THE ROLE OF FAMILY SUPPORT AND HIV/AIDS STIGMA ON ADHERENCE AND NON-ADHERENCE TO ANITRETROVIRALS AT NZHELELE IN LIMPOPO PROVINCE, SOUTH AFRICA

By

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DECLARATION

I declare that the dissertation entitled ***The role of family support and HIV/AIDS stigma on adherence and non-adherence to antiretrovirals at Nzhelele in Limpopo*** submitted to the University of Limpopo, for the Master of Public Health degree at this or other university; that it is my own work in design and in execution, and that all material contained herein has been duly acknowledged.

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Mathivha T.M (Ms) **Date**

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DEFINITION OF CONCEPTS

The following concepts are defined for clarification purposes:

- **Adherence**

For the patient, adherence means taking all the pills and doses in accordance with the manner prescribed by the doctor (HIV and AIDS Clinical Management Programme, 2004).

- **Acquired immunodeficiency syndrome (AIDS)**

AIDS is a disorder of cell-mediated immunity characterized by opportunistic infections, malignancies, neurologic dysfunction, and a variety of other syndromes. AIDS is the most severe manifestation of a spectrum of HIV-related conditions (Mark et al., 1999).

- **Antiretroviral (ARVs) drugs**

ARVs are medications for the treatment of infection. They block the enzymes used by HIV to replicate itself and by so doing suppress the replication of the HI virus (Evian, 2003).

- **Cluster of Differentiation (CD4)**

It is a molecule found on cytotoxic T lymphocytes and it is the major receptor for HIV and is the main target of HIV infection (Douglas et al., 2008)

- **Family Support**

Family support is when parents, children, sometimes including grand children and other relations give strength, help, or encouragement to someone who is on antiretroviral therapy, for example, with regard to reminding family members on how to take medications (HIV and AIDS Clinical Management Programme, 2004).

- **Highly Active Antiretroviral Therapy (HAART)**

Patients with HIV/AIDS are treated with a combination of three (or more) different types of ARVs; usually two nucleosides reverse transcriptase inhibitors (NRTIs) with either non-nucleoside reverse transcriptase inhibitor or one or two protease inhibitors. This type of regimen, as opposed to mono- or dual-therapy, is referred to as HAART (Pratt, 2003:366).

- **Human Immunodeficiency virus (HIV**)

HI virus is a virus caused by one of two related retroviruses (HIV-1 and HIV-2) resulting in a wide range of clinical manifestations varying from asymptomatic carrier states to severely debilitating and fatal disorders related to defective cell-mediated immunity (Mark et al., 1999).

- **HIV and AIDS Stigma**

HIV/AIDS related stigma is a real or perceived negative response to a person or persons by individuals, communities or societies. Some of the characteristics include rejection, denial, discrediting, underrating and social distance (Searle, 2004).

- **Polypharmacy**

The term polypharmacy generally refers to the use of multiple-medications by a patient. The term is used when too many forms of medication are used by a patient; more drugs are prescribed than clinically warranted, or even when all prescribed medications are clinically indicated but there are too many pills to take ("pill burden"). Furthermore, a portion of the treatments may not be evidence-based. The common result of polypharmacy is increased adverse drug reactions and higher costs. (http://www.answers.com/topic/polypharmacy?cat=health).

ABSTRACT

Objectives: To determine the level of adherence of people who are on ARVs and to determine the influence of HIV and AIDS stigma and family support on adherence and non-adherence to antiretrovirals.

Methods: A descriptive cross sectional study involving 175 HIV/AIDS adult patients attending Siloam hospital was conducted. These patients were on ARV drugs. They were investigated for the level of adherence and the influence of HIV and AIDS stigma and family support on adherence and non-adherence to antiretrovirals. Data were collected from respondents through self-administered questionnaires which were distributed to 175 randomly selected participants. The key variables were demographic information and social support and disclosure, current use of ARVs and personal experience of living with HIV/AIDS. Data were analyzed using descriptive statistics, numerical summaries, tables, graphs, ANOVA, Pearson chi-square test and statistical package for social sciences (SPSS).

Results: Forty comma eight percent (40,8%) of the respondents on ARVs were males and 28, 8 % females aged between 23-35 years; 23, 9% males and 40, 4% females ranged between 36-45 years; 35, 2% males and 30, 8% were 46 years old and above. The most commonly cited reasons for missing doses were: Social grant, forgetting, side effects and stigma. The most cited reasons for taking medication were: respondents wanted to feel better; to increase the CD4 count; and they feared death. The majority of the adhering participants, 68, 9% and 55, 8% of the non- adhering group never experienced negative reactions from their families after disclosure. There was no significant difference between the adhering and the non adhering group (P =0.250). A substantial number of ARV users of the adhering group 92, 2% participants disclosed that they were receiving support which included emotional/psychological support, financial support, physical care support as well as reminders to ensure that they took their medications on time. There was no significant difference between the adhering

and the non adhering group on the general satisfaction with the overall support they received from their family (p= 0.976).

Conclusion: Patients have a range of reasons for failing to adhere to their antiretroviral therapy and reasons for adhering. Support can improve adherence to therapy and patients can only receive support if they revealed their HIV positive status. It was recommended that the community should be sensitised about the availability of treatment and the importance of adherence

Keywords: Adherence, antiretrovirals, HIV/AIDS, stigma and family support

CHAPTER 1: INTRODUCTION

This introductory chapter provides a brief background to the topic under investigation and explains the research frame work.

1.1 BACKGROUND

An estimated 1.9 million people were newly infected with HIV in sub-Saharan Africa in 2007. In total, 22 million people are living with HIV in the region, which is two thirds (67%) of the global population of people with HIV. For the region as a whole, women are disproportionately affected in comparison with men, with especially stark differences between the sexes in HIV prevalence among young people. In South Africa, the estimated 5.7 million South Africans living with HIV in 2007 make this largest HIV epidemic in the world (UNAIDS, 2008).

Recent figures estimate that approximately 400 000 individuals with AIDS require immediate treatment with powerful antiretroviral drugs (Soul city and Khomanani, 2004) – the only effective means to treat the final stages of the disease. By the end 2008, 44% of the adults and children in South Africa needed of antiretroviral therapy had access to treatment. Five years earlier, the regional treatment coverage was only 2% (UNAIDS, 2008).

Patient adherence in taking medication is the key to the success of the antiretroviral programme. Patients are required to take three types of tablets twice a day at the same time each day for the rest of their lives. Treatment preparedness and support for patients commencing ARV therapy is therefore imperative.

As Antiretroviral (ARV) therapy is a life time commitment, it is vital that patients in the earlier stages of HIV be educated on wellness management

and encouraged to keep themselves healthy for as long as possible so that their CD4 counts remain high and thereby deferring the need to commence ARV therapy.

Adherence is described as engagement and accurate participation of informed patient in a plan of care. It has a broader meaning than compliance which encompasses the extent to which a patient follows instructions. It implies understanding, consent and partnership. But adherence includes entering into and continuing in a programme and care plan such as meeting appointments and tests as scheduled. Adherence to treatment encompasses more than adherence to medications like ARVs (Irunde et al., 2004).

In an ideal situation, 100% level of adherence is required for ARV treatment success. Though adherence is a problem in poor countries due to multifaceted factors, studies show that there is no significant difference in adherence between resource-limited and resource-rich countries, suggesting that all patients have problems in taking 100% of their pills. It is therefore recommended worldwide that for any ARV programme there should be a concurrent plan for adherence assessment and support (Irunde et al., 2004).

Various authors like (Sanjobo et al., 2008 ; Uzochukwu et al., 2009) tried to establish reasons for adherence and non-adherence and fell short of looking at the impact of socio economic factors, like social grants because most patients are defaulting from the treatment because of fear of losing the social grant. HIV/AIDS is not curable, but ARVs boost the immune system and increase the CD4 counts and also prolong the patient's lives. From personal observations, most patients who are HIV positive are unemployed and they depend on the social grant for their well- being.

The researcher developed interest in investigating reasons for adherence and non-adherence to antiretrovirals and the role of HIV and AIDS stigma and family

support amongst HIV positive people who have been taking antiretrovirals for the past 4 years at Nzhelele area in the Vhembe District.

1.2 RESEARCH FRAMEWORK

This section presents the aim and objectives of the study, statement of the problem and research questions

1.2.1 AIM OF THE STUDY

The aim of the study was to establish the influence of HIV and AIDS stigma and family support on adherence and non-adherence to antiretroviral therapy at Nzhelele area in the Vhembe District, Limpopo Province, South Africa.

1.2.2 OBJECTIVES OF THE STUDY

- To determine the level of adherence on people who are on ARVs ; and
- To determine the influence of HIV and AIDS stigma and family support on adherence and non-adherence to antiretrovirals.

1.2.3 STATEMENT OF THE PROBLEM

In 2003 the South African government took a decision to provide Antiretrovirals (ARVs) therapy in the public health sector. However since then, there has been lack of proper documentation on ARV treatment adherence and non-adherence in Vhembe District (South Africa). HIV positive people still find it difficult to disclose their HIV status with ease to family members because of fear of rejection due to the fact that HIV and AIDS are associated with people who are outcasts in societies. Such people include commercial sex workers and the gay community. This creates a major barrier for ARV treatment and care for people living with HIV and AIDS.

1.2.4 RESEARCH QUESTIONS

- What is the role of family support with regard to antiretroviral therapy
- How does family support influence adherence?
- What are the reasons for adherence to antiretroviral therapy?
- What are the reasons for non-adherence to antiretroviral therapy?
- What is the role of HIV and AIDS stigma on adherence and non-adherence to antiretroviral therapy?

1.3 CHAPTER OUTLINE

Chapter 1: Provides a background to the study, and it also explains the research frame work.

Chapter 2: Discusses available research on the role of family support and the role of HIV/AIDS stigma on adherence and non-adherence to ARVS. It also defines concepts used in the study.

Chapter 3: The researcher outlines the methodology of the study, which includes study site, study design, ethical considerations, sampling, data collection and data analysis.

Chapter 4: This chapter outlines the results of the study.

