

**KNOWLEDGE, ATTITUDES AND EXPERIENCES OF PEOPLE  
LIVING WITH HIV WHO ARE ON ANTIRETROVIRAL TREATMENT  
AT A PUBLIC HEALTH CLINIC IN LIMPOPO, SOUTH AFRICA**

**by**

**RODNEY AZWINNDINI MULELU**

submitted in partial fulfillment of the requirements for the degree of

**MASTER OF ARTS IN SOCIAL BEHAVIOUR STUDIES IN HIV AND AIDS**

at the

**UNIVERSITY OF SOUTH AFRICA**

**SUPERVISOR: MS. MARIE MATEE**

**15 AUGUST 2016**

## DECLARATION

I, Rodney Azwinndini Mulelu (Student No: 36219835) declare that **Knowledge, attitudes and experiences of people living with HIV who are on antiretroviral treatment at a public health clinic in Limpopo, South Africa** is my work and that all the sources used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

---

**R.A. Mulelu**

---

**Date**

## **DEDICATION**

This mini dissertation is dedicated to God, the creator of the universe, who has given me the opportunity to complete this study and to my fiancée Ms. Manaha Melina Moloto for her support.

## ACKNOWLEDGEMENTS

I would like to give thanks and acknowledge the following people for their support and encouragement:

- Ms. Elize Koen, my supervisor, for all she taught me and the support she has given me.
- Ms. Marie Matee, my supervisor, for all she taught me and the support she has given me.
- Dr. Silindiwe Sibanda, my online mentor, for all she taught me and the support she has given me.
- Mr. Leon Roets, the coordinator of the MA programme (Social Behavior Studies in HIV/AIDS) and my co-supervisor for his support during course work and research components of the degree.
- My family and friends for their encouragement and support. Special thanks to my fiancée Ms. Manaha Melina Moloto for her encouragement to register again at UNISA.
- Ms. Latif Shamila and the Limpopo Department of Health Research Committee for their approval of my research.
- The Management of the Witpoort Hospital for facilitating my access to the Wellness Clinic where the data were collected.
- Ms. Shibe Nailana and Mr. Patrick Sello, the dieticians at Witpoort Hospital for their assistance and support.

I thank you all, love you. God Bless you.

## **ABSTRACT**

The researcher investigated the knowledge, attitudes and experiences of people living with the Human Immunodeficiency Virus (HIV) towards antiretroviral treatment (ART) and who are accessing antiretroviral treatment at a public health clinic in Limpopo, South Africa. A qualitative method was used. The research findings revealed five themes: experiences, social support, knowledge, attitudes, unemployment and economic themes of the study. Factors reported influencing optimum adherence were the inability of the patients to take medication at work, laziness of the patients to collect medication, unemployment, economic hardship, poverty and lack of knowledge of employers regarding HIV/AIDS.

## **KEY CONCEPTS**

HIV/AIDS knowledge, HIV/AIDS attitude, People living with HIV, HIV/AIDS experiences, Adherence, Wellness clinic, antiretroviral treatment

<b>TABLE OF CONTENTS</b>	<b>PAGE</b>
DEDICATION	iii
ACKNOWLEDGEMENTS	iv
ABSTRACT	v
TABLE OF CONTENTS	vi
LIST OF TABLES	xi
LIST OF ACRONYMS AND ABBREVIATIONS	xii

## **CHAPTER 1: OVERVIEW OF THE STUDY**

1.1. INTRODUCTION	1
1.2. BACKGROUND OF THE STUDY	1
1.3. CONTEXTUALIZATION OF THE RESEARCH PROBLEM	4
1.4. MOTIVATION OF THE STUDY	5
1.5. PROBLEM STATEMENT	5
1.6. AIM OF THE STUDY	6
1.7. THE OBJECTIVES OF THE STUDY	6
1.8. ASSUMPTIONS	7
1.9. RESEARCH QUESTIONS	7
1.10. DEFINITION OF KEY CONCEPTS	7
1.10.1. Knowledge	7
1.10.2. Attitude	8
1.10.3. Experience	8
1.10.4. Antiretroviral Treatment (ART)	8
1.10.5. Human Immunodeficiency Virus (HIV)	8
1.10.6. Public Clinic	9

<b>TABLE OF CONTENTS (CONTINUED)</b>	<b>PAGE</b>
1.11. OUTLINE OF THE STUDY REPORT	9
1.12. CONCLUSION	10
 <b>CHAPTER 2: LITERATURE REVIEW</b>	
2.1. INTRODUCTION	11
2.2. HIV AND AIDS IN SOUTH AFRICA	11
2.3. HIV AND AIDS IN LIMPOPO PROVINCE	12
2.4. SOUTH AFRICA NATIONAL ART PROGRAMME	13
2.5. LEGAL FRAMEWORK INFORMING ANTIRETROVIRAL TREATMENT PROGRAMME	16
2.5.1. National Strategic Plan on HIV, AIDS, STI and TB (2012-2016)	16
2.5.2. National ART guidelines (2004 and 2015)	17
2.6. CHALLENGES REGARDING ANTIRETROVIRAL TREATMENT PROGRAMME IMPLEMENTATION	18
2.6.1. Linking and retention of patients to care	18
2.6.2. High levels of loss to follow up (LTFU) to antiretroviral treatment	19
2.7. BENEFITS OF THE SOUTH AFRICAN ART PROGRAMME	20
2.8. ADHERENCE TO ANTIRETROVIRAL TREATMENT	21
2.8.1. Importance of adherence	21
2.8.2. Nature of adherence	22
2.8.3. Challenges regarding adhering to Antiretroviral treatment	23
2.9. FACTORS FOR POOR ADHERENCE	25
2.9.1. Socio economic factors	25
2.9.2. General patient related factors	27
2.10. KNOWLEDGE, ATTITUDES AND EXPERIENCES REGARDING ANTIRETROVIRAL TREATMENT	29
2.10.1. Knowledge regarding Antiretroviral treatment	29
2.10.2. Attitudes towards Antiretroviral treatment	31
2.10.3. Experience of PLHIV on Antiretroviral treatment	31

<b>TABLE OF CONTENTS (CONTINUED)</b>	<b>PAGE</b>
2.11. THEORETICAL FRAMEWORK ADOPTED	32
2.11.1. Information, Motivation and Behavior Skills Model	33
2.12. SUMMARY	34
2.1.3. CONCLUSION	36
 <b>CHAPTER 3: RESEARCH METHODOLOGY</b>	
3.1. INTRODUCTION	37
3.2. RESEARCH DESIGN	37
3.3. SAMPLING STRATEGIES	38
3.3.1. Sampling strategy	38
3.4. INSTRUMENTATION	39
3.4.1. Development of the interview schedule for the participants	39
3.5. DATA GENERATION STRATEGIES	41
3.5.1. Face-to-face interviews	41
3.6. ACCESS NEGOTIATION AND ETHICAL CONDUCT	42
3.6.1. Informed consent	42
3.6.2. Voluntary participation	43
3.6.3. Confidentiality	43
3.7. TRUSTWORTHINESS OF DATA GATHERING	43
3.8. DATA ANALYSIS	44
3.8.1. Data analysis strategies for the study	44
3.9. THE INFERENCE PROCESS: SYNTHESING THE DATA	44
3.10. CONCLUSION	44
 <b>CHAPTER 4: RESEARCH FINDINGS, ANALYSIS AND INTERPRETATION</b>	
4.1. INTRODUCTION	45
4.2. BACKGROUND CHARACTERISTICS OF THE PARTICIPANTS	45
4.3. RESULTS OF THE FACE-TO-FACE INTERVIEWS	50
4.3.1. Identified main themes of the interviews	50



<b>TABLE OF CONTENTS (CONTINUED)</b>	<b>PAGE</b>
4.3.2. THEME 1: EXPERIENCES OF THE PARTICIPANTS TO ANTIRETROVIRAL TREATMENT	54
4.3.2.1. Life before start of Antiretroviral treatment	54
4.3.2.2. Missing doses	56
4.3.2.3. Poverty and hunger	57
4.3.2.4. Benefits of being on Antiretroviral treatment	58
4.3.3. THEME 2: SOCIAL SUPPORT	60
4.3.4. THEME 3: KNOWLEDGE ABOUT ANTIRETROVIRAL TREATMENT	63
4.3.5. THEME 4: ATTITUDES TOWARDS ANTIRETROVIRAL	64
4.3.6. THEME 5: UNEMPLOYMENT AND ECONOMIC SUPPORT	66
4.4. SYNTHESIS OF THE STUDY	67
4.5. CONCLUSION	68
 <b>CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS</b>	
5.1. INTRODUCTION	69
5.2. SUMMARY OF FINDINGS ACCORDING TO OBJECTIVES	69
5.2.1. OBJECTIVE 1: KNOWLEDGE OF PEOPLE LIVING WITH HIV TOWARDS ANTIRETROVIRAL TREATMENT	69
5.2.2. OBJECTIVE 2: ATTITUDES OF PEOPLE LIVING WITH HIV TOWARDS ANTIRETROVIRAL TREATMENT	70
5.2.3. OBJECTIVE 3: EXPERIENCES OF PEOPLE LIVING WITH HIV ON ANTIRETROVIRAL TREATMENT	71
5.2.4. OBJECTIVE 4: ECONOMIC FACTORS THAT SUPPORT PEOPLE LIVING WITH HIV	72
5.2.5. OBJECTIVE 5: SOCIAL FACTORS THAT SUPPORT PEOPLE LIVING WITH HIV	73
5.3. WEAKNESSES AND STRENGTH OF THE STUDY	74
5.3.1. Weaknesses of the study	74
5.3.2. Strengths of the study	74

<b>TABLE OF CONTENTS (CONTINUED)</b>	<b>PAGE</b>
5.4. RECOMMENDATIONS FOR FURTHER RESEARCH	75
5.5. RECOMMENDATIONS STEMMING FROM THE FINDINGS	75
5.6. CONCLUSION	76
LIST OF SOURCES	77
ANNEXURE A: INFORMED CONSENT FOR PARTICIPANTS	89
ANNEXURE B: INTERVIEW GUIDE FOR PARTICIPANTS	90
ANNEXURE C: REQUEST PERMISSION TO CONDUCT RESEARCH: LDOH	94
ANNEXURE D: REQUEST PERMISSION TO CONDUCT RESEARCH: UNISA	95
ANNEXURE E: APPROVAL TO CONDUCT RESEARCH:UNISA	96
ANNEXURE F: APPROVAL TO CONDUCT RESEARCH:LDOH	97

<b>LIST OF TABLES</b>	<b>PAGE</b>
TABLE 4.1: AGE OF THE PARTICIPANTS	46
TABLE 4.2. GENDER OF THE PARTICIPANTS	46
TABLE 4.3. MARITAL STATUS FOR THE PARTICIPANTS	47
TABLE 4.4. EDUCATIONAL LEVEL OF THE PARTICIPANTS	47
TABLE 4.5. PLACE OF RESIDENCE OF THE PARTICIPANTS	48
TABLE 4.6. PLACE OF RESIDENCE WETHER URBAN OR RURAL AREA OF THE PARTICIPANTS	48
TABLE 4.7: HOME LANGUAGE OF THE PARTICIPANTS	46
TABLE 4.8. EMPLOYMENT STATUS OF THE PARTICIPANTS	48
TABLE 4.9. MAIN SOURCE OF INCOME OF THE PARTICIPANTS	49
TABLE 4.10. THEMES EMERGED FROM INTERVIEWS	51

