client clinic visits, pill counting, adherence counselling, home visits by Social workers, HIV/TB tracers and Home based carers. As indicated by some of the health facilities that participated in this study, other clients on antiretroviral therapy can play an important role in monitoring their friends.

9.5.7 Improved client counselling and communication

Regular refresher courses need to be organised for health care workers to keep them updated with new developments within their field. It is the responsibility of the Government to ensure that health facilities are adequately resourced as health care workers need to communicate with clients on antiretroviral therapy on a regular basis. The Department of health has to ensure that there are well functioning land line telephones or loaded cell-phones in these facilities.

9.5.8 Encouraging disclosure

In order for a person who is diagnosed HIV positive to be supported he/she needs to disclose his/her status to someone that they trust. Disclosure enables the infected individual to access various services available for people living with HIV and AIDS. Taking antiretroviral therapy is

a huge responsibility and one cannot take the medication secretly as they may skip doses sometimes due to fear of being noticed taking medication. Disclosure is thoroughly discussed during HIV counselling and testing and on-going counselling if the client has not disclosed. Living openly with HIV amongst one's significant others also protects them from contracting HIV and they will be more careful not to touch body fluids of an infected person.

9.5.9 Establishing and maintaining support groups

It became apparent during data collection that many families in the Mopani District had more than one family member who is infected with HIV. Support groups established by health facilities are not viable. Families could be assisted by the Department of Health through NGOs to establish support groups of people living with HIV and AIDS within their families. Many people diagnosed with HIV view the church as their place of refuge, church leaders need to be equally capacitated to manage church members infected with HIV and to not only encourage church members to bring their medication to church, but develop strategies to assist them in adhering to such medication. This can be done through establishing treatment adherence clubs within churches that are supervised by trained treatment adherence counsellors.

9.5.10 Improve clinical assessments

It is not sufficient to only conduct CD 4 cell count and viral load tests on a regular basis. Results of such tests need to be communicated to clients on antiretroviral therapy regardless of their literacy levels. There seems to be reluctance amongst health care workers to communicate monitoring results to clients who are believed to be illiterate. Antiretroviral therapy (ART) data management needs to be improved more especially at public health facilities.

9.5.11 Strengthening family support

It became evident during data analysis that many people diagnosed with HIV disclose to their close family members. Families need to be empowered with HIV and AIDS information to enable them to care for and support infected family members on antiretroviral therapy. Family members can also be excellent treatment supporters as they spend most of their time with the client on antiretroviral therapy (ART). In situations where the client is unable to collect their medication themselves due to illness or work commitments, family members can collect the medication on their behalf.

Table 48: Major challenges for public health facilities and the Recommended Interventions

MAJOR CHALLENGES	INTERVENTIONS
Shortage of Medical Doctors.	Train and place more Medical Doctors at health facilities.
Inability to monitor clients on ART.	Use the aid of social workers and home based carers.
High HIV transmission rate amongst babies.	Educate mothers and fathers about Prevention of Mother-to-Child Transmission of HIV (PMTCT).
Interruption of services due to delays in receiving stipends.	The Department of Health needs to strengthen their funding model
Lack of support groups for people living with HIV and AIDS	Support groups need to be established and sustained with the assistance of the Department of Health and NGOs.
Poor Monitoring and evaluation of health facilities by the Department of Health.	<p>There is a need to have an effective monitoring and evaluation strategy that can be used by the provincial, district and sub-district co-ordinators.</p> <p>Monitoring of health facilities needs to be done on a monthly basis.</p>

<p>Down referral of clients from hospitals to primary health care facilities.</p>	<ul style="list-style-type: none"> • Primary health care facilities need to be capacitated to deal with the magnitude of clients on ART. • More health care workers and medical doctors need to be placed at primary health care facilities.
<p>Resistance and poor virological response more especially at public health facilities.</p>	<p>Strict monitoring of clients who fail to respond to treatment, including home visits.</p>
<p>70 clients on ART are lost to follow-up in a quarter at a certain hospital.</p>	<p>Effective monitoring strategies need to be employed.</p>
<p>Shortage of ART at public health facilities.</p>	<p>Public health facilities need to be well-resourced to be able to have their own pharmaceutical warehouse and officials at health facilities need to be well equipped to be able to place orders timeously.</p>

Table 49: Major Challenges for Private Institutions and the Recommended Interventions

MAJOR CHALLENGES	INTERVENTIONS
Sustainable funding	It is important for NGOs to be capacitated to be able to manage their funds and market their organizations vigorously so as to attract many donors.
High HIV prevalence rate amongst farmworkers.	Continue to educate on prevention programmes.
High illiteracy rate	Introduce Adult Basic Education and Training (ABET) in farming communities.
Lack of uniformity in the implementation of HIV and AIDS programmes.	The importance of HIV and AIDS programmes must be clearly communicated to all supervisors at all farms, so that they can be able to support farm workers on ART.

9.6 Summary

The demographic data of health care providers and lay counsellors was outlined. Information on the sampled health facilities was discussed. The importance of the mentorship programme was deliberated. Challenges confronting public health facilities regarding the shortage of health care providers were outlined. Required adherence levels for individual on ART and their health facilities were debated. The importance of monitoring clients on ART and methods used by health facilities were articulated. Data management as well as the interventions adopted to address the challenges were described.

The triangulation research methodology was applied. In-depth interviews with 31 respondents on ART were conducted, two Focus Group Discussions were also conducted with 14 respondents, a questionnaire was distributed amongst 17 Health Care Workers and clients' medical records were reviewed. The total sample consisted of 62 respondents. The study confirmed that females are more vulnerable to HIV than males. All the respondents, but one

was African, which further confirms that African people are more affected by the epidemic than the other races.

Social support is very important for people living with HIV and AIDS, because living with HIV secretly can be very stressful. Most people that were interviewed disclosed their HIV status to family members, therefore family support is very crucial. There were HIV positive couples as well as discordant couples in the study. People diagnosed with HIV have a choice on whether they would like to disclose their HIV status or not. All respondents in this study had disclosed their HIV status mostly to family members.

The government has done very well in educating communities about HIV and AIDS and as a result there were very few incidents of stigma and discrimination amongst respondents interviewed. The stigma scale was administered to all respondents. The level of stigma and discrimination also varies from individual to individual. Self-efficacy is also very important in managing HIV and AIDS. Acceptance and taking responsibility for one's health is very important. It became evident in the study that most respondents had accepted their HIV positive status.

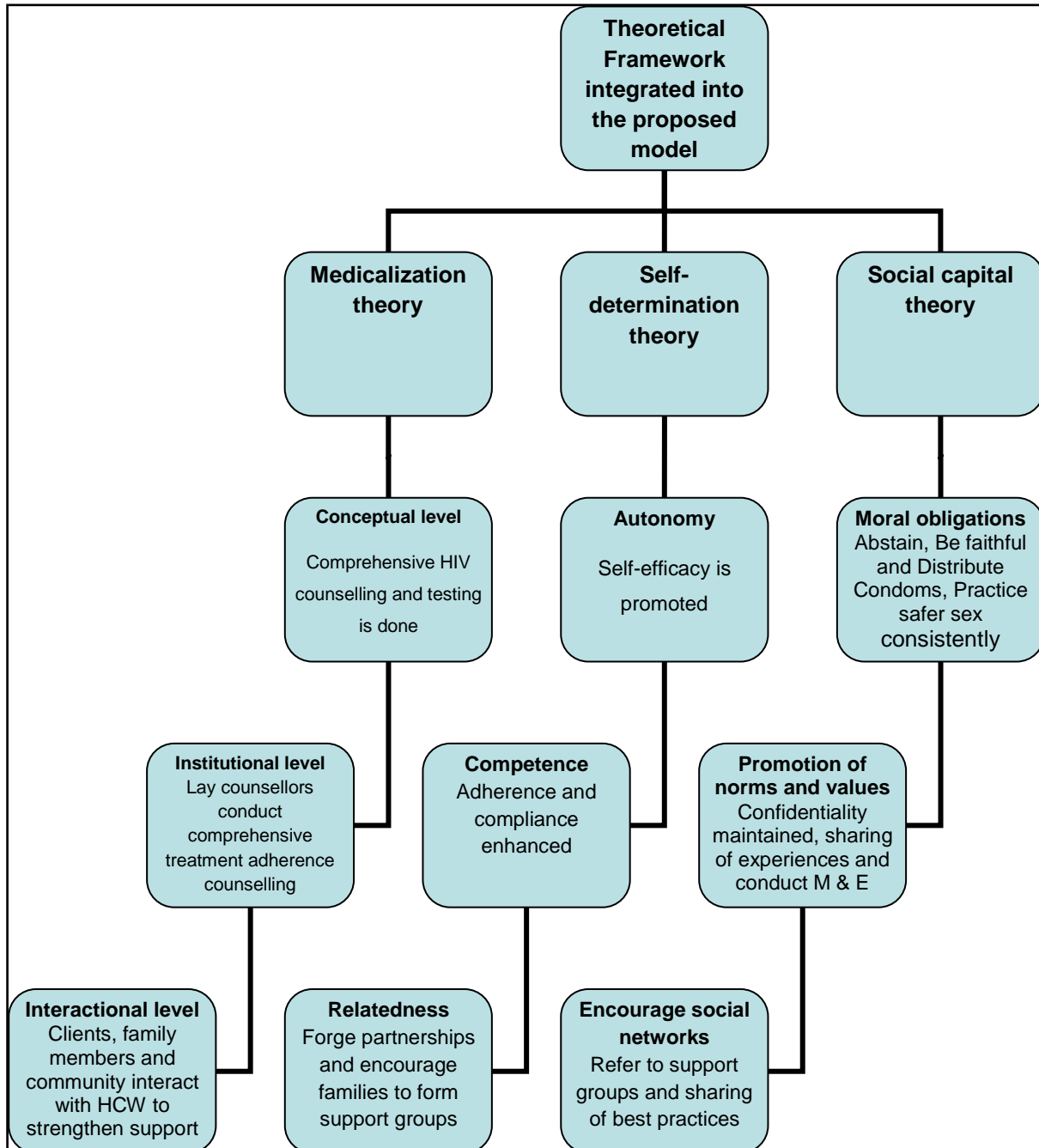
Negotiating for safer sex practices was still a challenge as most of the respondents indicated that they did not use any protection. Even though the National Department of Health makes an effort to ensure that condoms are widely distributed, there is still a shortage of female condoms. Amongst all the respondents who indicated that they used condoms, none indicated that they used female condoms. Some respondents had not even seen a female condom in their lives.