Chapter 5: This chapter focuses on the discussion of the findings and also the conclusion, limitations and recommendations.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter discusses available research on the role of family support and HIV/AIDS stigma on adherence and non-adherence to ARVS. The review includes background, socio economic factors of patients on HAART regimens, side effects of HAART on adherence and treatment characteristics affecting adherence.

2.2 OVERVIEW

Since 1996, an overwhelming wealth of information from the clinical trials has been published validating the use of highly active antiretroviral therapy (HAART) for the treatment of Human Immunodeficiency Virus (HIV) infection. Suppression of HIV replication, immune reconstitution, a halt in disease progression, increased survival, reduced morbidity and a better quality of life have been defined as the biological and clinical goals of treatment (Pallela et al., 1998).

Maximum and durable suppression of HIV viral replication to below the level of detection is necessary to achieve biological and clinical goals. To achieve success requires near-perfect adherence to combination regimens. Failure to suppress viral replication completely inevitably leads to the selection of drug resistant variants thus limiting the effectiveness of therapy (Condra, 1998).

Starting a regimen of antiretrovirals can be a very difficult change for someone who is newly diagnosed with HIV. For example, side effects from the antiretrovirals can make patients feel too sick to take medications correctly. Social stigma is another challenge that may cause patients not to take medicines in the presence of their friends or family members. This may even cause patients

to miss a dose. Patients may simply forget, may be busy working, or may forget to bring the pills with them (Jennifer, 2005).

Healthcare should not end when the patient steps out of the hospital, but should continue at home. Healthcare providers can encourage and educate family members regarding the HIV disease and its treatment. The family can provide valuable support for a patient taking antiretroviral medications simply by listening, reminding them when necessary, helping patients with the habit that may save their life, that is taking their antiretroviral correctly (Jennifer, 2005).

2.3 Socio economic factors of patients on HAART regimens

Literature consistently demonstrates that demographic characteristics are not strong predictors of adherence though some correlates of adherence are described below together with socio-economic factors such as age, level of education, financial concerns and social support.

2.3.1 Age

Age may influence adherence. Studies done by Wenger, et al. (1999) in Chicago have found that apart from the most elderly, adherence increases with age. In a study conducted in Geneva (Predictors of non-adherence to HIV combination therapies) associated with HAART, adherence and non-adherence showed a positive correlation with younger ages (Klosinki et al., 1998).

2.3.2. Level of Education

A lower level of general education and poorer literacy impact negatively on some patient's ability to adhere (Moralez et al., 1999; Sipler, et al., 1999), whilst a higher level of education has a positive impact (Catz et al., 1999).

2.3.3. Financial concerns

Patients on higher income brackets have less difficulty with adherence (Pratt et al., 1998). However, poverty seems to be a hindrance among people who are

living with HIV especially in the Third World where many people are still below the poverty datum line (Grieson et al., 2000).

2.3.4. Social support

Living alone and a lack of support have been associated with an increase in non-adherence (Williams & Friedland, 1997) and social isolation is predictive of non-adherence (Besch, 1995). Not living alone, having a partner, social or family support, peer interaction, and better physical interactions and relationships are characteristics of adherent patients (Eraker et al., 1984; Pratt et al., 1998; Motashari et al., 1998; Brown et al., 1998).

2.4 Side effects of HAART on adherence

2.4.1. The drug regimen

Almost all people living with HIV and AIDS (PLWHA) who are currently using anti-HIV drugs are on a regimen of three or more drugs (Grierson et al., 2000). The likelihood of a patient's adherence to a given regimen declines with polypharmacy, the frequency of dosing, the frequency and severity of side effects, and the complexity of the regimen (Williams & Friedland, 1997). Drug hypersensitivity is far more common in patients with HIV (Carr et al., 1997) and a regimen associated toxicity is a common predictor of, and reason for, non-adherence across many studies (Murri et al., 1999; Ickovics & Meisler, 1997). Side effects associated with each individual antiretroviral drug are well described, and whilst not universal for every patient, can be predicted. Usually adverse effects are detectable after the first few weeks of therapy and for some, side effects persist. Anticipation and fear of side effects also impact upon adherence (Broers et al., 1994). Poor adherence has been associated with a patient's desire to avoid embarrassing side effects in certain situations, for example, whilst on a date or attending a job interview (Burgos et al., 1998).

A typical HAART combination commonly consists of three agents or drugs namely, Stavudine, Lamivudine and Nevirapine for regimen 1B or Stavudine, Lamivudine and Efavirenz for regimen 1A and other medications for prophylaxis of opportunistic infections, medications for symptomatic relief like analgesics and cough remedies. These can result in a high pill load and the regimen complexity significantly impacts upon the patient's ability to adhere (Ickovics & Meisler, 1997).

2.5 Treatment Characteristics affecting adherence

2.5.1 Physical state and disease state

Studies have indicated that opportunistic infections, severity of symptoms and low CD4+ counts can predict adherence (Singh et al., 1996; Bond et al., 1991; Erlon et al., 1999), whilst lack of symptoms (despite laboratory evidence of the need for HAART) may affect adherence (Jones et al., 1999; Murri et al., 1999). Seeing an improvement in T-cells and viral load reflected in the indices used to monitor HAART may be a powerful incentive to maintain adherence (Kaplin et al., 1999; Pratt et al., 1998).

2.5.2 Depression and severe anxiety

Research done in Geneva showed that depression and severe anxiety are variables that predict non-adherence (Klosinski et al., 1998; Ickovics et al., 1997; Besch, 1995). Most people with HIV at some point in the course of their illness, experience a psychiatric disorder for example, depression and anxiety. Findings further indicate that about 70% of the patients with symptomatic HIV-diseases such as anxiety and depression (Buhrich & Judd, 1997; Hayman & Burhrich, 1994). Adherent patients demonstrate significantly less depression or other psychiatric disturbances (Singh, et al., 1996; Pratt et al., 1998; Catz et al., 1999).

AIDS related dementia (AIDS Dementia Complex-ADC) is a common finding in patients with advanced HIV disease and is characterised by abnormalities in

cognitive as well as motor function (Wright, et al., 1997). Studies describing adherence and ADC are rare. Cognitive deficits do impact negatively on adherence to HAART regimen. Even when cognition is unimpaired, it is difficult to remember to take medications (Meisler et al., 1993).

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter, the researcher outlines the methodology of the study which includes study site, study design, ethical considerations, sampling, data collection and data analysis.

3.2 STUDY SITE

Nzhelele is located in Ward 27 of Makhado Municipality of the Vhembe District. The area has only one district hospital, Siloam. Siloam Hospital serves the following villages: Phadzima, Beaconsfield, Rabali, Makhado, Khomele, Matsa, Mudimeli, Khakhu, Madala, Siloam, Dzanani, Tshikuwi and Straighardt.

3.3 STUDY DESIGN

The researcher used a descriptive cross sectional survey method. The quantitative method specifically a questionnaire was used, to determine the level of adherence of people who are on antiretroviral therapy and the influence of HIV and AIDS stigma and family support on adherence to antiretrovirals.

3.4 ETHICAL CONSIDERATIONS

After approval of the research proposal by the Research Committee of the school of Public Health. Approval was obtained from the University of Limpopo Ethics Committee to conduct the study. Permission to collect data was obtained from the provincial Department of Health and Social Development and also hospital authorities. Participants were informed about the aims, purpose, potential risk of the study and the discomfort it may entail.

The participants were also informed that their participation was voluntary and that they had a right to abstain from participation. Confidentiality of information collected from the participants was maintained. Participants were given consent forms (see Annexure A) to complete and only those who completed the consent form were included in the study.

3.5 SAMPLING

The population on ARVs from 2003 to 2006 at Nzhelele is 318 as indicated in Siloam Hospital Statistics of 2006. Based on the Morgan and Krejcie (1994) table a sample number of 175 was randomly selected.

Inclusion criteria

- Both female and male HIV people above the age of 18 ; and
- HIV positive people who have been taking antiretrovirals for the past 4 years (from 2003 to 2006).

Exclusion criteria

- HIV positive people under the age of 18;
- HIV positive people who started taking antiretroviral therapy in 2007; and
- HIV positive people who are not from the Nzhelele area.

3.6 DATA COLLECTION

The data were collected by means of a questionnaire. A structured questionnaire adapted from Human Science Research Council was used for data collection. The English version of the questionnaire was translated to Venda. The questionnaires determined the level of adherence on antiretroviral therapy in persons living with HIV and AIDS, as well as the influence of HIV and AIDS stigma and the role of family support on adherence to antiretroviral therapy by:

1. ARV adherence status as determined by standard operating procedures on antiretroviral therapy (ART)
2. Adherence counselling perceived level of family support determined by several closed ended questions.

3.7 DATA ANALYSIS

Data was analysed as follows:

- Descriptive statistics, numerical summaries, tables, graphs were used;
- ANOVA was used to summarise data;
- Pearson chi-square was used to make comparison between adherence and non adherence; and
- Data was analysed using computer software called statistical products and service solutions (SPSS).