## **LIST OF ACRONYMS AND ABBREVIATIONS**

AIDS	ACQUIRED IMMUNO DEFICIENCY VIRUS
ART	ANTIRETROVIRAL TREATMENT
ARV	ANTIRETROVIRAL
FDC	FIXED DOSE COMBINATION
HCW	HEALTH CARE WORKERS
HCT	HIV COUNSELLING AND TESTING
HIV	HUMAN IMMUNE VIRUS
HSRC	HUMAN SCIENCE RESEARCH COUNCIL
IMB	INFORMATION MOTIVATION BEHAVIOUR MODEL
IRIN	INTEGRATED REGIONAL INFORMATION NETWORKS
LTFU	LOST TO FOLLOW UP
LDOH	LIMPOPO DEPARTMENT OF HEALTH
MTCT	MOTHER TO CHILD TRANSMISSION
NDOH	NATIONAL DEPARTMENT OF HEALTH
NSP	NATIONAL STRATEGIC PLAN
PLHIV	PEOPLE LIVING WITH HIV
PMTCT	PREVENTION OF MOTHER TO CHILD TRANSMISSION
SASSA	SOUTH AFRICAN SOCIAL SECURITY AGENCY
SSA	SUB-SAHARAN AFRICA
SA	SOUTH AFRICA
WHO	WORLD HEALTH ORGANISATION
UNAIDS	UNITED NATIONS AGENCY FOR INTERNATIONAL DEVELOPMENT/JOINT UNITED HIV AND AIDS PROGRAMME
UNISA	UNIVERSITY OF SOUTH AFRICA

## **CHAPTER 1**

### **OVERVIEW OF THE STUDY**

#### **1.1. INTRODUCTION**

This study investigates the knowledge, attitudes and experiences of people living with the Human Immune Virus (HIV) and who are on antiretroviral treatment (ART). This chapter presents a background to the study undertaken. It provides information on the focus area of the study and it outlines the research problem and the ARV roll-out programme initiated by the South African National Department of Health. In addition, it also outlines the aims and objectives of the study and the research questions to be answered by the findings. The definitions of key terms are provided in this chapter and a brief outline of the different chapters of this dissertation is given. It is anticipated that the findings and recommendations of the study would be shared with the Limpopo Provincial Health Senior Management, in-cooperated into training workshops and be shared with Health Care Workers (HCW) in the province.

#### **1.2. BACKGROUND TO THE STUDY**

The South African government recognizes that the country has a very high burden of infection, with an estimated 6.4 million people living with HIV by the end of 2012. (HSRC 2012). In addition, South Africa's landscape of the national HIV epidemic has improved dramatically since 2001. South Africa has reduced new HIV infections by 41% between 2001 and 2011 (UNAIDS 2012). However, as the South African government enters the final years of achieving the Millennium Development Goals in 2015, much remains to be done to reach the targets. A number of government interventions and strategies have been put in place over the years to reduce the HIV infection rates in the country. The programmes such as the HIV Counseling and Testing (HCT) awareness campaign established in 2010 (NDOH 2010), the increased call for condom use and distribution, HIV and sex education in all sectors of the society, and the medical male circumcision programmes were all aimed at reducing HIV infection.

According to the HSRC (2012), the launch of the national HIV counseling and testing (HCT) campaign in April 2010 resulted in a remarkable increase in the number of people accessing testing. It is further indicated by the HSRC (2012) that between 2008 and 2012, annual HIV testing increased from an estimated 19.9% to 37.5% among men, and from 28.7% to 52.6% among women. South Africa has the largest antiretroviral treatment (ART) roll-out programme in the world, achieving a 75% increase in HIV treatment services between 2009 and 2011 (UNAIDS 2012). By October 2012, over two million people were receiving ART, surpassing the country's universal access target of 80% in accordance with the 2010 World Health Organization (WHO) treatment guidelines and offering treatment to people with a CD4 count under 350 (WHO 2010).

According to the National Department of Health (NDOH), the government is committed to ensuring universal access to antiretroviral therapy in order to improve the quality of lives and the country outcomes (Jones, 2009). According to Saleh (2012), the national ART roll out programme for South Africa requires human resources, financial planning and monitoring and evaluation systems, as well as institutional capacities.

For ART to be able to attack and suppress viruses, patients must adhere to treatment for life. Not following instructions to take medication, collecting medication and not taking it and missing out on doses will lead to drug resistance and to the medication not to work (Abdool & Karim 2010). Keeping patients on an ART programme needs commitment from all stakeholders, patients, family, programme managers, wellness clinic staff and political leaders. Furthermore, optimal adherence to ART has the potential for turning an HIV infection from an acute illness to a manageable chronic disease such as Diabetes and Hypertension.

The South African national ART programme was conceived to reduce and meet the high burden of infection that the country experiences (NDOH 2014). South Africans hope for a good quality of life for people living with HIV and in need of ART when the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa was approved by the National Department of Health in 2003 (NDOH 2003).

The National Department of Health's antiretroviral treatment revised guidelines state that adults and adolescents are eligible for ART if they meet medical criteria and psychosocial considerations (NDOH 2015). Furthermore, it means that the patients should meet these criteria to be able to start the treatment; the patient should be psychologically and medically ready to start ART, because ART is not an emergency.

According to NDOH (2015:48) the eligibility criteria for ART initiation have been revised to increase access to treatment, with effect from 1<sup>st</sup> January 2015. The medical criteria include children under the age of 5 years old, Adolescents and Adults with CD4 of < 500 cells/mm<sup>3</sup> or a diagnosis of WHO stage 3 and 4 diseases, irrespective of CD 4 count or WHO staging.

Furthermore, there is the psychosocial consideration that patients should have attended three or more scheduled visits, no active alcohol or substance abuse, disclosed of HIV status to at least one family member or joined support group and is able to visit the treatment centre on a regular basis (NDOH 2015:41).

Ross, Weinstein and Schackman (2015:1159) state that strict adherence to antiretroviral therapy (ART) is the key to sustained HIV suppression, reduced risk of drug resistance, improved overall health, quality of life, and survival. In addition, poor adherence to antiretroviral medication accelerates the development of drug resistant HIV, whereas without adequate adherence, antiretroviral agents are not maintained at sufficient concentrations to suppress HIV replication in infected cells and to lower the viral load.

According to Lyimo, De Bruin and Van den Boogaard (2012:716), it is important to identify and address challenges to complete adherence when starting ART, because adherence is such an important part of the treatment. It is clear that adherence is a cornerstone of a successful ART programme.

It can promote retention of patients on ART for longer periods and the attainment of optimal health. The NDOH (2011) emphasizes the importance of adherence and suggests having a communication strategy that includes daily adherence reminders and re-adherence counseling at every clinic visit.

### **1.3. CONTEXTUALISATION OF THE RESEARCH PROBLEM**

According to Mayosi, Lawn and Van Niekerk (2012:2029), the HIV and AIDS pandemic has been one of the most challenging health issues that the South African government has had to deal with. Furthermore, HIV and AIDS pose a serious threat to the social and economic development of the country.

In addition, South Africa has only 0.7% of the world population but is carrying 17% of the HIV and AIDS burden of the world. Adherence to ARV therapy is essential to maintaining long-term health benefits, and avoiding the development of viral resistance. Kaposhi, Mqogi and Schopflocher (2015:547) indicate that there is a need for strong support systems for PLHIV and that systems should be established within the facilities that render comprehensive care management and treatment of PLHIV, including ART. According to Kaposhi, Mqogi and Schopflocher (2015:547), counsellors trained on the ART programme could facilitate the establishment of support groups for people taking ART as their chronic medication and to reinforced community-based structures. People living with HIV and on ART have to be encouraged to identify social support structures in their communities and to disclose their HIV sero-status, as these factors directly impact on the success of an ART programme. Antiretroviral medication regimes for HIV infection are complex and inconvenient to PLHIV. They often produce side-effects and must be taken for long periods (Cummings, Gutin and Jailantilal 2014:602).

Peltzer et al. (2012:218) indicate that the minimum level of adherence required for ARVs to work efficiently is 95%. Furthermore, important socio-economic predictors of ART adherence include transport and access to health service. It is important for the patients to take seriously the issues of adherence and commit to their treatment for the ART programme to be a success. Dunbar-Jacob, Schenk and Mc Call (2012:271) report that failure to adhere to treatment satisfactorily leads to complications or progression of varied diseases. According to Dewing, Mathews and Lurie (2015:342) barriers to adherence included fear of disclosure, forgetfulness, health illiteracy, financial constraints and patients being away from their medications.



#### **1.4. MOTIVATION FOR THE STUDY**

The researcher observed the high defaulter (lost to follow up (LTFU) rate of people taking ART while working at Witpoort Hospital despite the fact that the clinic has ART treatment guidelines and the criteria for starting ART are readily available. The researcher worked as the Deputy Manager Dietetics in the hospital and ART patients were referred to me from the clinic on monthly basis for nutritional assessments and follow up. It was during the researcher work at the hospital that he noticed the high number of patients who did not return for follow up medication.

The researcher developed the interest in HIV and AIDS and the ART programme available to those suffering from the disease while working at the hospital. The topic of this research was motivated by nutritional counseling sessions the researcher conducted and experiences of working with people living with HIV (PLHIV) in the clinic. The findings that will be generated by this study will make a contribution to the understanding of what people living with HIV know about ART, their attitudes and experiences towards ART. In addition, the results will also contribute to the understanding of non-adherence and be useful in developing interventions that will take account the problems faced by people living with HIV and who are on ART at a public health clinic, in Limpopo, South Africa. People living with HIV and who are on ART are the key role players in the success of this treatment. An understanding of the patients' knowledge, attitudes and their experiences may contribute to the implementation of strategies that would improve their adherence rate and reduce the number of challenges they face with this treatment.

People living with HIV who are on treatment face many challenges such as non-adherence, insufficient ART knowledge, avoidance of re-infection, poor or no adherence to therapy, lack of psychosocial support, stigma attached to the ART programme, poor access to treatment, long waiting times in the clinic, poverty and hunger and transportation. The government should find a way to address these issues for an ART programme to be a success. All these challenges may lead to poor uptake of ART, poor adherence and ultimately development of treatment resistance to patients and even death.

## **1.5. PROBLEM STATEMENT**

South Africa is currently experiencing one of the most severe HIV and AIDS epidemics (UNAIDS 2012). By the end of 2012, there were approximately 6.4 million people (adults and children) living with HIV in the country (IRIN 2012). In the same year, 270,190 people died of AIDS related causes, 100,000 fewer than in 2001 (UNAIDS 2012). One of the most effective ways to treat HIV/AIDS is taking the ART medication. However, ART is a lifelong treatment and there have been challenges to the implementation of the ART in Limpopo Province.

Although ART is available and prescribed to those who need it and are eligible for it in South Africa, it seems that people on ART often do not comply with the treatment regimen due to a number of challenges, such non-adherence, knowledge of ART, side effects and they are lost to follow-up (Leach-Lemens 2010).

## **1.6. AIM OF THE STUDY**

The aim of this study was to assess the knowledge, attitudes and experiences of people living with HIV and who are on antiretroviral treatment (ART) at a public health clinic in Limpopo, South Africa.

## **1.7. OBJECTIVES OF THE STUDY**

The following objectives were formulated to guide this study. The researcher wanted to:

- assess the knowledge that people living with HIV have on ART.
- identify attitudes of people living with HIV towards ART.
- discover the experiences of people living with HIV and on ART.
- identify the economic factors that support people living with HIV who are on ART.
- identify the social factors that support people living with HIV who are on ART.

## **1.8. ASSUMPTIONS**

In this study in-depth interviews were conducted with selected patients living with HIV and who were on ART for more than six months.

The assumptions in this study were that:

- Not all people living with HIV who on ART have a good knowledge of ART.
- Not all people living with HIV and on ART have negative attitudes towards ART.
- Not all people living with HIV have bad experiences with ART.