There were several challenges that respondents encountered, but these do not prevent them from adhering to treatment. Side effects were some of the challenges experienced, and were effectively managed. It is however important to indicate that some side effects may not be as easy to manage compared to others. Side effects such as lypodystrophy or fat redistribution can be very harmful both physically and psychologically. Several respondents, more especially at Letaba Regional Hospital, complained about this.

Data collected in in-depth interviews complimented data from Focus Group Discussions (FGD's). Health Care Workers and lay counsellors were interviewed, through a questionnaire and it was disconcerting to find that there was no consistency in what they were doing as they gave conflicting statements. The review of respondents' medical records was crucial and it helped to back up information received from them. The number of adults and children on ART varies from health facility to health facility. All lay counsellors who participated in the study were employed by non-governmental organizations that were funded by the government. The level of education between Health Care Workers and lay counsellors differ in that Health Care Workers were found to be more educated than lay counsellors. However, with regard to HIV and AIDS training they have done similar courses and have been trained comprehensively. These health facilities provide comprehensive services to their communities. There is no uniformity regarding procedures at these facilities. For instance some health facilities insist that it is the sole responsibility of a client on treatment for them to fetch their own medication, whereas others allow family members and treatment supporters to collect the medication on behalf of the client on ART. Effective monitoring strategies are important in order to ensure that clients are not lost to follow-up.

CHAPTER 10

A GUIDE OF THE IMPLEMENTATION OF THE RECOMMENDED TREATMENT ADHERENCE MODEL



Flow Chart 4: Family-Centred ART Treatment Adherence: Proposed Model

It is envisaged that the proposed Treatment Adherence Model, developed during the study will add a fresh and enduring perspective in the fight against HIV and AIDS. The proposed model is explicated in the following pages. It is hoped that the governing authorities will take heed of this novel all-embracing approach and implement it in the fight against the pandemic.

It is crucial to realize that this model is adaptable to any environment, in that it can be applied at both private and public health facilities.

10.1. Conduct Community Outreach Programmes on HIV and AIDS

It is important for government departments and other relevant institutions to ensure that their services are easily accessible. This could be done through conducting community outreach programmes, more especially in secluded areas and to vulnerable groups. Farm workers, taxi drivers, truck drivers, commercial sex workers, schools, churches and universities need to be specifically targeted. Community members need to be encouraged to abstain, be faithful to their partners and use either male or female condoms consistently.

10.1.1 Easy access to HCT Services

In order for the country to curb the spread of HIV, it is essential that each individual should know their HIV status. Mobile clinics could be erected at public places such as shopping malls, taxi ranks, stadiums etc. Confidential HIV and AIDS counselling needs to be done by adequately trained counsellors. Community leaders and workplace managers need to lead by example, in that if they want their subordinates to take HIV seriously they need to volunteer to be counselled and tested themselves, so that their subordinates can be able to realize the importance thereof. Couple counselling needs to be promoted to enable those that have partners to be counselled together with their partners.

10.1.2 Efficient referral system

The referral system should be effective so as to enable those who test HIV positive to access further services. Referring clients who have tested HIV positive for CD 4 cell count and viral load tests is essential in that it will ensure that if the CD 4 cell count is very low, the client can be initiated on antiretroviral therapy. Support groups of people living with HIV and AIDS are also essential and counsellors need to make clients aware of such support groups, so that they can get the support that they need.

10.1.3 Empowerment on disclosure of one's HIV status

Being diagnosed HIV positive is not easy to comprehend. Empowerment on how, where, when and to whom to disclose is essential. Disclosure to significant others such as immediate family members and sexual partners is important so as to curb the spread of HIV. Disclosure of one's HIV status at the workplace is not compulsory, but depending on the kind of work one does and the environment, disclosure could be beneficial in that the client may receive support from their employer, supervisors and colleagues. People living openly with HIV or HIV ambassadors could assist in empowering other people diagnosed HIV positive with skills to live positively as well.

10.1.4 Human Rights and dealing with stigma and discrimination

South Africa has one of the most progressive Constitutions in the world. Chapter 2 of the Constitution has the Bill of Rights, this is a list of rights that each and every South African citizen should enjoy. Chapter 9 institutions such as the South African Human Rights Commission and Commission on Gender Equality need to make their services more accessible to the broader community. Educating communities on basic human rights is important.

10.1.5 Monitoring and Evaluation System

Monitoring and evaluation of HIV and AIDS programmes is essential as it enables the managers responsible to identify the challenges and to devise strategies or interventions so as to address the challenges. Paper based and electronic systems could be used to monitor programmes. Capacitating managers and employees on IT skills is also essential.

Standardization of services is important so as to ensure coherence. An effective communication strategy also needs to be developed so that information can be transferred effectively.

10.1.6 Self-efficacy and Management of side effects

Treatment adherence counselling should be done prior to initiating a client on antiretroviral therapy. It should also be emphasized that it is not all people on antiretroviral therapy that will experience side effects. It is important however that those who do are not caught by surprise by preparing them thoroughly and availing services to provide the necessary support.

10.1.7 Strengthening of family support

Families need to be assisted to establish support groups. Couple counselling has to be encouraged to enable couples to provide each other the necessary support. Home community based care services should be readily available for families that require assistance. Family counselling should be provided through social workers and psychologists and confidentiality should be maintained throughout the counselling process.

CHAPTER 11

CONCLUSION, GENERAL RECOMMENDATIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH

11.1 Conclusion

The aim of the study was to investigate challenges associated with antiretroviral therapy (ART) adherence. The study uncovered the following challenges, the support provided to clients on antiretroviral therapy is inadequate, as most of the facilities did not have active support groups of people living with HIV and AIDS. Many respondents did not even know about the existence of any support groups in their facilities. Some respondents experienced stigma and discrimination committed by close family members and community members. Poor self-efficacy was demonstrated by some clients on antiretroviral therapy (ART) at certain health facilities in this study where adherence was very poor amongst clients on ART. Disclosure of HIV status to sexual partners was a challenge for some respondents, as they feared being rejected or violently attacked. Strategies to promote adherence were identified by clients on ART as well as health care workers and lay counsellors.

It is imperative to point out that family and social support are some of the essential components to ensuring good adherence to antiretroviral therapy. Most of the respondents in this particular study obtained support from close family members. Female family members were more popular amongst the people preferred to disclose to as they are trusted to maintain confidentiality. Support groups of people living with HIV and AIDS likewise provide the necessary support that people on antiretroviral therapy need as they are able to share their experiences with fellow members. Families themselves could be assisted to establish support groups as many families have two or more members living with HIV. Community support offered through various institutions such as churches could similarly play a significant role in this regard.

The South African Government has made incredible efforts in educating communities about the transmission and prevention of HIV. The department of Health has also developed and implemented effective HIV prevention and treatment programmes. Stigma and discrimination

against people infected with HIV seems to be reduced, as only a few respondents indicated that they were affected. Some of the human rights violations were committed by close family members, this is a signal that more still needs to be done in educating families about HIV and AIDS. Couple counselling is equally very essential as it may assist sero-discordant couples (situations where one partner is HIV positive and the other one is HIV negative) to cope better with the condition. Illiteracy need not be an excuse for people not to be adherent. Various innovative strategies can be employed in order to assist all antiretroviral therapy clients to adhere to treatment. Adult Basic Education and Training (ABET) seem ideal for farming communities as it would help address the challenge of illiteracy.

Unemployment also needs to be addressed by the government, to allow people to provide for themselves and their families. The South African Constitution ensures the protection of people rights such as the right to confidentiality. Employees are not obligated to disclose to their employers, but can do so out of their own choice. It is hence imperative for the client on antiretroviral therapy to identify the individual to disclose to carefully. For HIV treatment to be effective, the infected client needs to accept their condition by learning to live positively with the illness.

A client on antiretroviral therapy (ART) is required to take the lead in their own health care for the therapy to be effective. Many people on ART are expert clients, in that they are aware of the challenges that accompany their treatment and how to address these challenges. Effective monitoring of HIV programmes is crucial as well as evaluation of such programmes. The National Department of Health needs to urgently address the challenge of the shortage of doctors. The Prevention of Mother-to-Child Transmission programme can assist in reducing mother-to-child transmission if properly implemented. Prevention of HIV should always be treated as a priority as prevention would be more cost-effective compared to treating a client. Health facilities employ varying strategies in dealing with challenges associated with the provision of ART. These health facilities need to share their strategies so that they can improve the quality of the services that they provide to their communities. The private health facility's ART model needs to be replicated by other farming communities. The support of leaders in managing HIV and AIDS cannot be over-emphasized. Vigorous marketing of non-governmental organizations is essential so as to sustain the programmes.

11.2 Recommendations

The following are the recommendations made based on the lessons learned from different phases of the study:

11.2.1 HIV counselling and testing as a path to accessing antiretroviral therapy

HIV counselling and testing is the entry to treatment, care and support. As availability of antiretroviral therapy (ART) in resource-limited settings expands, HIV counselling and testing (HCT) services act as a critical gateway to early diagnosis, treatment, care and support. More efforts to promote HCT should be made, there has to be more campaigns.

11.2.2 Linkage to and retention in HIV care

Individuals who test HIV positive should be effectively linked to HIV care programmes. An effective referral system should be put in place. Health care workers should follow-up on clients who were referred for a service. There has to be standardization of referral forms used by public health facilities.

11.2.3 Point-of-care CD 4 cell count technology

Mobile counselling and testing supported by DOT-ART supporters can improve linkage. This method needs to be introduced to enhance CD4 cell count monitoring and to shorten the turn-around time. It can also improve referral services for timely initiation of ART and decrease loss to follow-up.

11.2.4 Transportation stipends

Many people on antiretroviral therapy are unemployed and as a result they end up missing their appointments at their health facilities. All people receiving antiretroviral therapy could be given transportation stipends at their health facilities to ensure that they comply.