3.8 REPORTING AND UTILISATION OF RESULTS

Data reporting and dissemination of information include the following:

- Mini-dissertation;
- Presentation at conferences, seminars and to professional colleagues;
- Publication in peer reviewed journals; and
- Recommendations to the Department of Health

CHAPTER 4: RESULTS

4.1 INTRODUCTION

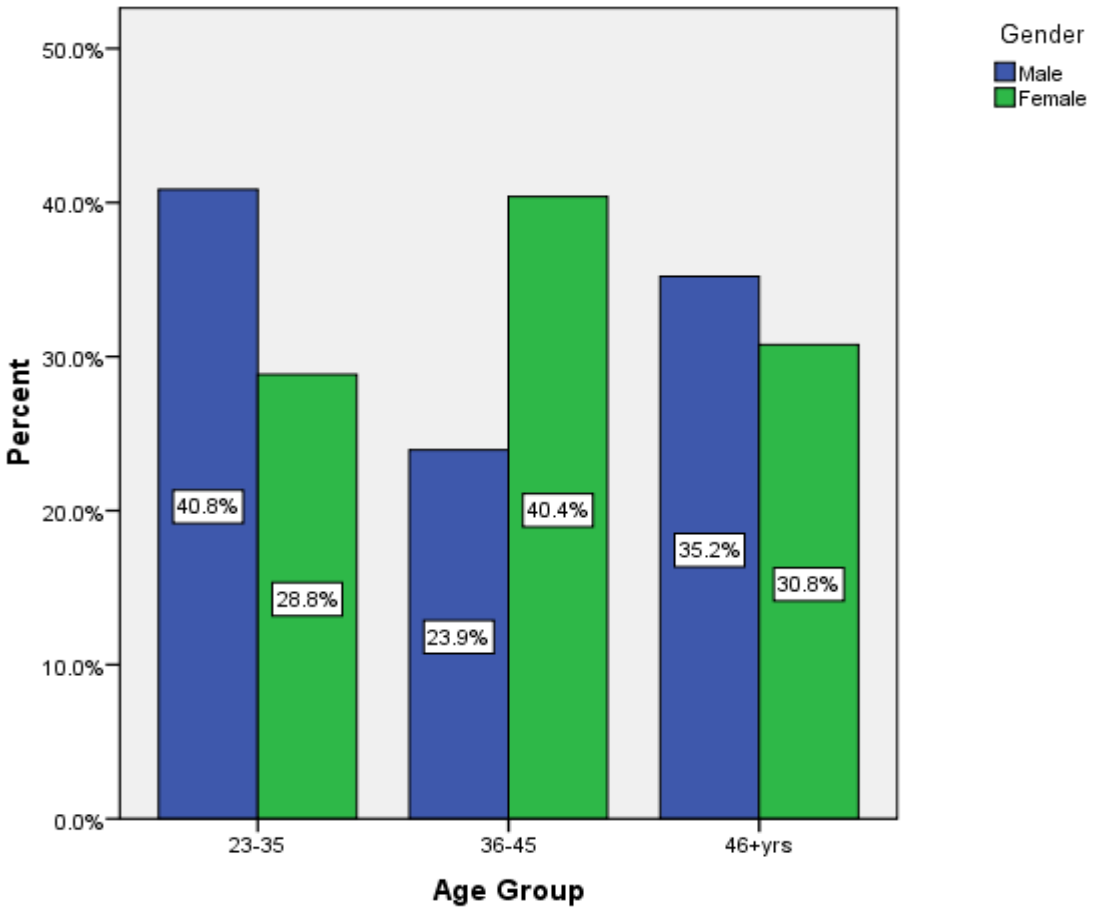
This chapter outlines the results of the study by including the demographic information, social support and disclosure, current use of ARVs and personal experiences of living with HIV/AIDS.

4.1 SECTION 1: DEMOGRAPHIC INFORMATION AND SOCIAL SUPPORT AND DISCLOSURE

4.11. Demographic information

The sample was selected from Nzhelele area in the Vhembe District. The total number of participants was 175, with 29 (40, 8%) males and 30 (28, 8%) females that ranged in ages between 23 and 35 years; 17 (23, 9%) males and 42 (40, 4%) females from 36 and 45 and 25 (35, 2 %) of males and 32 (30, 8%) females that were 46 and above in years, (See figure 4.1 below).

Figure 4.1: Percentage of participants per age group



4.1.2. Educational level

The respondents were asked about their educational level. The findings are summarised in table 4.1 below.

Table 4.1: Educational level by gender

	N	Gender	
		Males	Females
Never	17	11,3%	8,7%
Adult literacy	21	4,2%	17,3%
Gr 1-7	12	5,6%	7,7%
Gr 8-11	46	22,5%	28,8%
Gr 12	48	39,4%	19,2%
Dip/degree	31	16,9%	18,3%
Total	175	100%	100%

About 61, 9% of males and 48% of females had secondary education followed by 5, 6% of males and 7, 7% of females who had primary education. Eleven point three percent 11,3 % of males and 8,7% of females never attended school and 16,9% of males and 18,3% of females had diplomas or degrees (see table 4.1 above).

4.1.3. Marital Status

The respondents were asked to indicate their marital status. The findings are summarised in table 4.2 below.

Table 4.2: Marital status

	N	Gender		Total percentage
		Males	Females	
Married	82	54,9%	41,7%	41,7%
Cohabiting	15	1,4%	13,6%	8,6%
Single	30	19,7%	15,5%	17,2%
Divorced	18	8,5%	11,7%	10,3%

When asked about their marital status, 47, 1 % of the participants indicated that they were married, 8, 6 % were cohabiting; 17, 2% were single; 10, 3% were divorced; and 16, 7% were widowed (see table 4.2).

4.1.4. Number of children

The respondents were asked to indicate the number of children they have. The findings are summarized in table 4.3 below.

Table 4.3: Number of children

Number of children	N	Gender		Total percentage
		Males	Females	
0	13	9,9%	5,8%	7,5%
1	27	18,3%	13,6%	15,5%
2	47	25,4%	28,2%	27,0%
3	38	19,7%	23,3%	21,8%
4+	49	26,8%	29,1%	28,2%
Total	174	100%	100%	100%

When asked about the number of children7, 5% of the participants had no children, 15, 5% had 1 child, 27% had 2 children, 21, 8% had 3, 28, 2 % had 4 and more children (see table 4.3 below)

4.1.5. Currently living with at home

The participants were asked about whom they currently live with at home. The findings are summarised in table 4.4 below.

Table 4.4: Currently live with

Live with	N	%
Self	3	1,7
Partner	72	41,4
Parents	33	19,0
Siblings	5	2,9
Children	48	27,6
Relatives	4	2,3
Friends	1	0,6
Partner and child	8	4,6
Total	174	100

When asked about who the participants currently live with, 1,7% of the participants lived alone, 41,4% lived with their partners, 19,0% with parents, 2,9% lived with siblings, 27,6% lived with their children, 2,3% lived with relatives, 0,6% with friends and 4,6% with their partners and children (see table 4.4).

4.1.6. Source of income

When asked about employment 57, 7% of the male and 47,6% participants were employed and 42,3% of males and 52,4% of females were unemployed (see table 4.5 below). Table 4.6 below shows that 23,8% of males and 23,1% of females worked in government offices, 19,0% of males and 26,9% worked in the private sector; 31,0% of males and 30,8% of females were self-employed; and 26,2% of males and 52,4% of females did odd jobs.

Table 4.5: Source of income

Employed	N	Gender	
		Males (%)	Females (%)
Yes	90	57,7	47,6
No	84	42,3	52,4
Total	174	100	100

Table 4.6: Type of employment

Employment	N	Gender	
		Males (%)	Females (%)
Government sector	22	23,8	23,1
Private sector	22	19,0	26,9
Self employed	29	31,0	30,8
Odd jobs	21	26,2	19,2
Total	94	100	100

4.1.7. Reason for not working

When asked about reason for not working 40, 2% never worked; 4, 9% did not want to work; 32, 9% lost their jobs; and 22, 0% were too ill to work (see table 4.7 below).

Table 4.7: Reason for not working

Not working	N	%
Never worked	33	40,2
Don't want to work	4	4,9
Lost job	27	32,9
Too ill	18	22,0
Total	82	100

4.1.8. Reason for losing

When asked the reason for losing their jobs, 17, 8% of the participants said they lost their jobs due to the company closing down; 35, 6% due to HIV; 40, 0% due to other illnesses; and 6, 7% due to personal reasons (Table 4.8).

4.8 Reason for losing job

Lost Job	N	%
Company closed	8	17, 8
HIV	16	35, 6
Illness	18	40, 0
Personal	3	6, 7
Total	45	100

4.1.9. Financial situation of the family

When asked about the financial situation of their families, 17, 4% of the participants regarded the financial situation of their families very poor; 29, 9% as poor; 27, 5% as just managing; 18, 6% as comfortable; and 6,6% as well off (see Table 4.9 below).

Table 4.9: Financial situation

Financial situation	N	Gender	
		Males (%)	Females (%)
Very poor	29	14,9	19,0
Poor	50	26,9	32,0
Managing	46	34,3	23,0
Comfortable	31	17,9	19,0
Well-off	11	6,0	7,0
Total	167	100	100

4.1.10. Social grant

When asked whether they received social grants, 45, 7% of the participants said they received the grant (see Table 4.10 (a) on page 18). Of the total percentage of the participants who received the grant, 67,1% received child grant, 2,5% received disability grant , 22,8% received foster care grant, 6,3% received old age grant and 1,3% received the child and disability grant together (see Table 4.10 on page 18).

Table 4.10: Number of participants who received Grants

Grant	N	%
Yes	80	45, 7
No	95	54, 3
Total	175	100, 0

Table 11: Types of social grants

Type of social Grant	N	%
Child grant	53	67, 1
Disability	2	2, 5
Foster care	18	22, 8
Old age	5	6, 3
Child + disability	1	1, 3
Total	79	100

4.2 SECTION 2: CURRENT USE OF ARVs

4.2.1. Number of years taking medications

When asked about the number of years they had taking their medications, 10, 3 % of the participants had been taking ARVs for 3 year; 21, 1% had 4 years; 17, 1% had 5 years; 23.9% had 6 years; and 22, 5% had 7 or more years (see Table 4.12 below).

Table 4.12: Number of years

Years	N	%
3	18	10, 3
4	37	21, 1
5	30	17, 1
6	46	26, 3
7 and above	44	25, 1
Total	175	100, 0

4.2.2. ARV medications taken

Five (5) male and 68 female participants were on regimen 1B and 65 males and 37 females were on regimen 1A (see table 4.13 below)

Table 4.13: Regimen

Regimen	N	Gender	
		Males	Females
1A	102	65	37
1B	73	5	68
Total	175	70	105

4.2.3. Taking herbal/traditional medications

Sixty Eight coma eight percent (68, 8%) of the participants who were taking herbal medications were given medication by a traditional healer, whereas 31, 3% were given medication by a prophet (see table 4.14 below).

Table 4.14: Taking traditional medications

	N	%
Traditional healer	11	68,8
Prophet	5	31.3
Total	16	100

4.2.4. Doses of ARVs missed

When asked about the ARV doses they had missed, 85, 9% of the male and 69, 2% female participants said they never missed any doses. However 5, 6% of males, 14, 4% of females had missed one dose; 4, 2% of males and 9, 6% of females had missed two doses; 1, 4 % of males and 3, 8% of females missed three doses; and 2, 8% of males and 2, 9% of females missed four and above doses (see Table 4.15 below).