## **1.9. THE RESEARCH QUESTIONS**

The research questions were as follows:

- What knowledge do PLHIV have on ART?
- What are the attitudes of PLHIV towards ART?
- What are the experiences of PLHIV on ART?
- What are the economic factors that support people living with HIV and are on ART?
- What are the social factors that support people living with HIV who are on ART?

## **1.10. DEFINITIONS OF KEY CONCEPTS**

For the purposes of this study, the following key concepts were as follows:

### **1.10.1. Knowledge**

Machlup (2014) defines knowledge as familiarity with something, which includes facts, information, descriptions, or skills acquired through experience or education. It is also indicated that knowledge acquisition involves complex cognitive processes such as perceptions, communication, association and reasoning, and that knowledge is related to the capacity of acknowledgement in human beings. In this study, *ART knowledge* among people taking ART would mean knowledge of resistance, adherence and side effects as well as the ability of people on ART to correctly clarify myths and misconceptions about ART.

### **1.10.2. Attitude**

According to Russell and Elsenberg (2012:203), attitude is defined as “a psychological tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor. This definition encompasses the key features of attitudes—namely, *tendency*, *entity* (or attitude object), and evaluation. In this study, *attitudes* would mean negative or positive attitudes towards ART.

### **1.10.3. Experience**

According to Tsonis, (2012:1) experience is defined as an individual’s subjective experience of taking a medication (ART) in his/her daily life. It is an encounter that is given meaning before it happens and is often a reaction to the symbol that medication holds. In addition, It is also the knowledge of an event or a subject gained through involvement of exposure.

### **1.10.4. Antiretroviral Treatment (ART)**

Thompson, Aberg and Hoy (2012:387) state that ART is an acronym for Antiretroviral Treatment and refers to all drugs developed to prevent the HIV from replication. These drugs do not kill the HIV, but prevent it from multiplying (Wilson, Maartens, Cotton, Venter, and Bekker & Meyers 2002:332). These ART drugs improve the quality of life of people living with HIV.

### **1.10.5. Human Immunodeficiency Virus (HIV)**

HIV is an acronym for Human Immunodeficiency Virus. In case of an infection with the HIV, it kills the defense mechanisms of the human being and the person becomes vulnerable to opportunistic infections (Wilson, Maartens, Cotton, Venter, Bekker 2002:3, Thompson, Aberg and Hoy 2012:387).

### **1.10.6. Public Clinic**

Public Clinics are clinics that the National Health Department has established to provide HIV and AIDS-related services, including the rolling-out of ARV's to the people infected with HIV and in need of ART (NDOH 2003)

## **1.11. OUTLINE OF THE STUDY REPORT**

The following sections indicate the general outline and organization of the study report.

### **Chapter 1**

This chapter presents an overview and background of the research.

### **Chapter 2**

The second chapter reports on the literature review and explores on ART knowledge, attitude and experiences among people living with HIV and is on ART. The literature review focuses mainly on ART knowledge, attitude and experiences and presents the conceptual framework that has guided the study.

### **Chapter 3**

The third chapter reports the outline of the methodology and design. The study respondents and sampling technique, the process of data collection and analysis, as well as the ethical consideration in the research are defined and discussed in this chapter.

### **Chapter 4**

The fourth chapter presents the research findings and discussion and gives the analysis and interpretation of the study results. Here, the findings are clustered into five themes. Each theme is briefly defined, followed by direct quotations that provide support and clarity on the theme.

### **Chapter 5**

The fifth chapter presents the discussion and conclusions drawn from the study as well as the limitations of the study.

In addition, recommendations based on the findings of the research are formulated. Linkage of the literature and the results are also discussed in this chapter.

## **1.12. CONCLUSION**

In this chapter, the overview, motivation and objectives of the study were outlined. The chapter further outlined the problem statement; key terms used in the study were defined. The dissertation layout was presented. The next chapter presents a review of literature on the knowledge, attitude and experiences on people living with HIV and is on ART.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

In order to locate this study in terms of other studies on knowledge, experiences and attitudes of PLHIV who are on antiretroviral treatment (ART) and the relevant theoretical perspectives, literature from a wide range of international and national academic journals, online publications and other sources have been consulted. The focus in this chapter is on HIV and AIDS in Sub-Saharan Africa, on South Africa and the Limpopo Province, on the ART programme implementation in South Africa, its benefits and challenges, on the definition of the concept of adherence and identification of the factors for poor adherence, on the discussion of knowledge, attitudes and experiences concerning antiretroviral treatment of PLHIV and an exploration of a health seeking behavior model and its relevance to ART adherence.

#### **2.2. HIV AND AIDS IN SOUTH AFRICA**

The NDOH (2014) indicates that public sector antiretroviral provision has had a slow start in South Africa due to political denials despite a raging epidemic and a World Aids Conference that shed a light on the disparities of therapy access globally.

In addition, Laloo and Pillay (2013:132) indicate that South Africa has the largest number of people living with HIV (PLHIV), estimated at 6.4 million, and by far the largest number of people on antiretroviral therapy (ART) in the world: almost 2.5 million have started ART in South Africa with a total population of 54 million people. Besides the logistical challenges that a programme of this scale presents, the expanding number of people requiring treatment poses significant resource challenges (UNAIDS 2012).

Following a troubled period, in which the South African government failed to come up with an appropriate treatment plan and which was accompanied by wide controversy and active campaigning within civil society, the government announced a gradual ART roll-out in 2003 (NDOH 2003). South Africa's decision to start offering ART at

facilities and committing itself to fighting the disease has brought some relief after its long-standing indecisiveness on this issue.

According to the WHO (2013), there are between 1.6 and 2.0 million additional PLHIV eligible for ART initiation at CD4 T-cell counts of < 500 based on the 2015 WHO Antiretroviral Treatment Guidelines (NDOH 2015).

In addition, WHO (2013) indicates that between 300,000 and 500,000 people have become infected annually over the past decade, while the capacity of the National Department of Health system to start people on ART has expanded by only 20%.

It is difficult to overestimate the suffering that HIV has caused in South Africa. Not only the person living with HIV in South Africa - or in any other country - are affected, but also their families, friends and the wider community. However, after years of controversial AIDS treatment history and the refusal of the South African government to provide ART to people living with HIV in South Africa, the South African government finally announced its approval to start offering ART in 2004 (UNAIDS 2012).

According to the NDOH (2013), treatment programmes have access to medication choices and monitoring that is in line with international guidelines, with the most recent improvements including fixed dosed combination (FDC) ART, including treatment for pregnant and lactating women and access to salvage regimens as reflected in the government HIV treatment guidelines.

According to HSRC (2012) it is estimated that 12.2% of the population (6.4 million persons) were HIV positive, which is 1.2 million more PLHIV than in 2008 (10.6%, or 5.2 million).

### **2.3. HIV AND AIDS IN THE LIMPOPO PROVINCE**

According to NDOH(2012), the National Antenatal Sentinel HIV and Syphilis Prevalence Survey (2012) shows that the Limpopo Province is seven-highest in terms of HIV prevalence in the country, after six other provinces such as KwaZulu-Natal, Mpumalanga, Freestate, North West, Eastern Cape and Gauteng (NDOH 2013).



The report further indicates that Limpopo is amongst the few provinces that have shown an increase in the overall prevalence rate, that is, from 8.8% in 2010 to 9.2% in 2012. The Limpopo Province has five District Municipalities, the Capricorn, Vhembe, Mopani, Sekhukhune and Waterberg Districts.

It borders on Gauteng, the North West, Mpumalanga Provinces, the Republic of Mozambique, Zimbabwe and Botswana. There is a lot of migration to and from these neighboring countries and provinces. Dr. Mabasa (2013), the MEC for health in Limpopo province indicated that the Waterberg District (under which the chosen research site falls) continues to be the highest in new HIV infections in the Limpopo Province estimated at 30.3% at the end of 2012. This high rate of infections in the Waterberg District is attributed to high numbers of migration of contract workers in the Lephalale Local Municipality (Mabasa 2013). The ART programme implementation in the province was a call from National Department of Health for all hospitals in the country to be accredited to offer ART services (NDOH 2004).

#### **2.4. SOUTH AFRICAN NATIONAL ANTIRETROVIRAL TREATMENT PROGRAMME**

South Africa has the largest antiretroviral treatment (ART) programme in the world and has made significant strides in improving ART coverage (UNAIDS 2012). The South African government, with the assistance of international funders and non-governmental organizations (NGOs), has managed to roll out a very effective ART programme since 2004 free of charge to the people living with HIV (PLHIV). At the end of 2009, an estimated 37% of infected people were receiving treatment for HIV (WHO 2010). In mid-2011, following the launch of the HIV Counseling and Testing (HCT) campaign by the SA National Department of Health in early 2010, it was announced that the number of people on ART had increased significantly from 923,000 in February 2010 to 1.4 million in May 2011 (AVERT 2011). However, HRSC (2012) reported that South Africa has reached a target of universal access to treatment with 2 million people initiated on ART by October 2012.

The introduction of the revised treatment guidelines which prescribed that HIV-infected individuals should be initiated on ART at a CD4 count of 500 and less has an impact on the attainment of this (NDOH 2015). This directly promotes the strategy of

using 'treatment as prevention' which espouses the notion that putting people on ART earlier will positively impact on the lowering of the overall number of new HIV infections and therefore result in fewer people needing treatment (NDOH 2013)

With the inability of various countries to control the HIV epidemic and the increasing number of new HIV infections, the treatment as a preventative measure for HIV infections was introduced. ART has been shown to be effective in preventing the acquisition of HIV infection when given as a prophylaxis before or after exposure to HIV to prevent transmission from HIV infected persons (NDOH 2015).

A recent shift proposed in the approach to curbing the scourge of HIV is the 'test and treat' strategy. This is the model of universal voluntary HIV testing with immediate commencement of ART for those diagnosed HIV positive (NDOH 2012). Furthermore, it is proposed as another form of using treatment as a preventative measure for HIV infection. The model is likely; however, to have its own challenges relating to adherence and needs to be explored further as a prophylactic model for HIV. According to Sithole (2013), the provision of ART to persons living with HIV and requiring treatment in South Africa has brought hope to people who otherwise would not have survived. In addition, it has led to improved quality of life, reduced morbidity, mortality and the number of deaths resulting from AIDS-related illnesses and has generally prolonged the lives of many people living with the virus.

The UNAIDS (2012) reports that there is a noted decline in the number of AIDS-related deaths by at least 24% since 2005 and in 2011 there were 1.7 million deaths reported. Despite these advantages, though, the ARV roll-out programme has had its fair share of challenges such as non-adherence or poor adherence to ART and the resultant high incidence of patients being lost to follow up or dropping out of the programme. Rosen and Ketlhapile (2010:98) state that although public sector programmes for providing ART in the Sub-Saharan region have matured tremendously, a high rate of patient attrition is still evident. They further note that while much of the attrition is due to mortality, a loss to follow up or disappearance of patients from treatment, with no apparent reason, is very common.

According to Fox and Rosen (2007) approximately 59% had disappeared from the system and could not be accounted for in the first year of being initiated on treatment (Rosen & Ketlhapile 2010:98). The international studies such as the one conducted by Atav, Senir and Darling (2015) report that the knowledge of HIV and AIDS patients and the public in general regarding HIV and AIDS policies, such as the ART policy of South Africa, is still not sufficient to form a basis for change in behaviour among the at-risk groups and people living with HIV. According to NDOH (2015), the ART policy of South Africa does not address the issue of poverty among people living with HIV until their CD4 count is below 500, which is when the patient qualifies for a disability grant provided by the Social Department of South Africa. Furthermore, the policy indicates that people who are HIV positive and have a CD4 count of less than 500 or have reached stage 4 of the WHO clinical staging, qualify for a disability grant and should be started on ARV immediately. Obviously the protocol of initiation of ARV has to be followed.