11.2.5 Delivery of antiretroviral therapy to community centres

Instead of clients having to travel to their health facilities for treatment, drugs could be delivered to strategic community facilities for people on treatment to collect their medication. Home based carers, neighbourhood drug dispensaries and hospital as well as clinics need to collaborate to ensure successful delivery of drugs.

11.2.6 Sharing of best practices

Both private and public health facilities need to share their best practices. Private health facilities employ more effective and advanced strategies in enhancing treatment adherence and these could be replicated by other health care facilities.

11.2.7 Focus on Farm-workers

Farm-workers are some of the most vulnerable groups. The group is also highly mobile and has a tendency of having many multiple sexual partners. HIV counselling and testing services need to be expanded at farming communities. Farm workers living with HIV need to be empowered so that they can educate other farm workers on the dangers of HIV, disclosure and the importance of adhering to ART. The Department of Education needs to introduce Adult Basic Education and Training (ABET) in farming communities.

11.2.8 The role of the church

Many churches are now acknowledging that there are members who are HIV positive in their churches. The government needs to do more to empower church leaders. Educational workshops for church leaders could be conducted to capacitate them with information on HIV and AIDS and ART adherence.

11.2.9 Programmes to deal with stigma and discrimination

People in various communities should be encouraged to talk freely about HIV and AIDS. People on treatment who have recovered from illness should be encouraged to talk about their experiences so as to dispel myths about ART.

11.2.10 Empowerment programmes on disclosure

Once diagnosed HIV positive, it is important to disclose to someone who can be trusted to maintain confidentiality.

11.2.11 Family support

The family is the primary institution of socialization, hence many people choose to disclose to family members after being diagnosed HIV positive. Families need to be empowered to provide the necessary support. Spouses can also be very supportive, thus programmes targeted towards couples such as couple counselling need to be strengthened. Children of people living with HIV need to be protected from the trauma of having to deal with the news of their parents' positive HIV status. Strategies to disclose to children need to be devised and communicated to people living with HIV.

11.2.12 Disclosure within the workplace

There are more advantages to disclosing HIV status within the workplace than disadvantages. The workplace needs to be a conducive environment for employees diagnosed HIV positive to disclose. HIV and AIDS, antiretroviral therapy adherence programmes targeted towards educating employers and managers need to be implemented. Employees infected with HIV need to be empowered on how, to whom and when to disclose. People who are more assertive and have a healthy self-esteem adhere better than those who are less assertive and have a low self-esteem.

11.2.13 Support groups of people on antiretroviral therapy

Support groups of people living with HIV are very important in that they provide a platform for those who are HIV positive to share their experiences. Support groups also enable people on ART to cope better and prevent stress. People who are psychologically well cope better with their medication.

11.2.14 Family support groups

It became evident in the study that there are many families with more than one family member who is HIV positive. The department of health needs to assist families to establish support groups within families, so as to enhance treatment adherence.

11.2.15 Workplace support groups

Some employees are not able to go to their health facilities for support group meetings. Therefore, support groups could be established at the workplace to ensure that those who need emotional support are able to access it at their workplace.

11.2.16 Church support groups

Some church members are very open about their HIV status and educate other members about HIV and AIDS and ART adherence. Resources should be provided for them to enable them to establish and maintain support groups in churches.

11.2.17 Health facility support groups

There has to be a good working relationship between nurses and lay counsellors for them to be able to co-ordinate effective support groups. Referral to support groups should be done by health care providers and lay counsellors who provide counselling to HIV positive clients. There has to be respect amongst health care professionals so as to observe confidentiality.

11.2.18 On-line or internet support groups

Social support groups play an important role in coping with HIV and AIDS. When people are satisfied with the kind of social support they are receiving, they are likely to adjust better and cope well with ART. Individuals living with HIV and AIDS face social, emotional and psychological challenges due to their HIV status. The internet can be a feasible, acceptable and private form of information, social and emotional support. Internet services need to be provided at health facilities and the workplace to support those who are HIV positive and on antiretroviral therapy in order to enhance ART adherence. Issues of literacy have to be taken into consideration.

11.2.19 Management of Side-Effects

Side-effects that people on antiretroviral therapy experience need to be properly managed. Clients need to be educated on their medication and the side-effects that are associated with particular medication. Certain side-effects have the potential of damaging the self-esteem and self-confidence of individuals on ART. Lipodystrophy can inadvertently disclose one's HIV status, strategies to reduce fat redistribution need to be identified and conveyed to clients on ART. A multi-disciplinary approach needs to be adopted in dealing with side-effects.

11.2.20 The Role of Traditional Healers in Promoting ART Adherence

Many African people consult traditional healers and therefore, they can play a vital role in promoting treatment adherence. More programmes targeted towards educating traditional healers need to be implemented. Traditional healers can also educate community members on drug interaction as some alternative medications are known to interact with ART. Traditional healers can also play the role of treatment adherence supporters and adherence counsellors.

11.2.21 Nutrition and ART Adherence

Good nutrition is very important for people living with HIV, but cannot be a replacement for antiretroviral therapy. Clients on ART need to be encouraged to observe a healthy diet that comprises of fruit and vegetables. Risky health behaviours such as drinking and smoking need to be discouraged as they can impact negatively on treatment adherence. Clients need to be encouraged to develop vegetable gardens in their homes.

11.1.22 HIV and TB collaboration

The co-infection rate in South Africa is very high, HIV and TB collaboration is being implemented. There is however, a need to strengthen this collaboration so as to ensure that clients receive the necessary care and that opportunities to detect are not missed. Some clients have to take both HIV and TB medication simultaneously and need assistance to adhere.

11.2.23 The Mentorship Programme and ART Adherence

HIV and AIDS counsellors' emotional support is very important as it ensures that they offer services of good quality to their clients. The department of health needs to pay more attention to the implementation of the mentorship programme as it has a direct effect on ART adherence. Mentors appointed by lay counsellor NGOs need to work closely with mentors from the department of health.

11.2.24 NGO Funding-Model and Sustainability

The funding model applied by the department of health needs to be revised. Lay counsellors experience delays annually in receiving their stipends and these impacts negatively on service delivery as some are not able to go to their respective health facilities during the time that they will not be receiving their stipends. A funding model that involves provision of funding for a year instead of every quarter needs to be considered to avoid delays. Non-governmental organizations (NGOs) also need to be empowered to build in sustainability

plans in their projects to ensure continuity even in instances where donor funding comes to an end.

11.2.25 An Association for Lay Counsellors

Lay counsellors currently do not have an association that deals with their issues. An association specifically for lay counsellors needs to be established to enable them to have a formal structure to which their concerns can be addressed. Many lay counsellors are exploited by their NGOs and health care providers as they are not protected by some of the labour laws due to the informal nature of their appointments.

11.2.26 Standardization of Monitoring and Evaluation Tools

Public health facilities develop and implement their own monitoring and evaluation strategies. In order to ensure coherence there has to be standardization of monitoring and evaluation tools. This can also prevent confusion amongst people on ART.

11.2.27 HIV Electronic Register or E-register

Data management is very essential in HIV programmes, the paper-based system currently implemented in public health facilities needs to be replaced by an electronic system. Some of the challenges associated with ART such as loss to follow-up can be easily avoided by introducing an electronic system that can easily detect the whereabouts of clients on ART.

11.2.28 Training of health facility staff members on confidentiality

There is a need to train all health facility staff members on confidentiality. The training should include the support staff members as well, such as security guards, cleaners and receptionists. Some clients complain that non-professional staff members do not maintain confidentiality. The training would ensure that clients' right to confidentiality is not violated.

11.3 Recommendations for Further Research

- The study revealed that there are still many babies that are infected by HIV by their mothers. A study to identify the challenges and factors that contribute to Mother-to-Child Transmission of HIV could be conducted.
- It was also evident in the study that many families have either one or more people living with HIV. A study on how family members cope and deal with HIV within the family needs to be done.
- The lay counsellor programme was first implemented in 2002 in the Limpopo Province. Non-governmental organizations are funded by the government to implement this programme in various communities throughout the province. A thorough evaluation of the programme could be done.
- The clinical mentorship programme ensures that HIV and AIDS counsellor's well-being is taken care of and also helps to prevent stress and burn-out. The effectiveness of this programme needs to be evaluated.
- There were some HIV-positive couples in the study and it would be ideal to determine how these couples cope with living with HIV.
- There were also sero-discordant couples in the study, how these couples cope and deal with various challenges associated with having a partner who is HIV positive need to be uncovered.
- Many of the respondents regard the church as their refuge. It would be appropriate to conduct a study on the role played by religious leaders in curbing the spread of HIV.
- Support groups offer people living with HIV and opportunity to interact and share valuable information with other people on treatment, yet there are serious challenges in establishing and maintaining such groups. A research study in this regard would be beneficial.

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**INTERVIEW SCHEDULE: CHALLENGES TO ANTIRETROVIRAL THERAPY
ADHERENCE**

FACE- TO- FACE INDIVIDUAL IN-DEPTH INTERVIEWS

CHALLENGES TO ANTIRETROVIRAL THERAPY ADHERENCE

INTRODUCTION

Thank you for agreeing to participate in my study. My name is Tiny P. Mona. I am a Sociology PhD student at the University of Limpopo, and I am conducting a study on: **The Challenges to Treatment Adherence amongst People living with HIV in the Mopani District of the Limpopo Province**, for academic purposes. The information you provide will be treated with utmost confidentiality and will only be used for the purpose of this study. Some of the questions that I will ask you are very personal and sensitive. Your name will not appear on this interview form, and the information you will provide will not be used against you. The interview will take approximately 1 hour.