Table 4.15: Doses missed

Doses missed	N	Gender	
		Males (%)	Females (%)
None	133	85, 9	69, 2
1	19	5, 6	14, 4
2	13	4, 2	9, 6
3	5	1, 4	3, 8
4 doses and above	5	2, 8	2, 9
Total	175	100	100

4.2.5. Reason for not taking the medications

When asked about reasons for not taking medication, 5, 4% of the adhering group and 2,6% of the non-adhering group said it was because they lacked food; 32, 4% of the adhering group and 25, 6% of the non- adhering group said it was due to the elapsing of social grant; 21, 6% of the adhering group and 48, 7% of the non-adhering group said it was due to forgetfulness; 35, 1% of the adhering group and 12, 8% of the non-adhering group blamed side effects; and 2, 7% of the adhering group and10, 3% of the non-adhering group said it was due to stigma (Table 4.16).

Table 4.16: Reasons for not taking medications

Reason for missing doses	N	Adherence	
		No (%)	Yes (%)
Lack of food	3	2, 6	5, 4
Social grant	22	25, 6	32, 4
Forgot	27	48, 7	21, 6
Side effects	18	12, 8	35, 1
Stigma	5	10, 3	2, 7
Total	75	100	100

4.2.6. Reason for taking medications

When asked about their reasons for taking medications 38, 4% of the adhering group and 38, 9% of the non adhering group took their medications because they wanted to become better, 40, 4% of the adhering group and 35, 6% of the non adhering group was because they wanted the CD4 count to go up or improve and 21, 2% of the adhering group and 25, 6 % of the non adhering group was because they feared death (see table 4.18 below)

Table 4.17: Reason for taking medications

Reason for taking medications	N	Adherence	
		No (%)	Yes (%)
Better	113	38, 9	38, 4
Cd4 count up	114	35, 6	40, 4
Fear death	66	25, 6	21, 2
Total	293	100	100

4.2.7. Specific schedule

When asked about following the specific schedule 1, 1% of the participants never followed the schedule, 6, 3% followed sometimes, 16, 6% mostly followed and 76, 0% followed the schedule all the time, (See Table 4.18 below)

Table 4.18: Specific schedule

	N	%
Not at all	2	1, 1
Sometimes	11	6, 3
Mostly	29	16, 6
All the time	133	76, 0
Total	175	100%

4.2.8 What extent help they get from family

When asked to what extent does their family members help them to remember to take their medications 2, 5% of the adhering group and 17, 6% of the non adhering group were occasionally reminded and 4, 9% of the adhering group 41, 2% of the non adhering group were sometimes reminded whereas 92, 6% of the adhering group 41, 2% of the non adhering group were always reminded by their families to take medications (table 4.19 below).

Table 14.19 Reminded by family

Statement (family help)	N	Adherence (%)	
		No	Yes
Occasionally	12	17, 6	2, 5
Sometimes	27	41, 2	4, 9
Always	134	41, 2	92, 6
Total		100	100

4.4 SECTION 3: PERSONAL EXPERIENCES OF LIVING WITH HIV/AIDS

4.4.1 Rejection

4.4.1. 1 Welcomed at community level

When asked about being welcomed at community events 0 ,8% of the adhering group and 3 ,8% of the non adhering group always felt not welcomed and 21 ,5% of the adhering group 32 ,7% of the non adhering group felt not welcomed whereas 77 ,7% of the adhering group 63 ,5% of the non adhering group never felt not welcomed by the community.

Table 4.20: Experience because of HIV positive status

Statement	Adherence (%)	
	No	Yes
Always	3,8	0,8
Sometimes	32,7	21,5
Never	63,5	77,7
Total	100	100

4.4.1. 2 Discrimination at work places

When asked about being discriminated against at work 0, 8% of the adhering group and 3, 8% of the non-adhering group said they always experienced discrimination, 21, 5% of the adhering group and 32, 7% of the non-adhering group sometimes experienced being discriminated against, whereas 77, 7% of the adhering group and 63, 5 % of the non-adhering group never experienced being discriminated against at work (see Table 4.21 below)

Table 4.21: Discrimination at work places

Statement	Adherence (%)	
	No	Yes
Always	3,9	3,4
Sometimes	27,5	23,9
Never	68,6	72,6
Total	100	100

4.4.1.3. Experiencing rejection by the family

When asked about experiencing rejection by family members 2, 5% of the adhering group and 17, 3% of the non-adhering group always experienced rejection by family members and 8, 3 % of the adhering group and 25, 0% of the non-adhering group sometimes experienced rejection by family members, whereas 89, 3% of the adhering group and 57, 7% of the non-adhering group never experienced negative reactions from family members (see Table 4.22 below)

Table 4.22: Experience rejection by family

Statement	Adherence (%)	
	No	Yes
Always	17,3	2,5
Sometimes	25,0	8,3
Never	57,7	89,3
Total	100	100

4.4.1.4. Maltreatment at hospitals/ clinics

When asked about being maltreated at the hospital/clinic, 2, 5% of the adhering group and 5, 8% of the non-adhering group said they always experience maltreatment from the clinic/hospital staff; 13, 2% of the adhering group and 26, 9% of the non-adhering group sometimes experienced maltreatment, whereas 84, 3% of the adhering group and 67, 3% of the non-adhering group never experienced maltreatment (see Table 4.23 below)

Table 4.23: Maltreatment from hospital/clinic staff

Statement	Adherence (%)	
	No	Yes
Always	5,8	2,5
Sometimes	26,9	13,2
Never	67,3	84,3
Total	100	100

4.4.1.5 Acceptance from the family

When asked about acceptance from the family 84, 3% of the adhering group and 56, 9% of the non-adhering group said they always experienced acceptance from their family; 10, 7% of the adhering group and 29, 4% of the non-adhering group sometimes experienced acceptance from their families; whereas 5, 0% of the adhering group and 13, 7% of the non-adhering group never experienced acceptance from their families and the p value was 0.001 (see Table 4.24 below).

Table 4.24: Acceptance from family

Statement	Adherence (%)	
	No	Yes
Always	56,9	84,3
Sometimes	29,4	10,7
Never	13,7	5,0
Total	100	100
Pearson chi-square p value = 0.001		

4.4.1.6 Getting support from friend

When asked about getting support from friends, 65, 3% of the adhering group and 46, 2% of the non-adhering group always experienced support from friends; 24, 8% of the adhering group and 36, 5% of the non-adhering group sometimes experienced support from friends; whereas 9, 9% of the adhering group and

17, 3% of the non-adhering group never experienced support by friends (see Table 4.25 below)

Table 4.25: Support by friend

Statement	Adherence (%)	
	No	Yes
Always	46,2	65,3
Sometimes	36,5	24,8
Never	17,3	9,9
Total	100	100

4.4.1.7 Rejection by friend

When asked if their friends ever rejected them, 2, 5% of the adhering group and 5, 8% of the non -adhering group said they always experienced rejection by friends; 30, 0% of the adhering group and 19, 2% of the non-adhering group sometimes experienced rejection by friends; whereas 67, 5% of the adhering group and 75, 0% of the non- adhering group never experienced rejection from friends (see Table 4.26 below)

Table 4.26 Rejection by friends

Statement	Adherence (%)	
	No	Yes
Always	5,8	2,5
Sometimes	19,2	30,0
Never	75,0	67,5
Total	100	100

4.4.1.8 Rejection by sexual partner

When asked wether their sexual partners ever rejected them, 3, 4% of the adhering group and 2, 0% of the non-adhering group said they always experience rejection from their sexual partners; 16, 8% of the adhering group and 22, 0% of the non- adhering group sometimes experienced rejection by the

sexual partner; 79, 8% of the adhering group and 76, 0% of the non- adhering group never experienced rejection from their sexual partner (see Table 4.27 below)

Table 4.27: Rejection by sexual partner

Statement	Adherence (%)	
	No	Yes
Always	2,0	3,4
Sometimes	22,0	16,8
Never	76,0	79,8
Total	100	100

4.4.1.9 Turned away from clinic/hospital

When asked about being turned away from a clinic 0, 0% of the adhering group and 0, 8% of the non adhering group always experienced being turned away from a clinic, 5, 9% of the adhering group and 15, 7% of the non adhering group sometimes experiences being turned away form a clinic whereas 93, 3% of the adhering group and 84, 3% of the non adhering group never experienced being turned away from a clinic (see table 4.28 below)

Table 4.28: Being turned away from clinic/hospital

Statement	Adherence (%)	
	No	Yes
Always	0,0	0,8
Sometimes	15,7	5,9
Never	84,3	93,3
Total	100	100

4.4.1.10 Negative reaction of the family

When asked about experiencing a negative reaction from their families because of their HIV disclosure, 1, 6% of the adhering group and 1, 9% of the non-

adhering group said they always experienced negative reactions; 29, 5% of the adhering group and 42, 3% of the non-adhering group sometimes experienced negative reactions; whereas 68, 9% of the adhering group and 55, 8% of the non- adhering group never experienced negative reactions from their families. The p-value is 0.250 (see Table 4.29 below).

Table 4.29: Negative reaction of family

Statement	Adherence (%)	
	No	Yes
Always	1,9	1,6
Sometimes	42,3	29,5
Never	55,8	68,9
Total	100	100
Pearson chi-square p value = 0.250		

4.4.1.11 Participating in sports

When asked about being prevented from participating in sports or other recreational activities, 1, 7% of the adhering and 1, 9% of the non -adhering group always experienced being prevented from participating; 18, 3% of the adhering group and 23, 1 % of the non- adhering group sometimes experienced being prevented; whereas 80, 0% of the adhering group and 75, 0% of the non-adhering group never experienced being prevented from participating in sports (see Table 4.30 below).

Table 4.30: Prevention from participating in sports

Statement	Adherence (%)	
	No	Yes
Always	1,9	1,7
Sometimes	23,1	18,3
Never	75,0	80,0
Total	100	100

4.4.2 Attitude of people living with HIV/AIDS (Agree or disagree with the statements)

4.4.2.1 Difficulty in telling other people

When asked about difficulty in telling other people about their HIV status, 7, 4% of the adhering and 19, 2% of the non- adhering group strongly agreed that it was difficult to tell people about their HIV status; 43, 4% of the adhering group and 51, 9 % of the non- adhering group agreed; 23,8 % of the adhering and 11, 5% of the non-adhering group were neutral; whereas 23, 8% of the adhering group and 15, 4% of the non-adhering disagreed; and 3, 3% of the adhering group and 1, 9% of the non- adhering group strongly disagreed with telling other people(see table 4.31).