This leads to people intentionally having sex with someone who is HIV positive, or they stop taking the ARV drugs so that they can qualify, or so that the disability grant should not be stopped. For example, according to Sileo (2015:1), high-risk groups such as commercial sex workers, due to poverty and the need to survive will engage in unprotected sex in order to earn money. High-risk sexual engagement such as sex without using a condom yields more customers and a higher income. Change in behaviour is dependent on what the individual perceives as benefits as opposed to what the individual perceives as risks or threats (Sileo 2015:1).

Jean, Moh and Danel (2014:4) report that patients are more inclined to change their sexual behaviour after the initiation of ART and prevention counseling. Wamoyi, et al. (2011:633) indicate that sexual desire changes over time, with many in their research reporting diminished desire at 3 to 6 months of taking ART as compared to 18 to 24 months of use. Some patients reported that they feared re-infection or infecting others, or that engaging in sex would awaken the virus and weaken them, and that they might die.

Hoang, Ding and Groce (2015:746) researches on female African-Americans indicate that most respondents believe that they will pray to God, or according to their culture, they believe that their husbands or boyfriends are being faithful. It is evident in most of these studies that patients living with HIV and AIDS lack knowledge about antiretroviral treatment (Medley, Bachanas and Grillo 2015:286).

## **2.5. LEGAL FRAMEWORK INFORMING SOUTH AFRICAN ANTIRETROVIRAL TREATMENT PROGRAMME**

According to Sithole (2013), there are two important strategic documents informing the NDOH ART programme in South Africa: namely, the National Strategic Plan (NSP) and the National Antiretroviral Treatment Guidelines to assist with the implementation of the programme. These two documents are discussed briefly below.

### **2.5.1. National Strategic Plan (NSP) of 2012-2016**

According to NDOH (2012), the NSP reflects the progress made in achieving a clearer understanding of the challenges posed by these epidemics and the increasing unity of purpose among all the stakeholders, who are driven by a shared vision to attain the highest impact of policies towards long-term vision of zero new HIV and TB infections. NDOH (2012) indicates that ART expansion programme has resulted in an increase in ART facilities countrywide to about 2 552 currently and more people accessing treatment.

The NSP focuses specifically on expanding the quality and reach of health and wellness and is geared to addressing the gaps identified in the previous NSP of 2007-2011. The gaps identified include inadequate co-ordination of the public sector, private sector and non-government sector responses, the weak governance and co-ordination structures of SANAC (from ward to national level), the lack of robust monitoring and evaluation of the NSP, the failure to ensure a truly multi-sectoral and integrated response, weak focus on human rights and justice, and the lack of a comprehensive and integrated approach to HIV and TB prevention. The NSP suggests that these gaps be addressed through annual HIV testing for everyone in South Africa, initiation of every HIV-infected individual on ART when their CD4 count

is 500 and less and the strengthening of adherence counseling programmes to ensure retention in care.

### **2.5.2. National Antiretroviral Treatment Guidelines 2004 and 2015**

According to the NDOH (2015:16), the main purpose of these guidelines is to improve the clinical outcomes of people living with HIV, to reduce morbidity due to TB/HIV co-infection, to reduce HIV incidence and to avert AIDS-related deaths in the most cost-efficient manner by ensuring that people living with HIV start with the right therapy at the right time. The National Antiretroviral Guidelines also seek to ensure timely HIV diagnosis, management, treatment and initiation of ARVs for treatment for all eligible populations to achieve best health outcomes in the most cost-efficient manner. The NDOH (2004:52-57) focused on defining adherence and formulating strategies to support and improve adherence to ART, clearly defining roles and responsibilities of the Health Care Team.

The NDOH (2009) indicated that the Honourable President Jacob Zuma announced new key interventions to improve antiretroviral treatment (ART) access to special groups such as HIV positive infants, pregnant women and TB and HIV co-infection. This announcement resulted in more than 2.6 million people being initiated on ART by mid-2014 (NDOH 2015:14). Furthermore, in 2013, the fixed-dose combination pill (FDC) was introduced, made up of the regular three drugs used in the first-line regimen to improve adherence and retention.

In addition, in 2014, the South African Minister of Health, Dr. Aaron Motsoaledi announced that the threshold for initiation of ART will rise to CD4 count  $\leq 500$  cells/ $\mu$ l and that the PMTCT programme will now adopt the B+ approach, which entitles every pregnant and breastfeeding woman to lifelong ART regardless of CD4 count or clinical staging (NDOH 2014).

In the new guidelines effected by NDOH (2015), the approach focused on providing the patient with a comprehensive treatment plan and on-going monitoring to ensure adherence. In January 2015, the treatment guidelines were reviewed and a new set

was introduced which re-emphasized the importance of adherence and of socio-economic support so as to ensure positive treatment outcomes for patients and the identification of issues that impact on optimal adherence. There was also a shift in the approach used as the NSP emphasizes negotiating the treatment plan and allowing the person to commit to the plan. They further identified main factors that have an impact on adherence and these are personal and environmental factors (NDOH 2015:17-18).

Furthermore, these successes are underpinned by a range of interrelated, evidence-guided strategic and operational plans, monitoring initiatives, and policies and guidelines, paving the way for South Africa to attain its objective of reducing mortality from HIV and TB. However, there is a need, to strengthen the focus on adolescents and prevent them from acquiring HIV in line with Department of Health 2020 strategy (Vun 2014). These new guidelines will assist in providing the necessary guidance towards improved management of HIV across different populations in South Africa.

## **2.6. CHALLENGES REGARDING ANTIRETROVIRAL TREATMENT PROGRAMME IMPLEMENTATION**

Despite the success of the programme, it is not free of challenges. Some of the identified challenges that may have an impact on adherence to ART in the long term are discussed below. According to Sithole (2013), the success of the ART programme is determined by early identification of infection in PLHIV, rapid and appropriate starting of ART, high levels of viral suppression as well as the management of toxicities.

According to Sithole (2013), the current status of the ART programme and its implementation in South Africa is encouraging but significant challenges remain and some are discussed in the following subsections.

### **2.6.1. Linking and retention of patients to care**

According to WHO (2010), retention of patients to care is referred to as client's continued engagement in health services and captures the whole continuum of HIV

care from enrolment in care to discharge or death of the client. In addition, retention in care to antiretroviral treatment (ART) is a critical element of HIV care and associated with optimal individual, public health outcomes and cost effectiveness.

The challenges facing the ART programme in South Africa is the ability to initiate and retain people living with HIV on their treatment regimens, according to Stricker, Fox and Gill (2014:465). Furthermore, there is strong evidence that many patients with chronic illnesses such as asthma, hypertension, diabetes and those living with HIV have difficulty adhering to their recommended regimens.

The outcome of HCT is only successful if those who are HIV –negative are supported to reduce their risk of acquiring HIV and also those HIV positive are successfully linked to the continuum of care( NDOH 2015:39). According to Stricker, Fox and Gill (2014) indicated that despite the significance of retention in care, patients living with HIV are still find it difficult to follow the recommended behaviour by the health care providers. In addition, inadequate retention leads to decreased health outcomes such as morbidity, mortality, and drug resistances, risk of transmission, increased costs and lower productivity.

### **2.6.2. High levels of loss to follow up (LTFU) to Antiretroviral treatment**

According to Stricker, Fox and Gill (2014), loss to follow up (LTFU) represents clients who disengaged from care at any stage of the continuum of care. Despite the efforts of the health providers, for various reasons, there is still a significant loss of patients from the time that people are diagnosed with HIV to the first assessment of ART eligibility. According to NDOH (2015:39), the treatment cascade shows two main leakages: people lost between a positive HIV, CD4 test, and those lost between CD4 test and the return visit for CD4 test result.

Challenges facing people living with HIV include having to travel long distances to the clinic, long waiting times at the clinic, clinic staff shortages, inability to take time off work, lack of full understanding of the treatment plan and fear of stigma and discrimination.

However, if these patients are effectively linked to prevention, treatment and care services, HCT enables those being tested to make positive health –related decisions.

According to Lalloo and Pillay (2008:132), despite these gains, the challenge of late presenters at the facilities continues to occur throughout the world including South Africa, with the resultant ongoing burden of opportunistic infections including TB. In addition, the pace of the implementation of the ART programme in the provinces is still impeded by the human resources crisis that is being experienced by the Department of Health. The lack of trained professionals, because of the difficulty of attracting, training and retaining of health care workers, remains a formidable challenge for the Department of Health. Without addressing the human resources issue, which includes poor working conditions, low salaries, unsatisfactory career pathing and lack of incentives, it will be difficult to increase the pace of ART implementation in the province (Ford 2014:24).

## **2.7. BENEFITS OF THE SOUTH AFRICAN ANTIRETROVIRAL TREATMENT PROGRAMME**

Stricker, Fox and Gill (2014:465) indicate that the scaling up of antiretroviral treatment in South Africa has succeeded in increasing the number of people taking ARV. By the end of 2007, the WHO reported that an estimated 27% of people that required treatment were getting it. In addition, the number of people receiving ARV was estimated to have increased by 56% in 2009 according to a WHO report (UNAIDS and WHO, 2010). The National Strategic Plan calls for treatment care and support for 80% of HIV positive people by 2011 (UNAIDS, 2012). However, the target was not met due to challenges such as human resources, late initiation of ART, lost to follow-up, establishing of a tracer system and effective use of existing resources, which will all need to be addressed.

Li (2014:998) postulates that ARV drugs have revolutionized the management and care of HIV and AIDS patients. New results of these studies indicate that HIV and AIDS patients can recover to some extent from AIDS stage III to HIV infection. According to Van Zyl, Frenkel and Chung (2014:1643), ART has a number of benefits. Some of the benefits are that it delays the onset of AIDS and prolongs a



healthy life. Studies by Eaton (2014:23-34) indicate good outcomes following the use of ART in the public sector. Continued success, of course, will depend on patients' adherence to the therapy and their attitude towards ART. The introduction of the ART programme in South Africa brought hope to many people living with HIV and AIDS.

The reports quoted above provide evidence that the use of ARV drugs has saved the lives of thousands of people living with HIV. It has led to improved quality of life, reduced morbidity, mortality and number of deaths from AIDS-related illnesses and has generally prolonged the lives of many people living with the virus. According to the UNAIDS (2012), there is a noted decline in the number of AIDS related deaths by at least 24% since 2005.

## **2.8. ADHERENCE TO ANTIRETROVIRAL TREATMENT**

According to Eaton, Meziès and Stovee (2014:23-24) Antiretroviral Treatment (ART) requires life-long adherence to be effective, and to prevent the development of resistant strains. In addition, HIV is a chronic disease that eventually results in AIDS and death unless managed appropriately with ART. Successful ART results in suppression of HIV replication and halts clinical progression of the disease (Maartens et al. 2012:512). Non-adherence to ART is associated with incomplete viral suppression and the selection of drug-resistant viruses that will limit therapeutic options.

### **2.8.1. The importance of adherence**

Van Loggenrensberg, Gray and Gengia (2015:299) indicate that the success of antiretroviral therapy depends solely on the patient's level of adherence; therefore, adherence, toxicity and resistance are matters of concern in this research. The lack of adherence and possible resistance to ART need to improve in patients taking ART in order to overcome the challenges of the available drugs.

Adherence to ART is essential for the successful treatment of HIV and AIDS, as it results in the decrease in viral load (VL), morbidity and mortality while increasing the

chances of survival. It decreases the prospects of hospitalization and reduces the possibility of resistance to ART (Van Loggenrensberg et al. 2015:299).