I. SOCIO-DEMOGRAPHIC INFORMATION: CLIENTS ON ANTI-RETROVIRAL THERAPY

1. Age of the client on anti-retroviral therapy

2. Gender

Female	1
Male	2

3. Race

African	1
Coloured	2
White	3
Asian/Indian	4

4. Which language do you speak

Afrikaans	1
English	2
Sepedi	3
Tshivenda	4
Xitsonga	5
Other, please specify	6

5. Marital Status

Single	1
Married	2
Divorced	3
Separated	4
Widowed	5
Cohabiting	6

6. Is this your first marriage?

Yes	1
No	2

7. Highest Education level?

Matric	1
Certificate	2
Diploma	3
Degree	4
Other	5

8. What is your current employment status?

Employed	1
Unemployed	2
Self-employed	3
Contract Worker	4
Other (please specify)	5

9. What type of work do you do?

10. What is the combined personal income in your household?

None	1
R 2000 and below	2
R 3000 – R 4001	3
R 4001 – R 5000	4
R 5001 – R 6000	5
R 6001 – R 7000	6
R 7001 – R 8000	7
R 8001 – R 9000	8
R 9001 – R 10 000	9
More than R 10 000, please specify	10

11. What is your source of income?

12. How many biological children do you have?

None	0
One	1
Two	2
Three	3
Four	4
Five	5
Six	6
Above six	7

13. Which religion do you belong to?

None	0
Christianity	1
Hinduism	2
Islam	3
Buddhism	4
Judaism	5
Ancestral Veneration	6
Other, please specify	7

14. Does your religion preach/talk about HIV?

Yes	1
No	2

15. If yes, please explain how this is done?

16. What is your church's position on HIV and AIDS? Please explain.

II. STIGMA AND DISCRIMINATION

17. Have you ever experienced stigma due to your HIV status?

Yes	1
No	2

18. If yes, please explain what happened to you.

19. What did the experience do to you?

20. How did you deal with the stigma?

21. Have you ever experienced discrimination due to your HIV status?

Yes	1
No	2

22. If yes, please explain what happened to you.

23. What did the experience do to you?

24. How did you deal with the discrimination?

III. SUPPORT SYSTEMS AVAILABLE AND DISCLOSURE

25. Who was the first person that you disclosed your HIV status to? (Please mention the relationship).

Mother	1
Father	2
Bother	3
Sister	4
Husband	5
Wife	6
Sexual partner	7
Daughter	8
Son	9
Colleague	10
Pastor	11
Other, please specify	12

26. How did the first person that you disclosed to react?

27. How did you feel after disclosing?

28. Did you receive support from the person that you disclosed to?

Yes	1
No	2

29. If yes, how did they support you?

30. How would you rate the support that you received?

Very poor	1
Poor	2
Fair	3
Good	4
Very good	5
Excellent	6

31. For how long did the support last?

32. Do you feel empowered by the support that you received?

Yes	1
No	2

33. Please indicate why or why not?

34. Do you have a treatment supporter?

Yes	1
No	2

35. Please indicate why or why not?

36. Who is your treatment supporter? (Please mention the relationship).

Mother	1
Father	2
Bother	3
Sister	4
Husband	5
Wife	6
Sexual partner	7
Daughter	8
Son	9
Colleague	10
Pastor	11
Other, please specify	12

37. Please indicate whether you agree or disagree with the following statement.

My parents were always there for me, since I discovered that I am HIV-positive

Agree	1
Disagree	2

38. Do you belong to a support group?

Yes	1
No	2

39. Please indicate why or why not?

40. Do you feel empowered by the support group?

Yes	1
No	2

41. Have you disclosed to your colleagues at work?

Yes	1
No	2

42. What were your reasons for disclosing or not disclosing?

43. Have you disclosed to your sexual partner?

Yes	1
No	2

44. If yes, how did your sexual partner react to your HIV positive status?

45. If you have disclosed, how long did it take you to disclose to your sexual partner?

Less than a week	0
One week	1
Two weeks	2
One month	3
Three months	4
Six months	5
One year	6
Other (please specify)	7

46. What is your sexual partner's HIV status?

HIV Positive	1
HIV Negative	2
Indeterminate	3
Don't know	4

47. Do you practice safer sex?

Yes	1
No	2

48. If you don't, what are the reasons for not doing so?

IV. GENDER RELATED ISSUES

49. Have you ever taken care of a person living with HIV?

Yes	1
No	2

50. If yes, who was that person? (Please mention the relationship)

51. Who usually initiates sex between you and your partner?

My partner	1
Myself	2

52. Do you find it easy to negotiate for safer sex practices?

Yes	1
No	2

53. If not, why not? And if yes, do you use male or female condoms or both?

54. Do you find it easy to go to a health facility for services?

Yes	1
No	2

55. If not, why not?

V. HIV COUNSELLING AND TESTING

56. How did you learn about your HIV positive status?

57. When did you discover that you were HIV positive?

58. What kind of HIV counselling and testing did you receive?

None	0
Pre-test counseling	1
Post-test counseling	2
Both	3
On-going counselling	4

59. Did you give your consent to the HIV test?

Yes	1
No	2

60. If not, what were your reasons for not consenting?

61. Were you referred for CD4 cell count?

Yes	1
No	2

62. If yes, to which health facility were you referred?

63. How long did it take for you to receive the CD4 cell test results?

3 days	1
One week	2
Two weeks	3
Three weeks	4
One month	5
Other, please specify	6

VI. HEALTH MANAGEMENT

64. When did you start anti-retroviral therapy?

65. Did you experience any side effects?

Yes	1
No	2

66. If yes, which side effects did you experience?

67. How did you manage the side-effects?

68. For how long did the side-effects last?

69. Which antiretroviral therapy are you on?

70. Are you on the government's antiretroviral therapy programme?

Yes	1
No	2

71. If not, why not?

72. Do you have a Medical Aid?

Yes	1
No	2

73. If not, why not?

74. Is medication easily accessible to you?

Yes	1
No	2

75. If not, why not?

76. How often do you go for CD4 cell count and viral load tests?

Every 3 months	1
Every 6 months	2
Every year	3
Other, please specify	4

77. What is the level of your CD4 cell count?

Less than 50	1
Between 60 and 100	2
Between 100 and 200	3
Between 200 and 300	4
Between 300 and 400	5
Between 400 and 500	6
Between 500 and 600	7
Between 600 and 700	8
Between 700 and 800	9
Between 800 and 900	10
Between 900 and 1000	11
Other, please specify	12

78. What is your level of viral load?

Detectable	1
Undetectable	2

79. Have you accepted your HIV positive status?

Yes	1
No	2

80. If not, why not?

81. Have you thought of stopping taking anti-retroviral therapy?

Yes	1
No	2

82. If yes, please indicate why?

83. Have you ever consulted a traditional healer?

Yes	1
No	2

84. If yes what were the reasons for doing so, if no why not?

85. What effect would you say traditional medicine has had in your life?

VII. QUESTIONS ABOUT TREATMENT ADHERENCE AND COUNSELLING

86. What do you understand by the word adherence?

87. Did you receive treatment adherence counselling?

Yes	1
No	2

88. For how long did the treatment adherence counselling last?

Less than a week	1
One week	2
Two weeks	3
Three weeks	4
One month	5
Other, please specify	6

89. Would you say that you are adhering to treatment?

Yes	1
No	2

90. If yes what makes you feel confident that you are adhering to treatment?

91. What do you think are the challenges to treatment adherence?

92. What do you think are the enablers to treatment adherence?

93. What would you say have been the challenges of adhering to treatment for you personally?

VIII. QUESTIONS ABOUT RESISTANCE

94. What do you think causes resistance in ART?

95. What are you doing in order to prevent resistance?

IX. READINESS

96. Would you say that you were ready at the time that you started therapy?

Yes	1
No	2

97. What makes you think that you were ready or not ready?

X. POSITIVE LIVING

98. What do you understand about positive living?

99. Would you say that you are living positively with HIV?

Yes	1
No	2

100. What makes you think that you are living positively with HIV?

101. Do you use drugs, alcohol or smoke cigarettes?

Yes	1
No	2

102. Which drugs, cigarettes or alcohol do you use?

103. Do you sometimes have sex after using drugs or taking alcohol?

Yes	1
No	2

104. Does your partner smoke, use drugs or takes alcohol?

Yes	1
No	2

105. Are you able to afford buying fruits and vegetables?

Yes	1
No	2

106. How is your stress level?

Not stressed	0
Stressed	1
Very stressed	2
Don't know	3

107. How do you deal with stress?

108. Do you exercise?

Yes	1
No	2

109. What type of exercise do you do?

XI. SELF-EFFICACY

110. Would you say that you are taking responsibility for your health?

Yes	1
No	2

111. What makes you think that you are taking responsibility?

112. Do you consider yourself to be an assertive person?

Yes	1
No	2

113. What does being assertive mean to you?

114. Where do you often take your medication?

At home	1
At work	2
Inside the taxi	3
Other, please specify	4

115. How would you say being assertive assists you to take your treatment well?

116. What do you consider to be effective strategies for adhering to ART?

Thank you for sharing your perspectives with me. The information you have provided is very helpful. Do you have any questions for me? If so, please feel free to ask me.

**XEDULU YA VUENTI YA NKAMBELO-VUTIVI HIMINTHLONTHLO YA
MATIRHISELO YA MAPILISI YA TI ARV**

MALANDZELELO YA VUTSHUNGURI BYA ANTI-RETROVIRAL

MASUNGULO

Hi mina Tiny P. Mona, ndzi endla dyondzo ya Sociology PhD eYunivhesiti ya Limpopo. Ndza khensa loko u pfumerile ku teka xiave eka dyondzo leyi. Ndzi endla dyondzo hi mintlhonthlo leyi vanhu lava hanyaka na vuvabyi bya HIV va hlanganaka na yona eku landzeleleni ka vutshunguri eMopani District laha Limpopo. Vuxokoxoko lebyi u nyikaka byi ta tirhisiwa hi ndlela ya xihlundla ni vukheta. Mavito ya wena ma nge vutisiwi eka dyondzo leyi. Swin'wana swa swivutiso leswi ndzi nga ta ku vutisa swi khumbha swinene naswona swi ta pfuxa switwi swa wena. Swi nga endla awara ku hlamula swivutiso hinkwaswo. Loko u ri na swivutiso hi mayelana na dyondzo leyi, u amukelekile ku ndzi vutisa.