Table 4.31: Difficulty in telling people

Statement	Adherence (%)	
	No	Yes
Strongly Agree	19, 2	7, 4
Agree	51, 9	43, 4
Neutral	11, 5	22, 1
Disagree	15, 4	23, 8
Strongly disagree	1, 9	3, 3
Total	100	100

4.4.2.2 Feeling dirty about being HIV positive

When asked about feeling dirty about being HIV positive, 0, 8% of the adhering and 1, 9% of the non- adhering group strongly agreed that they feel guilty about being HIV positive; 23 ,1% of the adhering group and 17 ,3 % of the non-adhering group agreed; 24, 0 % of the adhering and 32 ,7% were neutral; whereas 43, 8% of the adhering group and 28, 8% disagreed; and 8,3% of the adhering group and 19, 2% of the non -adhering group strongly disagreed (see Table 4.32 below).

Table 4.32: Being HIV positive

Statement	Adherence (%)	
	No	Yes
Strongly Agree	1, 9	0, 8
Agree	17, 3	23, 1
Neutral	32, 7	24, 0
Disagree	28, 8	43, 8
Strongly disagree	19, 2	8, 3
Total	100	100

4.4.2.3 Guilty that they are HIV positive

When asked whether they feel guilty that they are HIV positive, 3, 3% of the adhering and 2, 0% of the non- adhering group strongly agreed that they feel guilty that they are HIV positive; and 22, 3% of the adhering group and 27, 5% of the non -adhering group agreed; 24, 0 % of the adhering and 32, 7% of the non-adhering group were neutral. However 43, 8% of the adhering group and 28, 85 of the non- adhering group disagreed and 3, 3% of the adhering group and 1, 9% of the non- adhering group strongly disagreed (see Table 4.33 below).

Table 4.33: Feeling guilty

Statement	Adherence (%)	
	No	Yes
Strongly Agree	2.0	3.3
Agree	27.5	22.3
Neutral	23.5	24.8
Disagree	31.4	43.0
Strongly disagree	15.7	6.6
Total	100	100

4.4.2.4 Ashamed that they are HIV positive

When asked about being ashamed that they are HIV positive, 5 ,8% of the adhering and 7, 8% of the non- adhering group strongly agreed that they are ashamed that they are HIV positive; 36, 7% of the adhering group and 29, 4% of the non- adhering group agreed; 25, 8% of the adhering and 41, 2% of the non-adhering group were neutral. However 25, 0% of the adhering group and 19, 6% of the non -adhering group disagreed; and 6, 7% of the adhering group and 2, 0% of the non- adhering group strongly disagreed (see Table 4.34).

Table 4.34: Ashamed about being HIV positive

Statement	Adherence (%)	
	No	Yes
Strongly Agree	7.8	5.8
Agree	29.4	36.7
Neutral	41.2	25.8
Disagree	19.6	25.0
Strongly disagree	2.0	6.7
Total	100	100

4.4.2.5 Feeling worthless because of their HIV status

When asked about feeling worthless because of their HIV status, 4, 1% of the adhering and 9, 6% of the non -adhering group strongly agreed that they feel worthless because they are HIV positive; 23, 1% of the adhering group and 19, 2% of the non -adhering group agreed; 24, 8 % of the adhering and 26, 9% of the non-adhering group were neutral. However 34, 7% of the adhering group and 34, 6% of the non- adhering group disagreed; and 13, 2% of the adhering group and 9, 6% of the non -adhering group strongly disagreed (see Table 4.35 below).

Table 4.35: Worthless because of being HIV positive

Statement	Adherence (%)	
	No	Yes
Strongly Agree	9.6	4.1
Agree	19.2	23.1
Neutral	26.9	24.8
Disagree	34.6	34.7
Strongly disagree	9.6	13.2
Total	100	100

4.4.2.6 Feel it is their fault that they are HIV positive

When asked about whether they feel it is their fault that they are HIV positive, 5, 8% of the adhering and 3, 8% of the non- adhering group strongly agreed that they feel that it is their fault that they are HIV positive; 24, 0% of the adhering group and 19, 2% of the non- adhering group agreed; and 22, 3 % of the adhering and 25, 0% of the non-adhering group were neutral. However 33, 1% of the adhering group and 32, 7% of the non -adhering group disagreed; and 16, 2% of the adhering group and 19, 2% of the non-adhering group strongly disagreed (see Table 4.36 below).

Table 4.36: Fault that I am HIV positive

Statement	Adherence (%)	
	No	Yes
Strongly Agree	3.8	5.8
Agree	19.2	24.0
Neutral	25.0	22.3
Disagree	32.7	33.1
Strongly disagree	19.2	14.9
Total	100	100

4.4.2.7 Hiding their status from others

When asked about hiding their status from others, 9, 8% of the adhering and 13, 5% of the non- adhering group strongly agreed that they hide their HIV status from others; 32, 0% of the adhering group and 44, 2% of the non -adhering group agreed; and 30, 3 % of the adhering and 23, 1% of the non-adhering group were neutral. However 23, 0% of the adhering group and 19, 2% of the non- adhering group disagreed and 4, 9% of the adhering group and none of the non adhering group strongly disagreed (see Table 4.37).

Table 4.37: Hiding HIV status

Statement	Adherence (%)	
	No	Yes
Strongly Agree	13.5	9.8
Agree	44.2	32.0
Neutral	23.1	30.3
Disagree	19.2	23.0
Strongly disagree	0.0	4.9
Total	100	100

4.4.2.8 Telling their sex partner about their HIV status

When asked about telling their sex partner about their HIV status, 19, 7% of the adhering and 26, 9% of the non -adhering group strongly agreed that that they can tell their sex partner that they are HIV positive; 47, 5% of the adhering group and 34, 6% of the non- adhering group agreed; and 8, 2 % of the adhering and 21, 2% of the non-adhering group were neutral. However 13, 1% of the adhering group and 9, 6% of the non -adhering group disagreed; and 0, 8% of the adhering group and 3, 8% of the non- adhering group strongly disagreed (see Table 4.38 below).

Table 4.38: Tell sex partner

Statement	Adherence (%)	
	No	Yes
Strongly Agree	30.8	30.3
Agree	34.6	47.5
Neutral	21.2	8.2
Disagree	9.6	13.1
Strongly disagree	3.8	0.8
Total	100	100

4.4.3 Stigma

4.4.3.1 Been hit or physically hurt

When asked whether they have ever been hit or physically hurt because of their status, 19, 7% of the adhering group and 26, 9% of the non- adhering group answered yes, whereas 80, 3% of the adhering and 73, 1% of the non adhering group answered no (see Table 4.39 below)

Table 4.39: Physically hurt or hit

	Adherence (%)	
	No	Yes
Yes	26.9	19.7
No	73.1	80.3
Total	100	100

4.4.3.2 Treated differently by a friend

When asked whether they were treated differently by a friend, 37, 7 % of the adhering group and 42, 3% of the non -adhering group answered yes. However 62, 3% of the adhering and 57, 7% of the non -adhering group answered no (see table 4.40 below).

Table 4.40: Treated differently by a friend

	Adherence (%)	
	No	Yes
Yes	42.3	37.7
No	57.7	62.3
Total	100	100

4.4.3.3 Treated differently by a family

When asked whether they had been treated differently by a family, 38, 5% of the adhering group and 42, 3% of the non -adhering group answered yes, whereas 61, 5% of the adhering and 57, 7% of the non -adhering group answered no (see Table 4.41 below).

Table 4.41: Treated differently by family

	Adherence (%)	
	No	Yes
Yes	42.3	38.5
No	57.7	61.5
Total	100	100

4.4.3.4 Friends and family stopped visiting

When asked whether their friends and family stopped visiting them, 19, 3% of the adhering group and 26, 0% of the non- adhering group answered yes, whereas 80, 7% of the adhering and 74, 0% of the non- adhering group answered no. The p-value was 0.334 (see table 4.42 below).

Table 4.42: Friends and family stopped visiting

	Adherence (%)	
	No	Yes
Yes	26.0	19.3
No	74.0	80.7
Total	100	100
Pearson chi-square p value = 0.334		

4.4.3.5 Have lost their place to stay

When asked whether they had lost their place to stay, 10, 7% of the adhering group and 17, 3% of the non -adhering group answered yes, whereas 89, 3% of the adhering and 82, 7% of the non- adhering group answered no (see Table 4.43 below).

Table 4.43: Lost a place to stay

	Adherence (%)	
	No	Yes
Yes	17.3	10.7
No	82.7	89.3
Total	100	100

4.4.3.6 They lost job

When asked whether they lost job 39, 3% of the adhering group and 21,2% of the non adhering group answered yes whereas 60,7% of the adhering and 78, 8% of the non adhering group answered no (see table 4.44 below).

Table 4.44: Lost job

	Adherence (%)	
	No	Yes
Yes	21.2	39.3
No	78.8	60.7
Total	100	100

4.4.3.7 Are there people they have not told about their HIV positive status?

When asked whether there are people they had not told about their HIV positive status because of fear of how they will react, 74, 6% of the adhering group and 76, 9% of the non -adhering group answered yes, whereas 24, 6% of the adhering and 23, 1% of the non- adhering group answered no (see Table 4.45 below).

Table 4.45: Told people about their HIV status

	Adherence (%)	
	No	Yes
Yes	76.9	74.6
No	23.1	24.6
Total	100	100

4.4.4 Disclosure

4.4.4.1 Disclosure of their status to their immediate friends

When asked about when they disclosed their status to their immediate friends, 3, 3% of the adhering group and 11, 5 % of the non- adhering group was not applicable, meaning that they did not have friends; 6, 6% of the adhering group and 13, 5% of the non- adhering group never disclosed, 3, 3% of the adhering group and 3, 8% of the non adhering group disclosed immediately; 3, 3% of the adhering group and 1, 9% of the non- adhering group disclosed within a day;

18,0% of the adhering group and 11, 5% of the non- adhering group disclosed after a week; 41, 8% of the adhering group and 23, 1% of the non- adhering group disclosed after a month; 15,6% of the adhering group and 21, 2% of the non- adhering group disclosed after a year; and 8, 2% of the adhering group and 13, 5% of the non -adhering group disclosed more than a year after learning about their HIV status (see Table 4.46).