### **2.8.2. The nature of adherence**

Adherence to ART is critical for people living with HIV and who are on ART, in order to maintain good health. For a patient living with HIV to successfully adhere to and comply with ART medication, the patient must be well motivated, knowledgeable, committed, and get support from the health worker and from friends and family according to Holtzman, Brady and Yehia (2015:445). Furthermore, adherence to ART must be close to 95% to achieve success. Good adherence will add between five and seven years to the life expectancy of people living with HIV.

Emamzadeh-Fard, Fard and Koosha (2012:346) noted that although ART reduces the numbers of HIV and AIDS related deaths significantly, appropriate adherence levels are recommended for optimum viral suppression in the therapeutic response process in PLHIV.

Studies conducted by Khalili, Rohani and Seyedalnaghi (2012) indicate that patients' mean adherence rates to ART in three months follow-up assessed by self-reporting methods was 65.5%, while by pill count method it was 60.4%. The study was about adherence to antiretroviral therapy among Iranian HIV/AIDS patients. It was noted that participants who were living with their family members had a significant increase in adherence rates. This shows that an adherence level of above 95% for patients living with HIV is still a challenge. Sithole (2013) concludes that adherence levels of 65% are not acceptable, because, she argues an acceptable rate would be above 95%. There are many patients on ART who continuously fail to adhere to their medication and this leads to first line regimen resistance (Sithole 2013).

### **2.8.3. Challenges regarding adhering to Antiretroviral treatment**

The biggest challenge facing the ART programme in Sub-Saharan Africa and South Africa is the ability to initiate and retain people living with HIV on the treatment regimens (NDOH 2012). It was indicated by Rosen and Ketlhpile (2010:98) that although public sector programmes in the Sub-Saharan region have matured, a high rate of patient attrition is still evident. They further indicate that while much of the attrition is due to mortality, loss to follow up or disappearance of patients from treatment with no apparent reason is very common.

Bucciardini, Fragolla and Abegaz (2015:136) reported that ART programmes in Africa only managed to retain approximately 60% - 70% of patients on therapy three years after initiation on therapy. Gengerg, Lee and Rodgers (2014:85) indicate that the study regarding the barriers to adhering to ART found that among patients living with HIV, many reported that they forgot the sequence of the treatment. In addition, they could not take the medication in front of their family members or friends because they did not know about their HIV status. Furthermore, some reported that the medication was too complex and they also lacked knowledge about the treatment.

According to Van Boekel (2013:23), a similar study conducted in Botswana also reported barriers such as stigma, discrimination, migration and side effects of ART as key challenges to adhering to and complying with ART. In this study, the cost of ARV drugs was found to be a serious challenge. Van Boekel (2013: 23) indicates from a study that trust between health care providers and the patient is crucial for successful implementation of an ART programme. The study was conducted in the Connecticut Department of Corrections in the United States of America, and they looked into trust between the health care providers and prison inmates and the acceptance and adherence to antiretroviral medication.

It is therefore essential that adherence should be improved by intervention designed to address the barriers. People living with HIV must be given accurate information for them to understand what it is that they as patients need to do.

Wasti et al. (2012) report that stigma; discrimination and the issue of privacy are some of the barriers to the success of ART implementation, especially regarding the problem of disclosure to family members and friends. HIV and AIDS patients need to disclose their status to one person, a member of the family or a friend, who will support them.

Wasti, et al. (2012) indicated that privacy is also considered another impediment to treatment and adherence, because in choosing to keep their positive status a secret, patients might not get treatment. It is also indicated that depression and psychiatric conditions such as depression and stress especially among adolescents, occur as a result of non-adherence to the treatment. It has been noted by Wasti et al. (2012) that adolescent patients taking ARV are unable to cope with depression or stress and this causes them to miss treatments. Warner (2013:23) states that participants with partners, such as people in heterosexual relationships, were associated with good adherence, that is, taking their ARV prescription as prescribed, while support from friends and other family members was not as significant.

Their findings also indicate that partners who were both HIV positive and both taking ARV supported each other more in taking ARV than friends and other members of family or relatives. A study conducted by Berg (2015) indicates that there are main barriers to ART success, not limited to the following: forgetfulness, the social and physical environment, the complexity of the regimen, side effects of the medication, inadequate knowledge on the part of the patient about ART, such as its benefits and side effects.

However, Berg (2015) points out that these barriers may be overcome by providing patients with sufficient health care information in terms of the benefit of ART, comprehensive pre-treatment, post-treatment and on-going counseling at each visit to the facility (Nchendia 2012).

## **2.9. FACTORS FOR POOR ADHERENCE**

According to Maartens et al. (2012:515) factors that may have either positive or a negative impact on an individual adherence behavior may be divided into three categories, namely patient related, regimen related and disease related (as cited by Mathebula 2014).

The major impact on adherence lies with the individuals on therapy and their interactions with their families, communities and care givers. The more favorable these relationships, the more likely the individuals are to remain adherent over time. The value of an individual accepting the HIV status and being properly prepared for therapy should not be underestimated. Many people simply just forget to take the medication. The use of devices such as pill boxes, cell phones and diaries to remind them to take their medication can be useful in this case according to Sithole (2013).

### **2.9.1. Socio-economic factors**

According to Kagee (2006:415), social and economic factors may combine to yield poor adherence outcomes in South Africa. Many people are living in poverty in South Africa and have limited or no financial resources to meet treatment requirements. These circumstances may lead to poor adherence outcomes.

On the other hand, however, Heyer and Ogunbanjo (2006:8) state that socio-economic factors are not consistently predictive of adherence. They assert that in studies carried out in India and South Africa, no association was found between adherence and the patient's economic status. A number of investigators relate the costs of accessing treatment at the level of the individual and his or her family to poor adherence outcomes.

For example, Roura et al. (2009:48) regard cost such as transport and waiting times as important barriers in addition to stigma, family pressures and religious beliefs. Hardon, Davey, Gerrits and Hodgkin (2007), in a review of studies conducted in Tanzania, Uganda and Botswana, conclude that although patients are highly

motivated to adhere to their medication as prescribed, constraints such as transport costs, user fees, long waiting times, hunger, stigma and discrimination, lack of social support, side effects and lack of appropriate counseling all undermine such intentions.

Mukherjee et al. (2006:124) also confirm that costs such as payment for transportation to and from clinics serve as a deterrent to ART adherence. They further state that the lack of adequate food has also been associated with poor adherence to ART. Socio-economic factors reported to have a significant impact on adherence are poor socio-economic status, poverty, illiteracy, low levels of education, unemployment, lack of effective social support networks, unstable living conditions, long distance from treatment centres (Lupu 2014:75).

Heyer and Ogunbanjo (2006:5), however, state that educational levels, literacy, income and housing status are not predictive of adherence. Heyer and Ogunbanjo (2006:5) report that poverty can influence adherence because access to the financial means to travel to and from the ART clinic, to pay for child-minders during a parent's absence to access treatment and to attend to several, competing needs and responsibilities all come into play (Simoni et al. 2009:192). For the poor and the unemployed, lack of financial resources to pay for the kind of food stuffs required to be taken alongside medication may be of particular concern (Hogerzeil 2013:680).

According to NDOH (2010:9), poverty is one of the major contributors to poor health and treatment outcomes through food insecurity in as far as HIV and TB acquisition and treatment adherence are concerned. The SA government, in order to support adherence through its Social Development Department, has introduced a chronic disease grant assistance for those HIV infected who cannot support themselves and their families (NDOH 2013:114).

The qualification criterion for the grant is that an HIV-infected person must be too sick to work and when their health improves the grant is terminated (SASSA 2012). From a study conducted in the Cape Peninsula, South Africa, with 29 patients, it was found that in order to keep their CD4 counts low, some manipulated the treatment so that their viral loads remained high (De Paoll, Mills & Gronningsaeter 2012: 6). Furthermore, the commonly cited reason for non-adherence is the fear of losing one's

grant and that this results in some patients 'managing' their CD4 counts by skipping some doses.

This ensures that the viral load is not completely suppressed and this enables them to continue receiving the grant as long as there is no improvement in the CD4 count. This can have devastating effects in terms of developing treatment resistance and treatment failure in the long run and the patient may end up with fewer treatment options (Sithole 2013). As far as social factors are concerned, the WHO (2006:28) suggests that positive attitudes of the community towards people living with HIV play a significant role in influencing adherence.

The WHO (2006:28) indicates that people living with HIV and on ART and receiving community-based support have been reported to be less likely to be lost to follow-up. According to AIDS Map(2012) indicated that of the 19,668 patients studied in a cohort, only 6% of that receiving community-based adherence support was lost to follow-up compared with 9% of those not receiving any community-based adherence support (AIDS Map 2012).

The findings of a study conducted by Yoder, Mkhize and Nzimande (2009:70) in five different sites in KwaZulu-Natal on the experience of patients on antiretroviral therapy suggest that challenges such as the availability of a treatment supporter, adequate household income and side-effects are all determinants of adherence, non-adherence and/or ultimate drop-out from treatment. Another important social factor, which is associated with adherence, is the support of significant others in a patient's life as they provide support and understanding for the patient. Heyer and Ogunbanjo (2006:6) confirm this by stating that the presence of social support systems such as supportive family members, friends and treatment supporters have been consistently associated with good adherence to treatment.

### **2.9.2. General patient-related factors**

Other factors identified as impacting on adherence are as follows:

- Treatment fatigue and pill burden. According to NDOH (2010), having to take a number of pills as a result of co-infection with other illnesses such as TB and hypertension can result in fatigue and pill burden. This can result in patients

adhering sub-optimally to their treatment. Some patients may also develop 'treatment or pill fatigue' after being on treatment for a long time and they may suddenly find it difficult to adhere to their recommended treatment regimens. Several research studies have reportedly shown adherence declining over time for people on long-term treatment and even with people who have been very successful in taking their medication (AIDSinfonet 2012).

- Lack of disclosure, fear of stigma and discrimination (Kagee 2006:419). People living with HIV are often subjected to a great deal of stigma and discrimination which may result in their not being willing to disclose their HIV status for fear of being discriminated against.
- Cultural and religious beliefs (Kagee 2006:422) play a very significant role in shaping and determining beliefs and values which may directly influence attitudes to treatment and adherence.
- Forgetfulness and a lack of planning (NDOH 2010:18). These factors may be manifest when the patient attends social functions on weekends or is away from home and no provision has been made in terms of having adequate treatment available.
- Lack of adequate financial resources and food insecurity (NDOH 2010:18) is cited as one of the major problems experienced in South Africa. This may result in the lack of money for transport to attend clinic or lack of money for food to be taken with the medication and this can affect adherence.

Sithole (2013) states that the individual's motivation, determination and an ability to manage his or her illness, available resources and support systems, understanding of possible consequences of non-adherence and expectation of positive treatment outcomes all interact to impact on adherence.



## **2.10. KNOWLEDGE, ATTITUDES AND EXPERIENCES REGARDING ANTIRETROVIRAL TREATMENT**

Dimatteo, Haskard-Zolnieriek and Martinl (2012:74) conducted a study and looked into the model to improve adherence to antiretroviral treatment. The model comprises of the three important clinical actions:

- (1) Ensuring that patients have the right *information (Knowledge)* and know how to adhere – including listening to patients’ concerns, encouraging their participation and partnership in decision-making, building trust and empathy, and enhancing recall;
- (2) Helping patients believe in their treatment and become *motivated* to commit to it – that is, addressing the cognitive, social, cultural normative and contextual factors that affect patients’ beliefs, attitudes and motivation; and
- (3) Assisting patients to overcome practical barriers to treatment adherence and develop a workable strategy for long-term disease management – including assessing and enhancing patients’ social support, identifying and treating their depression and helping patients overcome cost-related treatment barriers.