I. IVUXOKOXOKO BYA MUNHU HI VUENTI: VANHU LAVA VA TEKAKA/TIRHISAKA VUTSHUNGURI BYA ANTI-RETROVIRAL

1. Malembe ya mutirhisi wa vutshunguri bya anti-retroviral therapy

2. Rimbewu

Wansati	1
Wanuna	2

3. Rixaka

mu-Afrika	1
mu-Khaladi	2
Mulungu	3
mu-Asian	4

4. Xana u vulavula ririmi rihi?

5. Xiyimo xa vukati.

A wu si teka	1
U tekile	2
U tharile	3
Mi hambanile	4
Noni	5
A wu lovolangi/u wu lovoriwangi	6

6. Xana I vukati bya wena byo sungula?

- Ina
- E-e

7. Tidyondzo ta le henhla?

Matriki	1
Setifikheti	2
Diploma	3
Digiri	4
Swi n'wana	5

8. U tirha tirho muni?

U thoriwile	1
U wu thoriwanga	2
Wa titirha	3
Mutirhi wa tikotiraka	4
Swin'wana (kongomisa)	5

9. Xana i ntirho wa njhani lowu u tirhaka wona?

10. Xana i mali muni leyi u holaka yona loko yi hlanganisiwile?

Kutlula R11000 - R1001	1
R10000 - R9001	2
R8000 - R7001	3
R7000 - R6001	4
R6000 - R5001	5
R5000 - R4001	6
R3000 - R4001	7
R2000 ku ya ehansi	8
Yi n'wana	9

11. Xana i vangani vana va wena vangati?

U n'we	1
Vambirhi	2
Vanharhu	3
Mune	4
Ntlhanu	5
Ku hava	6
Ku tlula tsevu	7

12. U pfumela eka vukhongereri byi hi xana?

Xikreste	1
Xihundu	2
Xi-islam	3
Xi-buddaism	4
Xijuda	5
Swikwembu	6

13. Xana kereke ya wena ya chumayela hi HIV xana?

- Ina
- E-e

14. Loko nhlamulo yiri Ina, hlamusela leswaku swiendlisiwa ku yini?

15. Xana kereke ya wena yi yimile kwihi hi HIV na AIDS? Hlamusela.

II. MAKHOMELO YO BIHA NI XIHLAWUHLAWU EKA VANHU LAVA NGA NA HIV

16. U tshame unga hlangana ni xiyimo laha vanhu va nga na makhomelo yo biha hi vuvabyi by wena bya HIV?

- Ina
- E-e

17. Loko kuri ina, u swi endlise ku yini ku lwa ni matikhomelo lawa?

18. Xana u tshame u nga hlangana ni xihlawuhlawu hikwalaho ka HIV?

- Ina
- E-e

19. Loko kuri ina, u swi endlise ku yini?

III. NSEKETELO LOWU WU NGA KONA NA KU PALUXA XIHUNDLA

20. I mani munhu wo sungula loyi un'wi paluxeleke hi vuvabyi bya wena bya HIV? (U kombiriwa nyika vuxaka bya wena na munhu loyi).

21. Xana munhu wa kona loyi u nw'i byeleke u ti twile njhani?

22. Xana wena u titwile njhani endzhaku ka loko u n'wi byerile?

23. Xana u namupfuneti hi swa vutshunguri?

- Ina
- E-e

24. Kombisa leswaku hikokwalaho ka yini u ri na yena kumbe u nga ri na yena?

25. I mani a ku seketelaka hi swa vutshunguri? (U komberiwa ku hlamusela vuxaka bya wena na munhu loyi).

26. Xana u wela eka ntlawa wa nseketelo wa tshunguri?

- Ina
- E-e

27. Kombisa ku ri hikokwalaho ka yini u ri na wona kumbe u nga ri na ntlawa.

28. Xana u ti twa u nyikiwa matimba eka ntlawa wa nseketelo wa vutshunguri?

- Ina
- E-e

29. Xana u paluxile hi ta vuvabyi bya wena eka vatirhi kuloni?

- Ina
- E-e

30. Xana hikwalaho ka yini u va byerile kumbe u nga va byelangi?

31. Xana u n'wi paluxerile murhandziwa wa wena?

- Ina
- E-e

32. Loko ku ri ina, xana murhandziwa wa wena u ti twile njhani hi xiyimo xa wena xa HIV?

33. Loko u n'wi paluxerile murhandziwa wa wena, switekile nkarhi wo leha ku fika kwini?

Mavhiki mambirhi	1
N'hweti	2
Tin'hweti tinharhu	3
Tsevu wa tin'henti	4
Lembe	5
Swin'wana (Kongomisa)	6

34. Xana xiyimo xa murhandziwa wa wena xa HIV hi xihhi?

U ni xitsongwatsongwana	1
A nga na xitsongwatsongwana	2
A wu swi tivi	3
A swiolovi ku swi tiva	4

35. Xana u endla timhaka ta masungu hi ndlela leyi hlayisekeke?

- Ina
- E-e

36. Loko u nga endli, hikokwalaho ka yini?

IV. TI MHAKA TA RIMBEWU

37. Xana u tshama u pfuneta na ku hlayisa munhu loyi a hanyaka na HIV?

- Ina
- E-e

38. Loko ku ri Ina, I mani? (Nyika vuxaka)

39. Xana I mani loyi kotala a sungulaka timhaka ta masangu eka wena ni murhandziwa wa wena?

Hi mina	1
Murhandziwa wa mina	2

40. Xana swa miolovela ku ya eka tiyindlu ta vutshunguri ku ya kuma vuongori?

- Ina
- E-e

41. Loko ku ri e-e, hikokwalaho ka yini?

V. SWIPFUNO SWA MIEHLEKETO EKA HIV NA KU KAMBERIWA

42. Xana u xi tivile njhani xiyimo xa wena xa HIV?

43. Xana u swi tivile rini leswaku u ni vuvabyi bya HIV?

44. Xana amukerile hi switsundzuxo u nga se kamberiwa na loko u hetile ku kamberiwa?

- Ina
- E-e

45. Xana u va nyikile mpfumelelo leswaku va ku kambela HIV?

- Ina
- E-e

46. Xana u byeriwile hi ta CD4 cell count ya wena?

- Ina
- E-e

47. Loko ku ri Ina, xana u lerisiwile kwihi eka tiyindlu ta vutshunguri?

48. Swi tekile nkarhi wo fika kwihi ku kuma mbuyelo wa CD4 cell count?

VI. VULAWURI BYA RIHANYU

49. Xana u sungurile rini vutshunguri bya anti-retroviral?

50. Xana i nkarhi wo leha ku fika kwihi u sungule ku teka vutshunguri bya anti-retroviral?

51. Xana a wu twanga switwi swo vava kumbe swin'wana endzhaku ka ku teka vutshunguri?

- Ina
- E-e

52. Loko ku ri ina, hi swihi switwi swa kona leswi u nga swi twa?

53. Xana u swi lawule njhani switwi leswi?

54. Xana switwi leswi swi tekile nkarhi wo fika kwini?

55. Xana hi yihi anti-retroviral leyi u nga eka yona?

56. Xana u wela kona eka nongoko ya mfumo eka vutshunguri bya anti-retroviral?

- Ina
- E-e

57. Xana u na wona mpfuno wa swa vutshunguri (Medical Aid)?

- Ina
- E-e

58. Xana mpimo wa CD4 cell count wu fika kwini?

59. Xana mpimo wa viral load ya wena wu fika kwihi?

60. Xana u ya kangani ku ya kamberwa CD4 cell and viral load?

61. Xana u amukerile xiyimo xa wena xa HIV?

- Ina
- E-e

62. Xana wu vile kona nkarhi lowu u nga ehleketa ku tshika ku teka vutshunguri bya anti-retroviral?

- Ina
- E-e

63. Xana u tshame u ya eka n'anga ya xintima?

- Ina
- E-e

64. Loko nhlamulo ku ri ina kumbe e-e, hikwaloho ka yini u endlile sweswo?

65. Xana hi swihi swita- ndzhaku swo va u tirhisile murhi ya wa xintima?

VI. SWIVUTISO NA SWITSUNDZUXO SWO LANDZELELA VUTSHUNGURI NA SWIPFUNO SWA MIEHLEKETO

66. Xana u twisisa yini hi rito landzelela?

67. Xana u nyikiwile switsundzuxo swo landzelela vutshunguri?

- Ina
- E-e

68. Xana switsundzuxo swo landzelela vutshunguri swi teki nkarhi wo fika kwihhi?

69. Xana u nga vula leswaku u le ku landzeleleni sweletelo swa vutshunguri?

- Ina
- E-e

70. Xana i ncini lexi endlaka leswaku u va na matimba yo landzelela vutshunguri?

71. Xana hi yihlontlho leyi u hlanganaka na yona eku landzeleleni ka swiletelo swa vutshunguri?

72. Xana i ncini lexi ku kotisaka leswaku u landzelela switsundzuxo swa vutshunguri?

73. Xana hi yini mintlhontlho leyi wena u nga hlangana na yona u ri wexe eku landzeleleni ka switshungulo?

VII. SWIVUTISO MAYELANA NO TIARISA

74. Xana i ncini lexi tisaka ku tiarisa eka ART?

75. Xana u endla yini ku sivele ku tiarisa?

VIII. KU TILULAMISELA

76. Xana u nga vula u ku a wu tilulamiserile ku sungula vutshunguri xana?

- Ina
- E-e

77. I ncini lexi ku endlaka u ehleketa leswaku a wu lunghekile xana?

IX. RIHANYU RA KAHLE

78. Xana u twisisa yini hi rihanyu ra kahle?

79. Xana u nga vula leswaku wena u hanya rihanyu ra kahle u ri na HIV?

- Ina
- E-e

80. Incini lexi ku endlaka leswaku vula leswaku u hanya rihanyu ra kahle u ri HIV xana?

81. Xana wa nwa byalwa kumbe ku tirhisa swidzidziharisi?

- Ina
- E-e

82. Xana i byalwa bya njhani naswona i swidzidziharisi swihi?

83. Xana minkarhi yin'wana a wu endli timhaka ta masangu endzhaku ka ku tirhisa swidzidziharisi kumbe loko u nwile byalwa?