Table 4.46: Disclosure to Immediate friend

	Adherence (%)	
	No	Yes
N/A	11,5%	3,3%
Never	13,5%	6,6%
Immediately	3,8%	3,3%
Within a day	1,9%	3,3%
A week	11,5%	18,0%
A month	23,1%	41,8%
A year	21,2%	15,6%
> 1 year	13,5%	8,2%
Total	100	100

4.4.4.2 Disclose their status to boyfriend or girlfriend

When asked about when they disclosed their status to their boyfriends or girlfriends, 0, 8% of the adhering group and 4, 4 % of the non- adhering group was not applicable, meaning that they had no boyfriends or girlfriends;1, 7% of the adhering group and 11, 1% of the non- adhering group never disclosed; 15, 0% of the adhering group and 24, 4% of the non-adhering group disclosed immediately; 10, 8% of the adhering group and 13, 3% of the non-adhering group disclosed within a day; 19, 2% of the adhering group and 15, 6% of the non-adhering group disclosed after a week; 35, 0% of the adhering group and 11, 1% of the non -adhering group disclosed after a month; 11, 7% of the adhering group and 11, 1% of the non-adhering group disclosed after a year; and 5, 8% of the

adhering group and 8, 9% of the non- adhering group disclosed after more than a year of knowing their status(see table 4,47).

Table 4.47: Disclosure to Boyfriend/girlfriend

	Adherence (%)	
	No	Yes
N/A	2.1	4.2
Never	10.4	0.0
Immediately	10.4	2.5
Within a day	14.6	4.2
A week	12.5	10.9
A month	27.1	40.3
A year	12.5	25.2
> 1 year	10.4	12.6
Total	100	100

4.4.4.3 Disclosure of their status to their husband/wife

When asked about when they disclosed their status to their husbands/wives none of the adhering group and 4, 4 % of the non- adhering group did not have husbands/wives; 2, 5% of the adhering group and 2, 2% of the non-adhering group never disclosed, 29, 7% of the adhering group and 35, 6% of the non-adhering group disclosed immediately; 28, 0% of the adhering group and 28, 9% of the non-adhering group disclosed within a day; 20, 3% of the adhering group and 13, 3% of the non-adhering group disclosed after a week;12, 7% of the adhering group and 8, 9% of the non-adhering group disclosed after a month; 3, 4% of the adhering group and 2, 2% of the non-adhering group disclosed after a year; and 3, 4% of the adhering group and 4, 4% of the non-adhering group disclosed more than a year after knowing about their status (see Table 4.48).

Table 4.48: Disclosure to Husbands/Wives

	Adherence (%)	
	No	Yes
N/A	0.0	0.9
Never	6.0	0.9
Immediately	30.0	40.5
Within a day	26.0	21.6
A week	8.0	7.8
A month	10.0	13.8
A year	10.0	12.1
> 1 year	10.0	2.6
Total	100	100

4.4.4.4 Disclosure of their status to their brothers or sisters

When asked about when they disclosed their status to their brothers or sisters 4, 2% of the adhering group and 2, 1 % of the non adhering group was not applicable, meaning they did not have brothers or sisters; none the adhering group and 10, 4% of the non-adhering group never disclosed; 2, 5% of the adhering group and 10, 4% of the non adhering group disclosed immediately; 4, 2% of the adhering group and 14, 6% of the non-adhering group disclosed within a day; 10, 9% of the adhering group and 12, 5% of the non-adhering group disclosed after a week; 40,3% of the adhering group and 27, 1% of the non-adhering group disclosed after a month; 25, 2% of the adhering group and 12, 5% of the non-adhering group disclosed after a year; and 12, 6% of the adhering group and 10, 4% of the non-adhering group disclosed more than a year after knowing about their status (see Table 4.49).

Table 4.49: Disclosure to Brothers/ Sisters

	Adherence (%)	
	No	Yes
N/A	24.5	29.1
Never	18.4	1.7
Immediately	4.1	0.9
Within a day	0.0	3.4
A week	0.0	1.7
A month	14.3	13.7
A year	14.3	25.6
> 1 year	24.5	23.9
Total	100	100

4.4.4.5 Disclosure of their status to their parents

When asked about when they disclosed their status to their parents; 0, 9% of the adhering group and none of the non-adhering group was not applicable, meaning that they had no parents; 0, 9% of the adhering group and 6, 0% of the non-adhering group never disclosed; 40, 5% of the adhering group and 30, 0% of the non -adhering group disclosed immediately; 21, 6% of the adhering group and 26, 0% of the non-adhering group disclosed within a day; 7, 8% of the adhering group and 8, 0% of the non-adhering group disclosed after a week; 13, 8% of the adhering group and 10, 0% of the non-adhering group disclosed after a month; 12, 1% of the adhering group and 10, 0% of the non-adhering group disclosed after a year; and 2, 6% of the adhering group and 10, 0% of the non-adhering group disclosed more than a year after knowing about their status (see Table 4.50).

Table 4.50: Disclosure to Parents

	Adherence (%)	
	No	Yes
N/A	0, 0	0, 9
Never	6, 0	0, 9
Immediately	30, 0	40, 5
Within a day	26, 0	21, 6
A week	8, 0	7, 8
A month	10, 0	13, 8
A year	10, 0	12, 1
> 1 year	10, 0	2, 6
Total	100	100

4.4.4.6 Disclosure of their status to their relatives

When asked about when they disclosed their status to their relatives, 29, 1% of the adhering group and 24, 5% of the non-adhering group was not applicable, meaning that they had no relatives; 1, 7% of the adhering group and 18, 4% of the non-adhering group never disclosed; 0, 9% of the adhering group and 4, 1% of the non-adhering group disclosed immediately; 3, 4% of the adhering group and none of the non-adhering group disclosed within a day; 1, 7% of the adhering group and none of the non adhering group disclosed after a week; 13, 7% of the adhering group and 14, 3% of the no- adhering group disclosed after a month; 25,6% of the adhering group and 14, 3% of the non-adhering group disclosed after a year; and 23, 9% of the adhering group and 24, 5% of the non-adhering group disclosed after longer than a year (see table 4.51).

Table 4.51: Disclosure to Relatives

	Adherence (%)	
	No	Yes
N/A	36.5	47.9
Never	21.2	3.3
Immediately	1.9	0.0
Within a day	0.0	2.5
A week	1.9	0.8
A month	3.8	5.0
A year	3.8	14.9
> 1 year	30.8	25.6
Total	100	100

4.4.4.7 Disclosure of their status to their sex partner

When asked about when they disclosed their status to their sex partner, 6, 9% of the adhering group and 12, 8 % of the non-adhering group was not applicable, meaning that they had no sex partner; 1, 7% of the adhering group and 17, 0% of the non-adhering group never disclosed; 6, 9% of the adhering group and 10, 6% of the non-adhering group disclosed immediately; 4, 3% of the adhering group and 2, 1% of the non-adhering group disclosed within a day; 9, 5% of the adhering group and none of the non-adhering group disclosed after a week; 28, 4% of the adhering group and 23, 4% of the non-adhering group disclosed after a month; 31, 0% of the adhering group and 17, 0% of the non-adhering group disclosed after a year; and 11, 2% of the adhering group and 17, 0% of the non adhering group disclosed more than a year after finding out about their status (see Table 4.52).

Table 4.52: Disclosure to Sex partner

	Adherence (%)	
	No	Yes
N/A	55.8	58.2
Never	23.1	3.3
Immediately	0.0	1.6
Within a day	1.9	0.0
A week	5.8	4.9
A month	13.5	32.0
A year	0,0	0,0
> 1 year	0,0	0,0
Total	100	100

4.4.4.8 Disclosure of their status to their friends

When asked about when they disclosed their status to their friends, 21, 4% of the adhering group and 13, 7 % of the non-adhering group was not applicable, 2, 6% of the adhering group and 19, 6% of the non-adhering group never disclosed; 0, 9% of the adhering group and 2, 0% of the non-adhering group disclosed immediately; 1, 7% of the adhering group and 3, 9% of the non-adhering group disclosed within a day; 2, 6% of the adhering group and 5, 9% of the non-adhering group disclosed after a week, 14, 5% of the adhering group and 11, 8% of the non-adhering group disclosed after a month; 23, 1% of the adhering group and 25, 5% of the non-adhering group disclosed after a year; and 33, 3% of the adhering group and 17, 6% of the non-adhering group disclosed more than a year after finding out about their status (see Table 4.53).

Table 4.53: Disclosure to Friends

	Adherence (%)	
	No	Yes
N/A	38.5	38.8
Never	11.5	1.7
Immediately	11.5	0.8
Within a day	1.9	8.3
A week	7.7	14.0
A month	11.5	20.7
A year	5.8	9.1
> 1 year	11.5	6.6
Total	100	100

4.4.4.9 Disclosure of their status to colleagues at school or work place

When asked about when they disclosed their status to colleagues at school or workplace, 47, 9% of the adhering group and 36, 5 % of the non-adhering group was not applicable; 3, 3% of the adhering group and 21, 2% of the non-adhering group never disclosed; none of the adhering group and 1, 9% of the non-adhering group disclosed immediately; 2, 5% of the adhering group and none of the non-adhering group disclosed within a day; 0, 8% of the adhering group and 1, 9% of the non-adhering group disclosed after a week; 5, 0% of the adhering group and 3, 8% of the non-adhering group disclosed after a month; 14, 9% of the adhering group and 3, 8% of the non-adhering group disclosed after a year; and 25, 6% of the adhering group and 30, 8% of the non-adhering group disclosed more than a year after knowing about their status (see Table 4.54).