### **2.10.1. Knowledge regarding Antiretroviral treatment**

Seeling, Mavhunga and Thoma (2014: 268) postulate that knowledge about HIV and AIDS and the benefits of ART are regarded as crucial for accepting the offer to get tested. Therefore, efforts should be made to intensify the dissemination of HIV and AIDS information and to fight stigma and discrimination in society. Since cultural background plays an important role in the individual response to HIV-related stigma, counseling and health education of patients should be adapted to cultural characteristics. Kaposhi , Mqogi and Schopflocher (2015:547) conducted a study in the Eastern Cape and recommended that an inaccuracy of the ART programme should be addressed; this should include improving knowledge translation during training of ART programme staff, ensuring the implementation of established data

verification policies and procedures, rethinking the design of the programme to reduce the burden on health facilities and personnel, and standardizing information management procedures amongst the various governmental and non-governmental stakeholders.

Knowledge is referred to as the facts known about the treatment, feelings or experiences by a person or group of people, the state of knowing, awareness, consciousness, or familiarity gained by experience or learning specific information about the subject, according to Kaposhi, Mqogi and Schopflocher (2015:547).

A study conducted in Nigeria looked into PLHIVs knowledge about ARVs; they found out that HIV/AIDS knowledge was remarkably high. In addition, it was found that knowledge of ARV drug combinations, the appropriate time to start ARV, the benefits of taking ARV regularly and the possible results of not adhering to one's ARV medication was high among all the participants (Weiser, Tuller and Frongillo, 2010).

According to Munthali, Mvula and Maluwa-Banda (2014:60), scores achieved by participants on knowledge about HIV, including the cause, mode of transmission and progression of the disease, were high, with an average score of 86%. In addition, the majority of patients were aware that taking ART could have side effects and knew that missing doses could lead to disease progression.

In these studies it emerged that there was a need to reinforce educational messages that ART does not cure HIV and AIDS and that missing doses could cause drug resistance and lead to the progression of the disease. Whether or not good HIV and ART knowledge among these patients translates into good adherence needs further evaluation.

The patients' knowledge of ART is crucial in this study. It is the assertion of this thesis that if people living with HIV and AIDS were given information about the benefits and the side effects of ART and its impact on their wellbeing, the programme would have many more people on the treatment, if all systems were in place. It is also relevant to say that adherence would be less of a problem if people were given the relevant information and the support systems mentioned above were in place.

### **2.10.2. Attitudes to Antiretroviral treatment**

Sellam and Flower (2014:98) indicate that the concept “attitude” is defined as a stable predisposition, a general and enduring positive or negative feeling about some person, object or issue. In addition, attitudes originate from human cognition and are closely linked and influenced by perceptions.

Prejudice and stigmatization refer to “a specific attitude which is a combination of hostile feelings, negative emotions and hostile behaviour towards others”. Beaulieu, Andrien and Potvin (2014:1246) define attitudes as “feelings of emotions and beliefs which influence the determination of behavior towards objects, persons or the environment”. Furthermore, people’s attitudes are made up of the cognitive - the knowledge and information they possess - and the affective - their feelings and emotions and evaluation of what is important.

Many personal attributes, such as commitment, positive self-esteem, motivation, ability to deal with stress and adaptability, have been used in research to explore and describe HIV and AIDS-related attitudes towards people living with HIV (PLHIV), and ART. Attitudes also include stigma and discrimination towards these people and towards ART, perceptions about ART, such as suggestions that is poisonous and not good for human consumption and that ART kills people. These perceptions lead to patients not taking the medication correctly, which ultimately leads to their resistance to the treatment and possibly dying.

### **2.10.3. Experiences of people living with HIV on Antiretroviral treatment**

French, Greef and Watson (2015:1) postulate that knowledge gained from experience forms an essential aid to our understanding and activities in our everyday life. The experiences of PLHIV can be both negative and positive and this invariably affects their treatment process.

Nsanzimana, Prabhu and McDemmott (2015:216) indicate that *“experience results in knowledge and understanding gained either individually or as a group or society through day-to-day living.*

*The most immediate form of experience is personal experience, the body of knowledge gained individually through encountering situations and events in life".* Patients living with HIV and AIDS experience a significant improvement in their health with fewer or no opportunistic infections; most patients regain their appetite and gain weight and experience increased energy levels.

Yoder et al. (2009) conducted a study that looked into the experiences of patients in ART programmes in KwaZulu-Natal. The results of the study indicate that many patients experienced financial problems which mean they encountered problems in obtaining appropriate food and paying for transportation to the nearest facility to collect their medication.

A three-country study was conducted in Uganda, Tanzania and Botswana by Hardon et al. (2007), according to their study patients struggled with transport and user fees, long waiting times, lack of food, side effects from the medication, stigma and poor counseling.

A study by Ware (2009) also found that scarcity of resources was a constant problem for adherence, and that patients had to beg, borrow or otherwise struggle to find funds for transport to obtain their monthly medication.

## **2.11. THEORETICAL FRAMEWORK ADOPTED**

The theoretical framework and approaches guide and help the researcher to formulate ideas for the research (Brink 1996:66). The theoretical framework has implications for any decision made in the research process (Mertens 1998:3). Identifying the methodologies and methods that will be used in the research and justifying that choice is the starting point in developing a research proposal, according to Crotty (1998:3). This research was conducted using the Information Motivation and Behaviour (IMB) model of ART adherence in this study. This approach attempts to offer explanations for what motivates patients to seek health promoting behaviours and to adhere to their treatment regimens. This model enabled the researcher to identify the factors that are potential barriers to treatment adherence. This model is discussed in detail hereunder.

### **2.11.1. INFORMATION, MOTIVATION AND BEHAVIOUR SKILLS (IMB) MODEL**

The information, motivation, and behaviour skills model of ART adherence was initially developed in response to the HIV and AIDS epidemic, in order to understand, explain and promote HIV risk-reduction behaviour. The model proposes that there are three constructs to the model, which are information, motivation and behavioural skill (Amico, Toro-Alfonso and Fisher 2005:661). The IMB model is increasingly being used in research studies that identify, evaluate and address the deficit of informational, motivational and behavioural skills among ART patients that are not fully adhering to their treatment. The IMB model posits that information, motivation and behavioural skills are primary determinants of health-related behaviour (Starace et al. 2006:153).

This model holds that people infected with HIV and AIDS who are on ART and who are well informed, motivated and possess the behavioural skills that enable them to act effectively, will adhere to their ART programme (Starace et al. 2006:153).

People living with HIV who are on ART need accurate information on particular regimens, the correct ART intake, optimal adherence and the side effects associated with the regimen. If these patients lack motivation, and the skills required for them to take the ART as prescribed or even sufficient confidence, they will definitely experience challenges with adherence (Starace et al. 2006:153). Fisher and Amico (2008) report that sub-optimal adherence to antiretroviral therapy (ART) may have serious consequences for HIV patients, and for public health in general.

According to Mayberry and Osborn (2014), the information motivation behavioral skills (IMB) model of ART adherence can be used to understand the dynamics of ART adherence and to intervene with patients to promote optimal levels of adherence. Even though not much has been done to assess the applicability of the IMB model to adherence, it has the advantage of being well understood as it isolates adherence-related factors from other health-seeking behavior models. This model has its own limitations, however. The IMB model of ART adherence does not adequately deal with the socio-cultural and structural adherence-related factors such as stigma

associated with HIV and AIDS. However, in many contexts stigma does not necessarily impact on adherence to ART (Starace et al. 2006:153).

Change in behaviour also depends on the situation of the patient at a given point in time. In this particular study, for a patient to adhere to ART, the message must be positive, giving the benefits of ART and the dangers of suboptimal adherence. Patients are then likely to adhere to the therapy. This behaviour will develop into a perception which can be reinforced by change in behaviour (Amico, Toro-Alfonso and Fisher 2005:661).

To this end, the IMB model of adherence is an important step in the right direction. Despite its limitations and focus on ART adherence, the IMB model is similar to other health-related behavior models, in that it places the individual at the centre of attention.

Despite having the knowledge of information, the motivation and skills are necessary to perform the behavior. Individual factors such as experiences and support of the family and of community members, access to facilities and affordability can all have bearing on whether the patient adheres to his or her treatment. The challenge to the health care system is that developed health care interventions should be such that they take into account these factors. Efforts to promote behavioural change have been coupled with biological intervention for preventing the spread of HIV infection. Strategies aimed at this, which include raising HIV awareness, promotion of male and female condoms and reducing multiple partners among high-risk groups have proved effective among some sex-workers, however, they and their clients need to be motivated to use these condoms as indicated by this theory (Karim et al. 2010:340).

## **2.12. SUMMARY**

The literature review on ART knowledge, attitudes and experiences among PLHIV and who are on ART were reviewed in this chapter. The literature provided insight in to the study. Studies by Seeling, Mavhunga and Thoma (2014), Kaposhi, Mqogi and Schopflocher (2015) and Munthli, Mvula and Maluwa-Banda (2014) confirm that knowledge of ART is critical in attaining optimal adherence to antiretroviral treatment. These studies further indicate that efforts should be made to intensify the

dissemination of HIV and AIDS information and to fight stigma and discrimination in the community. In addition, the studies further revealed that there is a need to reinforce educational messages such as ART does not cure HIV and AIDS and that missing doses could cause drug resistance and lead to progression of the disease. It is relevant to say that if people were given information, supported and motivated to change their behavior, adherence would be less of a problem.

According to Sellam and Flower (2014), attitude is defined as a stable predisposition, a general and enduring positive or negative feeling about some person, object or issue. Beaulieu et al. (2014), indicates that personal attributes such as positive self-esteem, motivation, commitment and ability to deal and adapt to stress have been used in research to explore HIV and AIDS related attitudes towards people living with HIV. In addition, attitudes also include stigma and discrimination towards people living with HIV and AIDS and the perceptions that ART is poisonous and not for human consumption. These perceptions, lead to patients not taking ART correctly, which ultimately leads to resistance to the treatment.

The researcher reviewed literature on experiences of people living with HIV and who are on ART. From different studies reviewed (French, Greef and Watson 2015, Nsanzimana, Prabhu and McDermott 2015, Yoder 2009, Hardon 2007 and Ware 2009), it has emerged that experiences of people results in knowledge and understanding gained either individually or as a group or society through day-to-day living. Studies reviewed in this chapter, further indicates that the most immediate form of experience is personal experience, the body of knowledge gained individually through encountering situations and events in life.

Studies reviewed in the literature also revealed that many people living with HIV and who are on ART experience financial problems which mean that they are unable to obtain appropriate food, paying for transportation to the nearest facility to collect medication. Furthermore, scarcity of resources is a constant problem for people living with HIV and who are on ART to adhere to treatment on a monthly basis.

## **2.13. CONCLUSION**

In this chapter, the researcher reviewed literature on HIV and AIDS in South Africa, HIV and AIDS in Limpopo province, South African National antiretroviral treatment programme, and Legal framework informing South African antiretroviral programme, Benefits of South African ART programme, Adherence to ART and its challenges were discussed. Knowledge, attitude towards ART and experiences of ART among people living with HIV who are on ART were also discussed. An overview of a theoretical framework, the information, motivation and behavioral (IMB) skills model of adherence to ART has been presented in this chapter to explain the modifying factors that would influence the patient to change behavior and to adhere to treatment. In the following chapter the study population, sampling technique, data collection and analysis as well as ethical considerations in the study will be presented.



## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1. INTRODUCTION**

In this chapter the researcher describes the research design and methodology used in the study. The emphasis is on the chosen research approach for this study, sampling strategies, instruments developed and used to generate the data, data generation strategies, and access negotiation. The ethical considerations adhered to in the study are also considered. Issues of trustworthiness of the data, data analysis and inferences processes are described.