- Ina
- E-e

84. Xana murhandziwa wa wena u tirhisi swidzidziharisi kumbe u nwa byalwa?

- Ina
- E-e

85. Xana wa dya mihandzu?

- Ina
- E-e

86. Xana mpimo wa ntshikelelo wa miehleketo ya wena wu njhani?

87. Xana u endla yini loko u tshikileleka emiehleketweni?

88. Xana wa endla vutiolori?

➤ Ina

➤ E-e

89. Xana u endla vutiolori bya njhani?

X. VUSWIKOTI BYA WENA

90. Xana u nga vula leswaku u na vutihlamuleri hi rihanyu ra wena?

➤ Ina

➤ E-e

91. I ncini lexi ku endlaka leswaku u va na vutihlamuleri?

92. Xana u munhu wo ti tshemba?

➤ Ina

➤ E-e

93. Swi vula yini ku ti tshemba?

94. Hi yini ndlela leyi u vonaka onge yi nga pfuneta leswaku u landzelela vutshunguri?

Ndza khensa loko u ta va u kotile ku ni avela mavonelo ya wena. Vuxokoxoko hinkwabyo lebyi u byi nyikeke byi ta pfuna swinene. Xana u na swivutiso eka mina? Loko swi ri kona, u amukelekile ku ni vutisa.

HIV STIGMA SCALE

An HIV stigma scale was administered amongst respondents and they were required to respond to 26 questions by indicating whether they strongly disagreed, disagreed, agreed or strongly agreed with the statements. With regard to the analysis of data, the researcher assessed the responses from respondents looking at each individual health facility. Only responses that stood out in terms of the graph were analysed.

QUESTION	1 STRONGLY DISAGREE	2 DISAGREE	3 AGREE	4 STRONGLY AGREE
1. In many areas of my life, no one knows that I have HIV				
2. I feel guilty because I have HIV				
3. People's attitudes about HIV make me feel worse about myself				
4. Telling someone I have HIV is risky				
5. People with HIV lose their jobs when their employers find out they have HIV				
6. I never feel ashamed of having HIV				
7. People with HIV are treated like outcasts				
8. Most people believe that a person who has HIV is dirty				
9. It is easier to avoid new friendships than worry about telling someone that I have HIV				
10. Since learning I have HIV, I feel set				

apart and isolated from the rest of the world				
11. Most people think that a person with HIV is disgusting				
12. Most people are rejected when others find out that they are HIV positive				
13. I am very careful who I tell that I have HIV				
14. Some people who know I have HIV have grown more distant				
15. Since learning I have HIV I worry about people discriminating against me				
16. I never feel the need to hide that I have HIV				
17. I have been hurt by how people reacted to learning that I have HIV				
18. I regret having told some people I have HIV				
19. People I care about stopped calling after learning I have HIV				
20. People have told me that getting HIV is what I deserve for how I lived my life				
21. Some people close to me are afraid people will reject them if it becomes known that I have HIV				
22. People do not want me around their children once they know I have HIV				
23. Some people act as if it is my fault I				

have HIV				
24. I have lost friends by telling them I have HIV				
25. I have told people close to me to keep the fact that I have HIV a secret				
26. When people learn you have HIV, they look for flaws in your character				

Adapted from Berger (2007) Stigma and Discrimination, HIV Stigma Scale. Population Council.

ANNEXURE D.1

A GUIDE FOR FOCUS GROUP DISCUSSIONS

CHALLENGES TO ANTIRETROVIRAL THERAPY ADHERENCE

FOCUS GROUP DISCUSSION

Place:	Public Facility 1
Time of day:	12h00-13h00
Date:	January 2013
Number of Respondents:	7
Name of the interviewer:	Ms Tiny Petunia Mona
Tape ID:	001 and 002

My name is Tiny Petunia Mona, I am a Lecturer of Sociology at the University of Limpopo. I am also a PhD student at the University of Limpopo. I am conducting a study on: **The Challenges to Treatment Adherence in Antiretroviral Therapy in the Mopani District of the Limpopo province.** I would like you to share your experiences and challenges in taking ART. My role would therefore be to facilitate this group discussion to keep it focused so that we can achieve our goal. Everyone should participate actively to enable us to benefit from this focus group discussion. I would now like to give you the opportunity to introduce yourselves using an ice-breaker, tell us your first name and what you are going to bring for the braai and what you will bring should start with the first letter of your name. For instance “I am Tiny and I will bring T-bone steak to the braai”, your age and how long you have been on Antiretroviral Therapy. Everything that we are going to discuss will be treated with the utmost respect and confidentiality. Your names, phone numbers and other personal information will not be released to other people without your consent. You may withdraw from the discussion at any time during the process, and there will be no repercussions for doing so.

A digital tape recorder will be used in order to capture all the issues that we are going to discuss. The Focus Group Discussion will take one hour.

1. ADHERENCE

1.1 What do you understand by the word adherence?

1.2 What do you understand by the word compliance?

1.3 What is the difference between the two?

1.4 Would you say that you are adhering to treatment?

1.5 What makes you feel confident that you are adhering to treatment?

1.6 Did you experience any side effects?

1.7 How did you deal with them?

1.8 What do you think are the barriers to treatment adherence?

1.8.1 Patient factors

1.8.2 Environmental factors

1.9 What do you think are the enablers to treatment adherence?

1.9.1 Patient factors

1.9.2 Environmental factors

2. SOCIAL SYSTEMS AVAILABLE

2.1 Who was the first person that you disclosed your HIV status to?

2.2 How did the first person that you disclosed to react?

2.2 How did you feel after disclosing?

2.4 Do you have a treatment supporter?

Yes

No

2.5 Please indicate why or why not?

2.6 Who is your treatment supporter?

2.7 Do you belong to a support group?

Yes

No

2.8 Please indicate why or why not?

2.9 Do you feel empowered by the support group?

3. CHALLENGES OF DRUG ADHERENCE

3.1 What would you say have been the challenges of adhering to treatment for you personally?

3.2 What do you think are the benefits of initiating therapy early?

What do you think the risks of delaying therapy are?

What would you say are the predictors of good and poor adherence?

4. RESISTANCE

4.1 What do you think causes resistance in ART?

4.2 What are you doing in order to prevent resistance?

4.3 Would you say that you and your families were prepared for your ART?

4.4 What did you do in order to prepare your families?

5 READINESS FOR ART

5.1 Would you say that you were ready to initiate therapy at the time the you started?

Yes

No

5.2 What makes you think that you were ready?

5.3 Did you have a treatment supporter?

Yes

No

5.4 How did you feel about having a treatment supporter?

5.5 How did you go about selecting a treatment supporter?

6 POSITIVE LIVING

6.1 What do you understand about positive living?

6.2 Would you say that you are living positively with HIV?

6.3 What makes you think that you are living positively with HIV?

6.4 How do you manage stress?

6.5 Are you able to afford a healthy diet?

6.6 What do you do to keep fit?

6.7 Do you smoke cigarettes?

7. Now I want us to talk openly and honestly about our sex lives as it is part of positive living

7.1 The last time you had sex, did you use a condom?

7.2 If you did not use a condom what was the reason?

7.3 Do you have main partners?

7.4 How long have you been with your partners?

7.5 Do you always use condoms with your partners?

7.6 How do your partners feel about the use of condoms?

7.7 What do you do in order to encourage your partners to use condoms?

7.8 In the last month have you had sex with anyone to get money or other things?

8. Now I would like us to talk about drugs and alcohol as it is also part of positive living

- 8.1 How many of you use drugs or alcohol?
- 8.2 Which drugs or alcohol do you use?
- 8.3 When you use drugs or alcohol do you sometimes have sex?
- 8.4 How much money do you spend on drugs or alcohol?
- 8.5 Where do you get drugs or alcohol?
- 8.6 Do our partners use drugs or alcohol?

9 ASSERTIVENESS

- 9.1 Would you consider yourself to be an assertive person?
- 9.2 What does being assertive mean to you?
- 9.3 Is there a difference between assertiveness and aggression?
- 9.4 What are you doing in order to enhance your self-esteem?

10 BENEFITS OF BEING ON ART

- 10.1 Would you say that you are benefiting from the ART?
- 10.2 What makes you say that you are benefiting or not benefiting?
- 10.3 Has your health improved since you have started ART?
- 10.4 What is your CD4 cell count?
- 10.5 What is your viral load?
- 10.6 Have you gone back to work or are you looking for a job?
- 10.7 Do you feel that you have your energy back?

Yes

No

Now we have come to an end of our focus group discussion, thank you very much for participating actively. I really appreciate your presence and contributions and I have no doubt that each one of us has learned something today that will help to prolong our lives. May someone close for us with a prayer.

**CONSENT TO PARTICIPATE IN A FOCUS GROUP DISCUSSION ON
CHALLENGES TO TREATMENT ADHERENCE IN ANTIRETROVIRAL THERAPY**

The purpose of the group discussion and the nature of the questions have been explained to me.

I consent to take part in a focus group discussion about my experiences, including some ways to improve treatment adherence. My participation is voluntary. I understand that I am free to leave the group at any time. If I decide not to participate at any time during the discussion, my decision will not affect the services that I receive at this facility.

None of my experiences or ideas will be shared with anyone outside the focus group, unless all identifying information is removed first. The information that I provide during the focus group discussion will be grouped with answers from other people so that I cannot be identified.

I agree to participate in the study _____

I do not agree to participate in the study _____

Name and Surname _____

Signature: _____

Date: _____

Witness Signature

Date

DEMOGRAPHIC SURVEY FOR FOCUS GROUP DISCUSSION PARTICIPANTS

1. Age: _____

2. Gender: _____

3. Place where you live currently: _____

4. What language do you speak at home? _____

5. In what language do you prefer to communicate in this focus group discussion.

6. What is your marital status?

6.1 Married

6.2 Single

6.3 Divorced

6.4 Widowed

6.5 Cohabiting

7. Highest level of education achieved:

7.1 University degree

7.2 College diploma

7.3 University of Technology diploma

7.4 Certificate

7.5 Standard 10

7.6 Standard 8

7.7 Other (Please specify)

QUESTIONNAIRE FOR HEALTH CARE PROVIDERS AND LAY COUNSELLORS

FACILITY QUESTIONNAIRE

**COMPREHENSIVE CARE MANAGEMENT AND TREATMENT OF HIV (CCMT) SITE:
ANTIRETROVIRAL THERAPY (ART)**

ADHERENCE

You have been selected through the simple random sampling method to be part of respondents who will complete the questionnaire on: **Challenges to Treatment Adherence in Antiretroviral Therapy in the Mopani District of the Limpopo province**. This questionnaire distribution process will be facilitated by Ms Tiny Petunia Mona, a PhD student from the University of Limpopo. The study will take place at all the sub-districts of the Mopani district.