Table 4.54: Disclosure to Work or school colleagues

	Adherence (%)	
	No	Yes
N/A	36, 5	47, 9
Never	21, 2	3, 3
Immediately	1, 9	0, 0
Within a day	0, 0	2, 5
A week	1, 9	0, 8
A month	3, 8	5, 0
A year	3, 8	14, 9
> 1 year	30, 8	25, 6
Total	100	100

4.4.4.10 Disclosure of their status to the community

When asked about when they disclosed their status to the community, 58, 2% of the adhering group and 55, 8% of the non-adhering group was not applicable; 3, 3% of the adhering group and 23, 1% of the non-adhering group never disclosed; 1, 6% of the adhering group and none of the non-adhering group disclosed within a day; none of the adhering group and 1, 9% of the non-adhering group disclosed after a week; 4, 9% of the adhering group and 5, 8% of the non-adhering group disclosed after a year; and 32, 0% of the adhering group and 13, 5% of the non adhering group disclosed more than a year after diagnosis (see Table 4.55).

Table 4.55: Disclosure to Community

	Adherence (%)	
	No	Yes
N/A	55, 8	58, 2
Never	23, 1	3, 3
Within a day	0, 0	1, 6
A week	1, 9	0, 0
A year	5, 8	4, 9
> 1 year	13, 5	32, 0
Total	100	100

4.4.4 11 Disclosure to the spiritual or religious healer

When asked about when they disclosed their HIV status to the spiritual or religious healer; 38, 8% of the adhering group and 38. 5 % of the non-adhering group was not applicable; 1, 7% of the adhering group and 11, 5% of the non-adhering group never disclosed; 0, 8% of the adhering group and 11, 5% of the non-adhering group disclosed immediately; 8, 3% of the adhering group and 1, 9% of the non-adhering group disclosed within a day; 14, 0% of the adhering group and 7, 7% of the non-adhering group disclosed after a week; 20, 7% of the adhering group and 11, 5% of the non-adhering group disclosed after a month; 9, 1% of the adhering group and 5, 8% of the non-adhering group disclosed after a year; and 6, 6% of the adhering group and 11, 5% of the non-adhering group disclosed more than a year after finding out about their status (see Table 4.56).

Table 4.56: Disclosure to Spiritual or religious healer

	Adherence (%)	
	No	Yes
N/A	38, 5	38, 8
Never	11, 5	1, 7
Immediately	11, 5	0, 8
Within a day	1, 9	8, 3
A week	7, 7	14, 0
A month	11, 5	20, 7
A year	5, 8	9, 1
> 1 year	11, 5	6, 6
Total	100	100

4.4.4.12 Disclosure of their status to the nurse or doctor

When asked about when they disclosed their status to the nurse or doctor, 2, 5% of the adhering group and 5, 8 % of the non-adhering group was not applicable; none of the adhering group and 1, 9% of the non adhering group never disclosed; 67, 2% of the adhering group and 46, 2% of the non-adhering group disclosed immediately; 25, 4% of the adhering group and 36, 5% of the non-adhering group disclosed within a day; 1, 6% of the adhering group and 7, 7% of the non-adhering group disclosed after a week; 0, 8% of the adhering group and 1, 9% of the non-adhering group disclosed after a month; 0, 8% of the adhering group and 0, 0% of the non-adhering group disclosed after a year; and 1, 6% of the adhering group and none of the non-adhering group disclosed more than a year after knowing their status (see Table 4.57).

Table 4.57: Disclosure to the Nurse/doctor

	Adherence (%)	
	No	Yes
N/A	5, 8	2, 5
Never	1, 9	0, 0
Immediately	46, 2	67, 2
Within a day	36, 5	25, 4
A week	7, 7	1, 6
A month	1, 9	0, 8
A year	0, 0	0, 8
> 1 year	0, 0	1, 6
Total	100	100

4.4.4.13 Disclosure of their status to other persons living with HIV

When asked about when they disclosed their status to other persons living with HIV, 2,5 % of the adhering group and 1, 9 % of the non-adhering group was not applicable; none of the adhering group and 3, 8% of the non-adhering group never disclosed; 19, 7% of the adhering group and 21, 2% of the non-adhering group disclosed immediately; 24, 6% of the adhering group and 11, 5% of the non -adhering group disclosed within a day; 23, 8% of the adhering group and 19, 2% of the non-adhering group disclosed after a week; 18, 0% of the adhering group and 23, 1% of the non-adhering group disclosed after a month; 7, 4% of the adhering group and 9, 6% of the non-adhering group disclosed after a year; and 4, 1% of the adhering group and 9, 6% of the non-adhering group disclosed more than a year after diagnosis (see Table 4.58).

Table 4.58: Disclosure to other Persons living with HIV

	Adherence (%)	
	No	Yes
N/A	1, 9	2, 5
Never	3, 8	0, 0
Immediately	21, 2	19, 7
Within a day	11, 5	24, 6
A week	19, 2	23, 8
A month	23, 1	18, 0
A year	9, 6	7, 4
> 1 year	9, 6	4, 1
Total	100	100

4.4.4.14 Satisfaction with the overall support they get from their family

When asked about how satisfied they were with the general support from the family, 5, 8% of the adhering group and 5, 8 % of the non-adhering group was dissatisfied; 19, 2% of the adhering group and 17, 3% of the non-adhering group were not quite satisfied; 16, 7% of the adhering group and 19, 2% of the non-adhering group were moderately satisfied; whereas 58, 1% of the adhering group and 57, 7% of the non-adhering group were very satisfied. The p-value was 0, 976 (see Table 4.59).

Table 4.59: General satisfaction with the overall support

	Adherence (%)	
	No	Yes
Dissatisfied	5, 8	5, 8
Not quite	17, 3	19, 2
Moderately	19, 2	16, 7
Very satisfied	57, 7	58, 3
Total	100	100
Pearson chi-square p value = 0.976		

4.4.4.15 Mean total for adhering and non-adhering groups

For rejection total the mean for adhering group was 2, 52 and for the non-adhering group was 2, 42. For stigma total, the mean for the adhering group was 28, 27 and for non-adhering group was 29, 84; whereas for attitude, the mean for the adhering group was 24, 60 and for non-adhering group was 25, 41. (see Table 4.60).

Table 4.60: Mean totals

	Adherence	N	Mean
Rejection tot	Yes	52	2,52
	No	122	2,42
Stigma tot	Yes	52	28,27
	No	122	29,84
Attitude tot	Yes	52	24,60
	No	122	25,41

CHAPTER 5: DISCUSSION, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

5. 1 DISCUSSIONS

This report describes the findings of the study that explored the role of family support and HIV/AIDS stigma on adherence and non-adherence to ARVs. The study used quantitative methods. The aim of the study was to establish the influence of HIV and AIDS stigma and family support on adherence and non-adherence to antiretroviral therapy at Nzhelele area in the Vhembe District, Limpopo Province, South Africa. The discussion integrates the literature with the results from the study.

5.1.1 Reasons for adherence and non adherence

In most studies, adherence refers solely to dose adherence, but successful treatment with ART also includes adherence to scheduling (Alemayehu et al., 2008). In this study, the researcher looked into the reasons for adherence and non-adherence and the role of family support and HIV/AIDS stigma on ART.

On the one hand, the reasons cited by the participants for missing their doses were the social grant; forgetting; side effects; and stigma (see Table 4.16 on page 22). Similar results were also reported in Addis Ababa by Alemayehu et al (2008). These reasons should be assessed for an individual patient and appropriate adherence-enhancing intervention should be undertaken. In this case, adherence counselling might incorporate strategies like: the use of memory aids; pill box count; and alarm clocks as reminders: Furthermore, there is also a need to educate and inform patients about the side effects of the ARVs and the reasons for taking medications were that, they wanted to feel better, to increase the CD4 count and they feared of death (see Table 4.17 on page 22). This study shows that patients have a range of reasons for failing to adhere to their antiretroviral therapy and reasons for adhering.

5.1.2 Social support, stigma and disclosure

Adherence is usually most effective if the patient has a stable relationship with family or friends who can offer social support, practical and emotional support (Evian, 2003:97)

In the present study the majority of the participants 40, 5% of the adhering group disclosed immediately to husbands/wife and parents (see table 4.48) this finding agrees with the findings of Martinson et al (2002), where it was indicated that many treatment programmes encouraged disclosure to at least one family member or friend as disclosure is seen to have a positive impact on adherence.

Disclosure and stigma seem to be different sides of the same coin. On the one hand disclosure may cost the individual their job, social support and their family but it differed with the findings of this study since the majority of the participants never experienced negative reaction from the family after disclosure and the p-value was 0.250 (see table 4.29) and it indicated that the association between adherence, non-adherence and negative reaction does exit and therefore there is no significant difference. On the other hand, a substantial number of ARV users who had disclosed were receiving support from family members. This support included emotional/psychological support, financial support, physical care and support, as well as reminders to ensure that they take their medications on time (see table 4.19). This agrees with the findings by Evian (2003) where it was indicated that adherence is usually most effective if the patient has stable relationships with the family or friends who can offer social, practical and emotional support and the majority of the participants were very satisfied with the overall support they got from their family and the p-value was 0,976 which indicated that there is no significant difference between adhering and non adhering group (table 4.59).

Lack of social or family support and fear of stigmatisation are generally associated with poor adherence (Forgarty et al., 2002). In this study, the level of support from friends and family was greater than expected when compared to the literature; participants who disclosed their HIV status generally received support from their family and friends (see table 24)**.** This is strong evidence that people are becoming more acquitted with HIV.

A study that was carried out by rowel et al. (2005) discovered that some patients put more trust in traditional healers because they are supposed to heal HIV, while Western medicine only slows the process down. In contrary to the findings of my study, it was observed that most of the participants in this study were knowledgeable bout the importance of not mixing ARVs with traditional medications. Only 12 (70, 6%) of participants were given by traditional healers were as 5 (29, 4%) were given by the prophet (see table 4.14).

The mean for rejection total between the adhering and non-adhering group showed no statistical significance difference, stigma total between the adhering and non-adhering group also showed no statistical significance difference and lastly the attitude total between adhering and non-adhering group also indicated that there was no statistical significance difference between the mean (table 60 above).

5.2 CONCLUSION

The level of adherence found in this study seems to be encouraging. The findings indicated various reasons for adherence and non-adherence to ARVs. The reasons should be assessed for individual patients and appropriate adherence-enhancing intervention should be undertaken. Finally, the results indicated that support can improve adherence to therapy and patients can only receive support if they reveal their HIV positive status. Adherence is a process

not a single event. Therefore adherence to medication is the first important factor to be addressed when planning HAART services.