#### **3.2. RESEARCH DESIGN**

The research was conducted using the qualitative enquiry method to collect data. According to Gioia, Corley and Hamilton (2013:1) qualitative researchers exemplify a common belief that this method can provide a deeper understanding of the social phenomenon than would be obtained from purely quantitative data. The goal of the study was to evaluate the knowledge, attitudes and experiences of people living with HIV and on ART in the health facility. Given this goal, a qualitative method approach was called for.

Perez, Holt, Gokert and Chanoi (2015:1205) also indicate that qualitative design explores attitudes, behavior and experiences through such methods as open-ended, face to face interviews and focus groups. In this study, data were collected using interviews conducted with the people living with HIV who are on ART. Creswell (2013) postulates that qualitative research is any data gathering technique that generates open-ended, narrative data.

It tends to be exploratory and descriptive in nature and designed to develop an understanding of individuals in their natural environment. In this study, the researcher interviewed participants to be able to gain an understanding of the concept being

studied. Qualitative design was preferred because it gave the participants an opportunity to talk and expand more on the topic and answer open-ended questions (Hurley, Cummings and Browner 2013). The aim was not to generalize, but to get the understanding of the issues related to knowledge, attitude and experiences of the participants.

According to Calitz, Strydom and Roux (2014:153), the main goal of exploratory studies is to express a new area of interest to gain an understanding of a concept. In addition, exploratory studies lead to a greater understanding of the concept researched and may not necessarily provide a detailed, accurate and replicable body of data (Barbie 2010:117). In this study, the researcher followed an explorative method to achieve an understanding of a concept researched not necessarily accurate and replicable data as mentioned by Barbie (2010:117).

### **3.3. SAMPLING STRATEGIES**

According to Denscombe (2014) sampling is defined as the selection of some units to represent the entire population from which the units were drawn. There is very little or no assumption that the sample will be representative of the larger population and as a result the findings cannot be generalized. In purposive sampling, the researcher uses his/her own judgments when selecting possible participants for the study. (Robinson 2014: 25). In this study, the researcher used purposive sampling strategy to select the participants.

#### **3.3.1. Sampling strategy**

Sandelowski (1995:179) states that efficient sample size in a qualitative study is dependent on the amount, depth and richness of the data the researcher wants to gather.

Following the intensity sampling strategy as described by Collins, Onwuegbuzie and Jiao (2006:83), the researcher purposely recruited participants attending the wellness clinic in the facility. The participants for the face-to-face interviews were purposefully

chosen as they present themselves at the wellness clinic. On a daily basis, clients present to a dietician consulting room for dietetic services. As they present to the Dietician (researcher), the researcher had an opportunity to request them to participate in the study. Those accepted to be part of the study were interviewed and five participants accepted to participate in the interviews.

### **3.4. INSTRUMENTATION**

This section describes the development of the research instruments, in particular the development of the interview schedule for the participant's face-to-face interviews.

#### **3.4.1. Development of the interview schedule for the participants**

The development of the research instruments was informed by reading and preparation done during the research proposal writing stage. The conceptual framework (model) which the researcher adopted in this study was also used to develop questions in the interview schedule. All the questions developed were focused around the questions and objectives of the study. The interview schedule was also piloted with two participants at the study area. This helped in making sure that data collected is relevant, reliable and useful. The interview schedule first draft was submitted to the supervisor for comments. The supervisor comments were incorporated and resulted in a final interview schedule.

An informed consent form was also developed and attached to the interview schedule. The consent form indicated the purpose of this study and observed the following ethical principles

- The participant's participation was voluntary and each participant had the right to withdraw at any point, for any reason, and without prejudice.
- Only the researcher had access to the raw data and no names appeared on the interview schedule.

The interview schedule included closed and open-ended questions. The open-ended items were meant to allow the participants to provide more details on the problems faced and to make suggestions for improving the provision of ART services.

The interview schedule consisted of six sections, demographical information, knowledge, attitudes, experiences, socioeconomic factors questions that relate to the study's objectives.

In particular, the following matters were covered in the interview schedule:

**SECTION A: Demographic information:** The researcher wanted to establish the background information of the participants in terms of home language, marital status and any information that might be of relevance in this study.

**SECTION B: Participants knowledge questions:** In this section the researcher sought to obtain the participants knowledge and assessed using questions developed in the interview schedule (Annexure B). The researcher asked questions about antiretroviral treatment knowledge and what do they do in the human body. The researcher also asked questions pertaining to whether there is any information regarding ART that was provided to the participants, whether they know the names of ARV they are taking?

**SECTION C: Participants attitudes questions:** The researcher wanted to obtain information of the participant's attitudes towards ART. The questions in relation to attitudes were developed (Annexure B), such as what are their feelings towards ART, whether they think that ARV help them, or whether other people are against ARV, why they are against ARV?, whether ARV cure HIV and AIDS, or is ARV make people sick?, why they did decide to start the treatment and whether they can advise other people to take the treatment.

**SECTION D: Participants experiences questions:** In this section, the researcher sought to gain a better understanding of participants experiences on ART, gain an understanding of how life was before and after the start of ART, whether the issue of adherence discussed, the importance of adherence and the danger of missing doses and whether starting ART was easy or difficult to them.

**SECTION E: Participants economic factors questions:** The researcher wanted to obtain information of the participant's economic factors that encourage or discourage them to take treatment. The researcher also wanted to understand whether the participants are earning an income, which provides the financial support and whether they are any economic services assisting participants in the community.

**SECTION F: Participants social factors questions:** In this section, the researcher wanted to gain an understanding of participant's social factors that support them to take their treatment regularly. The researcher also wanted to gauge whether the participants have disclosed their status to anyone such as friends and family and whether they are members of any support group in the community.

### **3.5. DATA GENERATION STRATEGIES**

Since a qualitative research design was used (Corbin and Straus 2014), the researcher followed one data generation strategy. It is discussed in greater detail below. Creswell (2013) reports that data collection is defined as the precise and systematic gathering of information relevant to the research purpose, objectives and questions. The researcher was totally involved and able to interact with the participants.

#### **3.5.1. Face-to-face interviews**

Irvine, Drew and Sainsbury (2013:87) state that an *interview schedule* is defined as a written list of questions, open or closed-ended, prepared for use by an interviewer, in a person to person interaction. In addition, this may be face-to-face or by use of telephone or any media. The researcher used face-to-face interviews as a method of data collection.

The face-to-face interviews were approached as structured conversations based on the on a pre-arranged set of questions (Irvine, Drew and Sainsbury 2013:87-106). The interview sessions were scheduled over five days in the Witpoort Hospital

dietician private room in June 2013. All sessions interviews were tape-recorded and notes were taken as a back-up.

The researcher commenced each interview by greeting his interviewees and thanking them for taking part in the study. Each interview took about half an hour to an hour. All interviews were conducted in Sepedi, but interviewees were also allowed to express themselves in their language of choice.

### **3.6. ACCESS NEGOTIATION AND ETHICAL CONSIDERATIONS**

The researcher did not encounter any difficulties with accessing his units of observation (which were five people living with HIV who are on ART) as he had been working in this Hospital as a Dietician. In considering the ethical implications of the study, the researcher tried to remain true to the notion of this study as a critical examination of underlying social systems with the purpose of furthering human rights and social justice (Mertens 1998:135). In addition, the provision of dietetic services to people living with HIV was regarded as a human right and those rights are being upheld in the interest of social justice. It was not difficult for the researcher to conduct the interviews as an insider of the research site, because he followed all the relevant ethical considerations in conducting social research. The basic considerations when conducting social research involve recognizing and making ethical choices, making principled decisions, ensuring confidentiality and obtaining informed consent from participants whilst maintain research integrity (Babbie and Mouton 2001:520). The basic procedural considerations that guided the data generation and data analysis steps followed in this study are discussed below.

#### **3.6.1. Informed consent**

The researcher provided accurate information to his participants regarding the purpose of the study and what participation entailed.

### **3.6.2. Voluntary participation**

The participants in this study had the right to voluntarily decide whether or not to participate. Participants also had the right to terminate their participation at any time during the study without fear of intimidation or penalties. The researcher informed all the participants about the purpose of the study and participants voluntarily participated.

### **3.6.3. Confidentiality**

Interviews were conducted in a private room. According to Henn, Weinstein and Foard (2006:85), confidentiality refers to protecting and not sharing personal information of the participants without their consent. In this study, the collected information, recordings, informed consent forms and other project materials were kept in a locked space at researcher's office. The information was accessible to the researcher alone. The tape recorder was password protected and only available to researcher. The researcher is planning to dispose of the raw data five years after the degree has been conferred.

## **3.7. TRUSTWORTHINESS OF DATA GATHERING**

According to Geissbuhler, Jafran and Buchan (2013:1), trustworthiness is defined as a term used to demonstrate rigor in qualitative research. In addition, trustworthiness is required in any study to prevent errors of either a constant or intermittent nature. The researcher wanted to uncover more and more descriptions by probing, taking notes and tape recording the interviews. Participants were allowed to express themselves openly in their own preferred language. A combined process of transcription and translation of the data collected from the participants was conducted. This process was done before the thematic analysis commenced.

### **3.8. DATA ANALYSIS**

The interviews data, which was collected by means of tape recorder, was transcribed. The theoretical framework used in the research guided the conceptualization of the categories and themes in the data analysis.

#### **3.8.1. Data analysis strategies for the study**

In this study, data analysis will start with listening to the tape recordings numerous times. The tape recorded interviews will be transcribed and translated to English. Similar patterns were extracted from the interview transcripts. The data were coded and analyzed manually. Themes were identified. In *thematic analysis*, the researcher is predominantly interested in the emergence of themes from the collected data.

### **3.9. THE INFERENCE PROCESS: SYNTHESISING THE DATA**

In this study, data collection focused on gaining more information and meaning from the participant's experiences in their own words. The reporting and interpretation of data analysis will be done for each theme identified in the following chapter.

### **3.10. CONCLUSION**

In this chapter, the researcher provided an overview of the research design. A descriptive, explorative qualitative research design was used to explore the knowledge, attitudes and experiences of people living with HIV and on ART. The researcher used the questions developed for the interview schedule as a criterion to evaluate knowledge, attitudes and experiences of people living with HIV and who are on ART at a public health clinic in Limpopo.

The researcher took measures to ensure trustworthiness and complied with the requirements for correct ethical processes and procedures. The researcher presents and discusses the findings in the following chapter.



## CHAPTER 4

### PRESENTATION AND DISCUSSION OF FINDINGS

#### 4.1. INTRODUCTION

This chapter focuses on the presentation of the findings from the research study. The demographic characteristics of the participants are presented. The findings of the study are discussed in the following sequence.

First, the demographic characteristics of the five (5) participants are described in terms of age, gender, marital status, level of education, place of residences, whether the participants reside in urban or rural area home language, employment status and finally the main source of income. The demographic profile was discussed in a table format.

Secondly, from the transcripts it was possible to identify main themes and these became the basis for the analysis of the data obtained. The identified themes were categorized under the following themes and sub themes: Theme 1: Experiences of PLHIV on ART, Sub themes: Life before starting the treatment, missing doses, poverty and hunger, and benefits of being on ART, Theme 2: Social Support of PLHIV on ART, Theme 3: Knowledge of PLHV about ART, Theme 4: Attitudes of PLHIV on ART, Theme 5: Unemployment and economic support for PLHIV. Each identified theme and sub-theme is briefly introduced, followed by direct quotations from the participants that provide the support and clarity on the identified themes and the participant's knowledge, attitude and their experiences towards ART.

#### 4.2. BACKGROUND CHARACTERISTICS OF THE PARTICIPANTS

The demographic data on the sample of patients living with HIV and on ART is presented in terms of gender, age, marital status, current place of residence, residence by area whether rural or urban, level of education, home language, employment status and main source of income. Table 4.1 (below) shows the distribution of the participants by age. From this information it is clear that the largest

proportion of respondents falls within the age category of 30 to 39 years of age, namely 60%. Those 40 years and older account for 20% of the sample and those younger than 30 years comprise 20% of the sample.