The questionnaire will take approximately 1 hour for you to complete. I will ask you questions about your work as a health care worker/counsellor, including your experiences at the facility where you work. The information you will provide will only be used to understand the Comprehensive Care Management and Treatment (CCMT) of HIV programme better so as to develop an intervention strategy for the Department of Health in the Limpopo province.

The information you provide will only be used for research purposes. Your name and the name of your facility will be kept confidential and a code will be used to connect your answers with your facility without revealing your identity.

It is important for you to realize that your participation is voluntary and you are not obliged to answer any question in the questionnaire and you may refuse to answer questions that make you feel uncomfortable. If you have questions about this research you may ask me.

SECTION A: DEMOGRAPHIC INFORMATION

Name of researcher: Ms Tiny Petunia Mona

Date of data collection: _____

Code of the respondent: _____

Day Month Year

Country: South Africa

Province: Limpopo

District: Mopani

1. Sub-district

Ba-Phalaborwa	1
Greater Giyani	2
Letaba	3
Maruleng	4
Greater Tzaneen	5

2. Name of health facility

Hlokomela Training Trust	1
Lulekani Health Centre	2
Maphutha-Malatjie Hospital	3
Letaba Hospital	4
Kgapane Hospital	5
Nkhensani Hospital	6
Kremetart clinic	7
Sekororo Hospital	8

3. Age of respondent

RANGE	NUMBER
20-25	1
26-30	2
31-35	3
36-40	4
41-45	5
50-55	6
56-60	7
Other, please specify	8

4. Race of respondent (tick what is applicable)

African	1
Coloured	2
Indian/Asian	3
White	4
Other, please specify	5

5. Gender of respondent

Female	1
Male	2

6. What type of facility do you work in?

Mobile	1
Health Care Centre	2
Clinic	3
Hospital	4

7. The facility is operated by:

Religious organization	1
NGO	2
Private	3
Charitable organization	4
Government	5

8. Which of the following describes the nature of your position?

Person in charge of HIV and AIDS services	1
Health care provider	2
Person living with HIV and Lay counsellor	3
Lay counsellor	4
Other please describe	5

9. How much salary/stipend do you receive per month?

R 10001-R 11000	1
R 9001-R 10000	2
R 7001-R 8000	3
R 6001-R 7000	4
R 5001-R 6000	5
R 4001-R 5000	6
R 3001-R 4000	7
R 2001-R 3000	8
Other	9

SECTION B: QUALIFICATIONS AND WORK STATUS

10. What is your highest level of qualification?

Matric	1
Diploma	2
BTech	3
Degree	4
Honours degree	5
Masters	6
Doctorate	7
Other please describe	8

11. How many years of experience do you have in your work?

1-3	1
4-6	2
7-9	3
10-12	4
13-15	5
16-18	6
19-21	7
22-23	8
24-26	9
27-30	10
Other, please specify	11

12. What HIV and AIDS training have you received?

Ten day HIV Counselling and Testing	1
Five day PMTCT	2
Five day Treatment Adherence	3
Three day couple counselling	4
Three day HIV/TB collaboration	5
Three day STI's management	6
59 day Home Community Based Care	7
Other please describe	8

13. Do you receive any form of mentorship?

Yes	1
No	2

14. Do you receive individual or group mentoring? (Tick what is applicable)

Individual mentoring	1
Group Mentoring	2
Both	3

15. How often do you receive mentoring?

Once a month	1
Once a quarter	2
Every six months	3
Once a year	4
Other, please specify	5

16. How many hours per week do you work at the facility?

NUMBER OF HOURS	NUMBER
4-6	1
7-9	2
Other, please specify	3

17. What type of work do you usually do at this facility? (Tick all that apply to you)

Direct patient/client care	1
HIV Counselling	2
Health education	3
Supervision	4
Research	5
Dispensing	6
Health assessments	7
Other please describe	8

18. How many clients have you personally seen at your facility in the last 30 days?

NUMBER OF CLIENTS	NUMBER
30-40	1
41-50	2
51-60	3
61-70	4
71-80	5
81-90	6
91-100	7
Other, please specify	8

19. Who is your employer?

The Department of Health	1
An NGO (Funded by the department of health)	2
An NGO (Not funded by the department of Health)	3
Private company	4
Other please describe	5

20. Have you experienced a delay in receiving your salary/stipend in the past six months?

Yes	1
No	2

21. How long would you say the delays have lasted on average?

Number of days	1
Number of weeks	2
Number of months	3
Other, please specify	4

22. Does the interruption of receiving your salary interfere with your work?

Yes	1
No	2

23. Are you currently a member of any professional association?

Yes	1
No	2

24. Do you have the right to strike?

Yes	1
No	2
Don't know	3

25. Have you gone on a labour strike in the past 12 months?

Yes	1
No	2

SECTION C: CCMT SITE

26. Which HIV-related services does your facility provide (Tick all that apply)

ART for adults	1
ART for children	2
HCT	3
PMTCT	4
Management of Opportunistic diseases	5
HCBC	6
Support group of PLHA's	7
Treatment Adherence Counselling	8
Couple Counselling	9
Other please describe	10

27. Which of the following laboratory tests does your facility routinely conduct? (Tick all that apply)

Viral load	1
CD4 Cell counts	2
Elisa	3
PCR	4
Other please describe the method	5

28. How many adults are currently being treated with ART at your facility?

29. How many children are currently being treated with ART at your facility?

SECTION D: POLICIES REGARDING ANTIRETROVIRAL THERAPY

30. How often is ART dispensed for clients?

Daily	1
Weekly	2
Monthly	3
Every three months	4
Don't know	5
Other please describe	6

31. Who is authorized to collect treatment for the client on ART?

Client	1
Treatment supporter	2
Any family member	3
Home Based Carer	4
Don't know	5
Other please describe	6

SECTION E: CLINICAL DATA AND ART MONITORING

32. How frequently are the following data available in the records for each clinic visit of ART clients at this facility? (Tick the items applicable)

TYPE OF DATA	ALWAYS	USUALLY	SOMETIMES	NEVER
Dosing schedule for ART				
Names of other medications taken by clients				
Reported side effects				
Client self-report of recent adherence				
Health Care Worker's written findings from client medication calendar				
Pill counts of medicine in client's possession				
Health Care Worker's assessment of recent client adherence				
Number of ART pills dispensed				
Expected day's supply of ART dispensed				
Date of next scheduled clinic visit				
How close was actual visit to scheduled visit				
Was the client referred for adherence counselling				
Did the client receive adherence counselling				
Reported reasons for non-adherence				
Does the client have Treatment Supporter				
Did the Treatment Supporter receive adherence counselling				

SECTION F: INDIVIDUAL CLIENT LEVEL ADHERENCE TO ART

33. How is an individual client's adherence to ART monitored in this health facility?

ADHERENCE MEASURE	BY CLINIC STAFF	BY PHARMACY STAFF	NOT USED
Client self-report			
Client medication calendar			
Pill count			
Clinicians subjective judgement			
Client complying with regular appointments			
Directly observed treatment at health facility (ART policing)			
Directly observed treatment at home (ART policing)			
Other, please specify			

34. What rate of adherence to ART does the facility consider to be satisfactory for an individual client?

35. Clinic or Health Facility Level of Adherence to ART

36. Do you monitor rates of adherence to ART at the health facility level (that is, adherence rates averaged across multiple clients)?

Yes	1
No	2

37. If you do not monitor adherence at facility level, what are the reasons for not doing so?

38. What source of data is used to calculate this ART adherence rate at the health facility?
(Tick all that apply)

Records from individual clients' routine adherence monitoring	1
Special survey conducted to monitor adherence	2
Not known	3

39. How do you calculate the ART adherence rate at the health facility? (Give formula)

40. What rate of ART adherence does the clinic consider to be satisfactory at the health facility?

41. What is the most recent rate of ART adherence at the health facility?

Adherence level _____ Date reported (Month, Year) _____

SECTION G: DEFAULTER MONITORING

42. Are clients given scheduled appointments for their next attendance?

Yes	1
No	2

43. Do you have a formal system in place to monitor whether clients receiving ART attend scheduled appointments?

Yes	1
No	2

44. If yes, please describe how this is done

45. If a client does not attend a scheduled visit, do you have a way of knowing if they are ill, have died or have dropped out?

Yes	1
No	2

46. If yes, please describe how this is done

47. At what point is a client considered an ART drop-out or defaulter? (Tick the item applicable)

After failing to attend for a certain length of time, specify how long_____	1
After missing a certain number of scheduled appointments, specify how many _____	2
Clients are never counted as dropouts or defaulters	3
Other, please specify	4

48. Are there systems in place at this facility for following up with ART clients who do not appear for an appointment?

Yes	1
No	2

49. If yes, please describe how this is done

50. Which interventions do you currently use or plan to use at this clinic to promote client adherence to ART? (Tick all that are applicable)

TYPE OF INTERVENTION	ALREADY IN USE	PLAN TO USE
Patient counselling before starting ART		
On-going counselling after starting ART		
Home/community Based carers/volunteers		
Require a treatment supporter to observe treatment		
Social support (food parcels, food supplements, day care)		
Fast track service at health facility		
Use devices to promote adherence (Diary, pill box, alarm, reminder phone calls)		
Other interventions (please describe)		

51. Do you use any interventions to improve the health provider's motivation to promote better client adherence?

Yes	1
No	2

52. If yes, please describe how this is done

53. Have you carried out any evaluation of your intervention approaches to improve adherence to ART at this facility?

Yes	1
No	2

54. If yes, please describe how this is done

55. Are you receiving sufficient support from the Department of Health?

Yes	1
No	2

56. If yes, please describe how this is done.

57. What do you think would be some useful intervention approaches to improve ART adherence rates at your facility?

INTERVENTION	RECOMMENDED	NOT RECOMMENDED
Social support		
Psychological Support		
Health Care Facility Location		
Health Care Provider capacity and Motivation		
Use reminders for patient adherence		
Improved adherence monitoring		
Improved patient counselling and communication		
Other, please specify		

Adapted from: Johnson, A and Witt, H. 2007. Adherence to Antiretroviral therapy practices in Resource-constrained Settings. Submitted to the U.S. Agency for International Development by the Rational Pharmaceutical Management Plus Program. Arlington, VA: Management Sciences for Health.