5.3 LIMITATIONS

Limitations of this study are as follows:

- The findings of this study must be interpreted in the light of its limitations, as the study was conducted at a single site. The findings may not be generalizable to other clinical settings.
- The measurement of adherence is only based on patients` reports of missed doses and scheduling instructions by ARV users. This may be subject to social desirability and recall biases. Literature suggests that patients tend to overestimate adherence (Chesney, 2000).

5.4 RECOMENDATIONS

- Sensitize the community on the availability of treatment and the importance of adherence. As stigma is reduced, it could also help to reduce discrimination and encourage more people to disclose their HIV status as stigma is reduced;
- With regard to policy makers, the researcher recommends that the initial adherence assessment and preparation should include a discussion on the sources of social support for the individual patient and an attempt should be made to come up with possible solutions prior to starting HAART;
- Enlisting support to help patients take their medications correctly, from the family, community health workers, and people living with HIV and AIDS support groups should also be emphasized; and
- With regard to the medical staff, the researcher recommends that medical staff should make sure that no patient starts medication without going through three preparation visits or counselling to ensure readiness. This preparation counselling should include the following:
  - ✓ Explaining the goal of therapy and near perfect adherence;

- ✓ Monitoring the patient's medication (e.g., Pill counting.) where non-adherence is suspected;
- ✓ Informing patients of potential side effects, including severity and duration; and investigating coping mechanism;
- ✓ Providing adherence tools where necessary, such as a written calendar of medications and pill boxes; and
- ✓ As part of the intervention, establishment of a support group in which discussions on adherence are encouraged.

❖ The researcher also recommends that follow up studies be conducted.

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APPENDIX A

QUESTIOANNAIRE FOR PATIENTS

SECTION 1: DEMOGRAPHIC INFORMATION

1. What is your highest educational level?

a) Never attended school
b) 1-5 classes of school
c) 6-11 classes of school
d) Completed 12 classes of school
e) University level
f) Adult literacy

2. What is your current marital status?

a) Currently married
b) Cohabiting (Not married but living with partner)
c) Single (Never married)
d) Divorced or separated or widowed
e) Other

3. If divorced or separated or widowed, was the divorce/separation/ death of your partner due to HIV?

a) Yes
b) No
c) Don't` Know

4. How many children do you have?

a) Living……
b) Dead……..
c) None

5. Who do you currently live with at home?

a) By yourself
b) Partner/spouse
c) Parents
d) Siblings

e) Children
f) Relatives
g) Friends/Roommates
h) Other (specify)

6. Are you employed?

a) Yes
b) No

7. Where do you work?

a) Government office
b) Private sector
c) Self employed
d) NGO
e) Other (specify)…….

8. What is the reason for not working?

a) Don't want to work
b) Lost job due to HIV
c) Too sick to carry on working
d) Never worked
e) Other (specify)…….

SECTION 2: SOCIAL SUPPORT AND DISCLOSURE

1. How long have you known about your HIV status?

…….. (Year, Month)

2. Have you disclosed your HIV to anyone?

a) Yes
b) No

3. If yes, whom have you disclosed your status to?

a) Partner/spouse
b) Parent
c) Sibling
d) Other relatives

e) Friends
f) Neighbours/community members
g) Other (specify)

4. Do you receive support from your family?

a) Yes
b) No

5. What kind of support do you get from your family?

a) Emotional/psychological support
b) Financial support
c) Physical care and support
d) Other (specify)……..

6. In general, how satisfied are you with the overall support (help) you get from your family?

a) Not satisfied
b) Not quite satisfied
c) Moderately satisfied
d) Very satisfied

SECTION 3: CURRENT USE OF ARVs

1. How long have you been taking ARV medications?

……. (Years, Month)

2. Please could you tell us which ARV medications you are currently taking, the doses and frequency?

Drug name	Number of pills each time	*Number of times per day(Doses per day)*	*Number of pills to be taken per day*	

3. Are you taking any herbal/traditional medication?

a) Yes
b) No

4. How many medications are you taking in all (including ARV, traditional medications)?

……..(Number)

5. How many doses have you missed over the last 7 days?

a) None
b) One dose
c) Two doses
d) Three doses
e) Four or more doses

6. People may miss taking their medications for various reasons.

What are the reasons for not taking your medications (more than one answer if possible)

a) ……..
b) ……
c) ……
d) ……..

7. People take their medications for different reasons.

What are your reasons for taking your medications (more than one answer if possible)

a) .....
b) ……
c) ……..

d) ……..

8. Most ARV medications need to be taken on a schedule, such as 2 times a day. How closely did you follow your specific schedule over the last 4 days?

a) Never
b) Some of the time
c) Most of the time
d) All of the time

9. To what extent do your family members help you to remember to take your medications?

a) Never
b) Occasionally
c) Sometimes
d) Always

10. Were you informed about the life long duration of ARV treatment that you are to taking?

a) Yes
b) No

SECTION 4: PERSONAL EXPERIENCES OF LIVING WITH HIV/AIDS

1. How often have you experienced the following because of your HIV status?

Statement	**Always**	**Sometimes**	**Never**	**N/A**	**Don't know**	**Refuse**
a) not welcomed at community events	1	2	3	4	5	6
b) discriminated against at work	1	2	3	4	5	6
c)experience rejection by family	1	2	3	4	5	6
d)maltreatment from hospital/clinic	1	2	3	4	5	6
e)acceptance from	1	2	3	4	5	6

my family						
f)support from friends	1	2	3	4	5	6
g)rejection by friends	1	2	3	4	5	6
h)rejection by sexual partner	1	2	3	4		6
i) being turned away from a clinic	1	2	3	4	5	6
j)negative reaction of my family to my HIV disclosure	1	2	3	4	5	6
k)prevented from participating in sports or other recreational activities	1	2	3	4	5	6

2. How strongly do you agree or disagree with the following statement?

Statement	**Strongly Agree**	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**
a) It is difficult to tell other people about my HIV infection.	1	2	3	4	5
b) Being HIV positive makes me feel dirty.	1	2	3	4	5
c) I feel guilty that I am HIV positive.	1	2	3	4	5
d).I am ashamed that I am HIV positive.	1	2	3	4	5
e) I sometimes feel worthless because I	1	2	3	4	5

am HIV positive					
f) It is my fault that I am HIV positive.	1	2	3	4	5
g) I hide my HIV positive status from others	1	2	3	4	5
h) I feel certain that I can tell my sex partner I have HIV.	1	2	3	4	5

3. Indicate if you have experienced any of the following because you are HIV positive?

	Yes	**No**
a) ever been hit or physically hurt	1	2
b) treated differently by your friend	1	2
c) treated differently by your family	1	2
d) friends and family stopped visiting you	1	2
e) lost a place to stay	1	2
f) lost a job	1	2
g) Not telling certain people that I am HIV positive because I am afraid of their reaction?	1	2

4. From the time you first found out about your status when (if ever) did you disclose to the following?

Statement	**N/A**	**Never**	**Almost immediately**	**Within a day**	**A week**	**A Month**	**A year**	**Longer than a year**
a) Immediate friend	0	1	2	3	4	5	6	7
b)Boyfriend/	0	1	2	3	4	5	6	7

girlfriend								
c) Husband/ wife	0	1	2	3	4	5	6	7
d) Brother/ sister	0	1	2	3	4	5	6	7
e) Parent	0	1	2	3	4	5	6	7
f) Relatives	0	1	2	3	4	5	6	7
g) Sex partner	0	1	2	3	4	5	6	7
h) Friends	0	1	2	3	4	5	6	7
i) Work or school colleagues	0	1	2	3	4	5	6	7
j) Community	0	1	2	3	4	5	6	7
k) Spiritual or religious leader	0	1	2	3	4	5	6	7
l) Nurse/ doctor	0	1	2	3	4	5	6	7
m) Person living with HIV	0	1	2	3	4	5	6	7

5. Who in your family has been most supportive since you disclosed your status?

a) Father	1
b) Mother	2
c) Sister	3
d) Brother	4
e) Cousins	5
f) Aunt	6

g) Uncle	7
h) No one	8

End

Thank you for participating in this project. Should you have any comments, please feel free to write them below

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APPENDIX B

CONSENT FORM

TITTLE OF RESEARCH: Investigating the role of family support and HIV/AIDS stigma on adherence and non-adherence to antiretroviral therapy.

INVESTIGATOR: MATHIVHA TSHIFULARO MAUD, MPH Student

Before agreeing to participate in this research study, it is important that you read the following explanation of this study. This statement describes the purpose, procedures, benefits, risks, discomforts, and precautions of the programme. Also described is your right to withdraw from the study at any time.

Explanation of procedures

You are being asked to participate in a research project to establish the role of HIV/AIDS stigma and family support and reasons for adherence and non-adherence to ARVs.

The approach of the research is through the use of a questionnaire. It will take approximately 1 hour to complete the questionnaire. The questionnaire will be collected immediately after completion.

Risk and Discomfort

You will not be at physical or psychological risk and should experience no discomfort resulting from answering the questionnaire.

Benefits

There are no direct benefits for participating in this project. However, this research will determine the reasons for adherence and non-adherence to ARVs and the role of HIV/AIDS stigma and family support. It will also provide and contribute to the on-going government strategies and policy implementation.

Participant's initials: _____

Confidentiality

All information gathered from the study will remain confidential. Your identity as a participant will not be disclosed to any unauthorized persons; only the researchers and the University of Limpopo (Turfloop Campus) ethics committee will have access to the research materials. Any references to your identity that would compromise your anonymity will be removed or disguised prior to the preparation of the research reports and publications.

Withdrawal

Participation in this study is voluntary; refusal to participate will involve no penalty You are free to withdraw consent and discontinue participation in this project.

Costs and /or payments to subject for participation in research

There will be no costs for participating in the research. In appreciation of your time given to this session, you will get a token of appreciation (negotiable).

Agreement

This agreement states that you have received a copy of this informed consent. Your signature below indicates that you agree to participate in this study.

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Signature of subject Date

Subject name (printed)

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Signature of researcher Date