Thank you for sharing your perspectives with me. The information you have provided is very helpful. Do you have any questions for me? If so, please feel free to ask me.

“AIDS is no longer just a disease, it is a human rights issue”

- Nelson Rolihlahla Mandela

ANNEXURE F

ETHICAL CLEARANCE CERTIFICATE (ATTACHED)

ANNEXURE G

REQUEST TO CONDUCT RESEARCH DOH (ATTACHED)

ANNEXURE H

PERMISSION TO CONDUCT RESEARCH DOH (ATTACHED)

ANNEXURE I

**APPLICATION TO CONDUCT RESEARCH FROM THE PRIVATE HEALTH
FACILITY (ATTACHED)**

ANNEXURE J

DATA COLLECTION SCHEDULE (ATTACHED)

UNIVERSITY OF LIMPOPO
Turfloop Campus



Research Development and Administration

TURFLOOP RESEARCH ETHICS COMMITTEE
CLEARANCE CERTIFICATE

Private Bag X1106
SOVENGA
0727
SOUTH AFRICA
Tel.: (015) 2682401
Fax: (015) 268 2306
Int. Tel.: +27 15 268 2401
Int. Fax: +27 15 268 2306
E-mail:
noko.monene@ul.ac.za

MEETING: 29 January 2013

PROJECT NUMBER: TREC/FHM/05/2013: PG

PROJECT:

Title: A sociology study on challenges to treatment adherence in anti-retroviral therapy amongst people living with HIV and AIDS in the Mopani District, Limpopo Province.

Researcher: Ms TP Mona

Supervisor: Prof PM Mokhahlane

Co-Supervisor: N/A

Department: Sociology

School: Social Sciences

Degree: PhD in Sociology


PROF. TAB MASHEGO

CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE





LIMPOPO

PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Selamolela Donald

Ref:4/2/2

Mona TP

Flora Park

Polokwane

0699

Dear Ms Mona TP

Re: Permission to conduct the study titled: A sociological study on challenges to treatment adherence in anti-retroviral therapy amongst people living with HIV and AIDS in the Mopani District, Limpopo Province.

1. The above matter refers.
2. Permission to conduct the above mentioned study is hereby granted.
3. Kindly be informed that:-
 - Further arrangement should be made with the targeted institutions.
 - In the course of your study there should be no action that disrupts the services.
 - After completion of the study, a copy should be submitted to the Department to serve as a resource.
 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.

Your cooperation will be highly appreciated.

General Manager: Strategic Planning, Policy and Monitoring

Date: 11/01/2013

APPLICATION TO CONDUCT ACADEMIC RESEARCH AT

Name of researcher:

Contact details of researcher:

Telephone number:

Cell number:

Email:

Physical address:

Postal address:

Research title:

Date/s and place of proposed research:

Details of research team (name of researcher/s, research assistant/s, supervisor, and any other team members):

Details of degree/diploma/certificate for which research is required:

Through which institution is this research being conducted ? (Name and contact details of department, school and institution)

Do you have approval from the Ethics Committee of this institution to conduct the research?

If yes, provide:



Reference number for the approval:

Name and contact details of the Ethics Committee

Does the research require access to written records or documentation of HTT or any of its associated projects? Explain:

How is the research funded? If by grant, please specify funder and grant details.

Summarise your proposed research process and objectives. Include estimated timeframe:

APPLICATION TO CONDUCT NON-ACADEMIC RESEARCH AT HTT

Name of research organisation and/or individual researcher:

Contact details of research organisation/individual researcher:

Telephone number:

Cell number:

Email:

Physical address:

Postal address:

Title of research:

Reason for research:

Organisation/individual for whom research is being conducted

Name:

Contact details:

Date/s and place of proposed research:

Details of research team (name of researcher/s, research assistant/s, supervisor, and any other team members):

How is the research funded? Please specify, and give contact details

Does this research require any biomedical intervention which requires approval from an Ethics Committee? If yes, provide:

Reference number for the approval:

Name and contact details of the Ethics Committee

Does the research require access to written records or documentation of HTT or any of its associated projects? Explain.

Summarise the proposed research process and objectives. Include estimated timeframe.



GENERAL INFORMATION REQUIRED (FOR BOTH ACADEMIC AND NON ACADEMIC)

ETHICS

What ethical procedures/codes will you adhere to in the research process, for example:

- How will you inform participants about the research?
- How will you obtain participant's informed consent?
- How will you ensure anonymity, if necessary?
- Who will have access to the data?

HTT RESOURCES REQUIRED

What HTT staff involvement do you envisage?

How much time do you envisage this involvement would require?

What other HTT resources would you hope to use? Office space, telephones, logistical support to organise access/translate etc)

BENEFIT

How will HTT and/or its projects benefit from the research process and/or findings?

How will the research participants benefit from the research process and/or findings?

PUBLICATION AND DISSEMINATION

Will the findings be published?

Where and when?

How will the findings be disseminated and to whom?

HTT requires that it be supplied with a copy of the research findings and all publications and materials developed from these. Who will undertake to do so?

COMMERCIAL APPLICATION

Who will exercise ownership of the data?

Will the data be used to inform any commercial enterprise? Specify

When will the data be destroyed?

ACKNOWLEDGEMENTS

HTT requires that the organisation and its projects be acknowledged as a research site, as participants and as stakeholders in the outcome of the research

Where and how will HTT and its projects be acknowledged?



LIMPOPO

PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Selamolela Donald

Ref:4/2/2

Mona TP

Flora Park

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0699

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 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.

Your cooperation will be highly appreciated.

General Manager: Strategic Planning, Policy and Monitoring

Date: 11/01/2013

22 Mopani Street
Flora Park
Polokwane
0699
11 January 2013

THE DISCTRICK EXECUTIVE MANAGER

The Department of Health
Mopani District
Old Parliament Building
Giyani
0826

Dear Dr Bogale,

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am a PhD student at the University of Limpopo and have been granted permission to conduct research by the Turfloop Research Ethics Committee as well as the Department of Health's Research Ethics Committee.

My topic is: A sociological study on the challenges to treatment adherence amongst people living with HIV and AIDS in the Mopani District, Limpopo province.

I have identified the following health facilities as sites where data will be collected:

DATE	SUB-DISTRICT	HEALTH FACILITY	ACTIVITY
15 January 2013	Maruleng	Sekororo Hospital	In-depth interviews with four clients on ART. Assessment of two files of clients already interviewed.
16 January 2013	Maruleng	Sekororo Hospital	Assessment of two files of clients already interviewed. Administering of questionnaire to two health care providers. (One health care worker and one lay counsellor).
17 January 2013	Ba-Phalaborwa	Maphutha-Malatjie Hospital	In-depth interviews with four clients on ART Assessment of two files of clients already interviewed.
18 January 2013	Ba-Phalaborwa	Maphutha-Malatjie Hospital	Assessment of two files of clients already interviewed. Administering of questionnaire to two health care providers. (One health care worker and one lay counsellor).
21 January 2013	Ba-Phalaborwa	Lulekani Health Centre	In-depth interviews with three clients on ART Assessment of three files of clients already interviewed. Administering of questionnaire to two health care providers. (One health care worker and one lay counsellor).
22 January 2013	Greater Tzaneen	Letaba Hospital	In-depth interviews with four clients on ART Assessment of two files of clients already interviewed.
23 January 2013	Greater Tzaneen	Letaba Hospital	Assessment of two files of clients already interviewed.

			Administering of questionnaire to two health care providers. (One health care worker and one lay counsellor).
24 January 2013	Greater Tzaneen	Letaba Hospital	Facilitation of a focus group discussion with seven people on ART and in a support group
25 January 2013	Greater Letaba	Kgapane Hospital	In-depth interviews with four clients on ART Assessment of two files of clients already interviewed.
28 January 2013	Greater Letaba	Kgapane Hospital	Assessment of two files of clients already interviewed. Administering of questionnaire to two health care providers. (One health care worker and one lay counsellor).
26 January 2013	Greater Giyani	Nkhensani Hospital	In-depth interviews with four clients on ART Assessment of two files of clients already interviewed.
27 February 2013	Greater Giyani	Nkhensani Hospital	Assessment of two files of clients already interviewed. Administering of questionnaire to two health care providers. (One health care worker and one lay counsellor).
19 February 2013	Greater Giyani	Kremetart Clinic	In-depth interviews with four clients on ART Assessment of two files of clients already interviewed.

20 February 2013	Greater Giyani	Kremetart Clinic	<p>Assessment of two files of clients already interviewed.</p> <p>Administering of questionnaire to two health care providers.</p> <p>(One health care worker and one lay counsellor).</p>
02 February 2013	Maruleng	Hlokomela	<p>Assessment of four files</p> <p>Interviews already done with four clients on ART and two health care providers. A focus group discussion was also done.</p>

CRITERIA FOR SELECTION

Clients

- Males and females who have been on anti-retroviral therapy for at least six months.
- They should be above the age of 18.
- They may or may not belong to a support group.

Health Care Providers

- Male and female health care providers who have been working in the ARV clinic for over one year.
- They should be placed at the ARV clinic.
- They can either be a professional nurse, medical doctor or lay counsellor.


Anticipated respondents and procedure

- In total 30 clients on anti-retroviral therapy will be interviewed.
- Sixteen health care workers will be interviewed.
- Three focus group discussions will be facilitated.
- Thirty files of people on ART will be reviewed so as to back-up data from in-depth interviews and focus group discussions.
- All interviewed clients on ART will receive money for transport.
- Lunch and juice will be served during focus group discussions.

Attached, please find the ethical clearance certificate from the Turfloop Research Ethics Committee (TREC) and a letter of approval from the Department of Health's Research Ethics Committee.

Your assistance in this regard will be highly appreciated.

Yours Sincerely



Tiny P. Mona (Ms)