According to Harter (2002), life stages are characterized by a need to form meaningful relationships, start families and develop careers as personal developmental milestones. It is, therefore, anticipated that most of the people in this category would be concerned about their health and well-being as it has a bearing on their ability to form meaningful relationships, start a family and be able to develop and keep a fulfilling career.

**Table 4.1. Age of the participants (N=5)**

<b>AGE RANGES</b>	<b>FREQUENCY</b>	<b>PERCENTAGE (%)</b>
Younger than 30 years	1	20
30-39 years	3	60
40 years and older	1	20
<b>Total</b>	<b>5</b>	<b>100</b>

Table 4.2 (below) shows that of the five (100%) participants, four (80%) were females and one (20%) was male. This is consistent with the normal trends in terms of gender distribution of people that are living with the virus and also the general population where there tend to be more females than males (Stats SA 2011). It is, however, important to take into cognizance that this study sample is very small and cannot be generalized to a wider population.

**Table 4.2. Gender of the participants (N=5)**

<b>GENDER</b>	<b>FREQUENCY</b>	<b>PERCENTAGE</b>
<b>MALE</b>	<b>1</b>	<b>20</b>
<b>FEMALE</b>	<b>4</b>	<b>80</b>
<b>TOTAL</b>	<b>5</b>	<b>100</b>

Table 4.2 indicates that three (60%) of the participants were single whilst no one was married, one (20%) divorced and one (20%) separated. The fact that none of the participants is married might be an indicative of fear of discrimination. The two

participants who divorced and separated respectively indicated that they felt cheated and decided to move out of the relationship.

**Table 4.3. Marital status of the participants (N=5)**

<b>MARITAL STATUS</b>	<b>FREQUENCY</b>	<b>PERCENTAGE (%)</b>
Single	3	60
Married	0	0
Divorced	1	20
Separated	1	20
Widowed	0	0
<b>Total</b>	<b>5</b>	<b>100</b>

Table 4.4 (below), depicts the level of education amongst the study participants. It shows that four (80%) of the participants had at least a secondary school level of education whilst one (20%) had primary school education only. The fact that the majority of participants had a secondary level of education might be indicative of the participants' ability to know their treatment well, understand and recognize its importance and the possible consequences in the long run of not adhering to treatment. There has, however, not been any correlation between illiteracy and non-adherence in terms of literature on adherence and in fact the contrary has been established (Heyer and Ogunbanjo 2006: 5-9).

**Table 4.4. Educational level of the participants (N=5)**

<b>EDUCATIONAL LEVEL</b>	<b>FREQUENCY</b>	<b>PERCENTAGE</b>
<b>PRIMARY</b>	<b>1</b>	<b>20</b>
<b>SECONDARY</b>	<b>4</b>	<b>80</b>
<b>TOTAL</b>	<b>5</b>	<b>100</b>

The Table 4.5 below indicates that the participants' places of residence were distributed throughout the two villages which fall within the catchment area of the public health clinic.

**Table 4.5. Place of residence of the participants (N=5)**

<b>PLACE OF RESIDENCE</b>	<b>FREQUENCY</b>	<b>PERCENTAGE</b>
<b>THABO MBEKI</b>	<b>4</b>	<b>80</b>
<b>LIBU</b>	<b>1</b>	<b>20</b>
<b>TOTAL</b>	<b>5</b>	<b>100</b>

Table 4.6 (below) on the other hand, depicts that the all the participants (100%) resided in a predominantly rural area which is close to the hospital. The study area is predominantly rural and this profile is indicative of that fact.

**Table 4.6. Place of residence whether urban or rural area (N=5)**

<b>PLACE OF RESIDENCE</b>	<b>FREQUENCY</b>	<b>PERCENTAGE (%)</b>
Rural	5	100
Urban	0	0
<b>Total</b>	<b>5</b>	<b>100</b>

Table 4.7 (below) shows that four (80%) participants' home language is Sepedi, while one of them (20%) is Zulu-speaking. It is an indication that the area is dominated by Sepedi speaking people. That is why the researcher made sure that the interviews were conducted in Sepedi and the one participant who speaks Zulu, could speak and understand Sepedi very well.

**Table 4.7. Participants home language (N=5)**

<b>HOME LANGUAGE</b>	<b>FREQUENCY</b>	<b>PERCENTAGE (%)</b>
Sepedi	4	80
Zulu	1	20
Tshwana	0	0
<b>Total</b>	<b>5</b>	<b>100</b>

Table 4.8 below shows that three (60%) of the participants were employed whilst two (40%) were unemployed. Of the three participants who were employed at the time, the data reveal that they were working piece-jobs at the farms around the areas. The two who were unemployed had been medically boarded and were no longer employed.

**Table 4.8: Employment status of the participants (N=5)**

<b>EMPLOYMENT STATUS</b>	<b>FREQUENCY</b>	<b>PERCENTAGE</b>
<b>EMPLOYED</b>	<b>2</b>	<b>40</b>
<b>NOT EMPLOYED</b>	<b>3</b>	<b>60</b>
<b>TOTAL</b>	<b>5</b>	<b>100</b>

The findings of this section of the study showed that the main source of income for the participants was a salary in line with the number of people employed and this was shown to be three (60%) as displayed in Table 4.9 (below). It also revealed that one (20%) of the participants was medically boarded and on pension.

The other participant (20%) was having absolutely no source of income. This is very likely to have an impact on adherence to their treatment in terms of regular attendance at the clinic, ensuring that they have adequate food to take with treatment and money to cover transport and other related costs.

**Table 4.9. Main source of income of the participants (N=5)**

<b>MAIN SOURCE OF INCOME</b>	<b>FREQUENCY</b>	<b>PERCENTAGE (%)</b>
Salary	3	60
Pension after medically boarded	1	20
No income	1	20
<b>Total</b>	<b>5</b>	<b>100</b>

### **4.3. RESULTS OF THE FACE TO FACE INTERVIEWS**

The researcher adopted a thematic analysis method to analyze data from the interviews. From the transcripts it was possible to identify main themes and these became the basis for the analysis of the data obtained.

#### **4.3.1. IDENTIFIED MAIN THEMES OF THE INTERVIEWS**

Table 4.6 depicts the main themes that emerged from the interviews and these themes outline the information provided during the interviews. Each participant is identified by a code, like for example “participant 3”. The important concerns expressed by the participants are highlighted in the analysis. In practice the themes are strongly linked to each other and as such, some repetition of key points was unavoidable.

**Table 4.10. Themes emerged from the interviews**

Identified Theme	Findings from participants
<p><b>Theme 1:</b>  <b>Experiences of PLHIV on ART</b></p>	
<p>Life before you start the treatment (ART)</p>	<p><i>“I was always sick. I consulted many doctors and could not get the cause of my sickness. Doctors could not even tell me to check blood. One lady requested me to come to hospital to test, I came and tested and found out that I am positive. I used to take heart treatment and was difficult before I took treatment” (Participant 2)</i></p> <p><i>“I was very sick, a lot. My CD4 was very low. I got treatment at the hospital. They told me that I must take the treatment. I was very weak. I went to the doctor and took a blood test and was told that I am HIV positive” (participant 3)</i></p> <p><i>“I saw my body becoming weak, and was in and out of hospital. I then ask(ed) them to test me. No, it was ok. People were saying maybe I was bewitched and it was not like that, it was AIDS. I spoke to the nurses and they said I must start with the treatment.” (Participant 4)</i></p> <p><i>I used to get sick all the time, I did not know what was the problem and coming to the hospital has helped me a lot. The treatment that made me dream somehow, “laughs”. Yes, I did change my behavior, used to drinking a lot and (I) stop(ed) drinking alcohol and other (things)” (Participant 5)</i></p>

<p>Missing doses of PLHIV on ART</p>	<p><i>“I started getting lazy going to hospital for treatment. One of the ladies who were attending the clinic came to see me, because she was not seeing me at the hospital. She requested me to go to hospital to take treatment. She told the care-givers to come and talk to me to go to hospital. My body was weak and was doing nothing at home” (Participant 1)</i></p> <p><i>“You know, we are males, sometimes you go far to work there, and people that you work with and (the) employer does not understand your disease, but you try to explain to them, but they don’t understand. I ended up missing my treatment. I stopped treatment not more than 2 months (ago).” (Participant 5)</i></p> <p><i>“No, I want to live and I don’t want to die now”. (Participant 2)</i></p>
<p>Poverty and Hunger of PLHIV on ART</p>	<p><i>“Many people are weak and don’t have power to work. I think giving them (a) grant or food will be ok. Many people struggle because of not having food.” (Participant 1)</i></p> <p><i>She said with a sigh: “... I have a problem of getting food, this treatment makes you to eat a lot and I don’t earn much...” (Participant 4)</i></p>
<p>Benefits of being on ARV treatment</p>	<p><i>“So I got used to treatment and things got better and I was right [healthy], my weight improved because I lost weight from 45 kg, it improved to 66 kg. So this year I able to go back to work.” (participant 3)</i></p>



<p><b>Theme 2:</b> <b>Social support for PLHIV on ART</b></p>	<p><i>“The only person who knows is my daughter who will disclose to my parents when my last days come, because she’s my blood she’s with me through all hardships.” (Participant 2)</i></p> <p><i>“I think home is an important support system, people who are close to you, someone, or all, need to know at home so that they remind you.” (Participant 1)</i></p> <p><i>“There are a lot of support groups here. We attend Thursdays and Fridays. My family supports me a lot. I try to assist other people. Other people believe when you talk about yourself, your experiences, and what you have gone through. [...] I told my mother, I told my brother, they all support me...” (Participant 3)</i></p>
<p><b>Theme 3:</b> <b>Knowledge of PLHIV on ART</b></p>	<p><i>“They assist immune system to go up and if you cannot eat well, you start eating and gaining weight. They give you tablets to eat well, if you vomit, not to vomit.” (Participant 3)</i></p> <p><i>If you don’t drink on time and always, the disease will come back and grow.” (Participant 2)</i></p>
<p><b>Theme 4:</b> <b>Attitudes of PLHIV towards ART</b></p>	<p><i>“I was unable to walk when I came here, and my CD4 were 120, now my CD4 is 300, I could not work.” (Participant 2)</i></p> <p><i>“My concern is that, when are we going to get healed? When is the tablet for healing going to come?” she asked. “I am ok at the moment, I can work for myself, and the treatment is ok.” (Participant 3)</i></p> <p><i>“I am concerned about what food to eat? And sometimes there is no money to buy food. Treatment is</i></p>

	<p><i>ok; it is helping me a lot.” (Participant 4)</i></p> <p><i>“I used to get sick a lot and (have) no money. I needed money to buy food when taking treatment and taking care of my kids.” (Participant 1)</i></p>
<p><b>Theme 5: Unemployment and economic support of PLHIV on ART</b></p>	<p><i>“Many people are weak and don’t have power to work, I think giving them a grant or food will be ok. Many people struggle because of not having food to eat.”(Participant 2)</i></p> <p><i>“(I) Think the government should give us (a) grant for the disease.” (Participant 3)</i></p> <p><i>“About the grant, we must be assisted. It is difficult if the tablets are finished and you don’t have money for transport to the hospital.” (Participant 5)</i></p>

#### **4.3.2. Theme 1: Experiences of PLHIV on Antiretroviral treatment**

This section (and the subsequent ones) reports on the identified themes that were generated from the interviews transcribed with all the participants. However, some of the statements may appear in more than one theme where they reflect different meaning and experiences.

##### **4.3.2.1: Life before you start the treatment**

This sub-theme describes the experiences, as shared by the participants, before finding out their HIV positive status, how long after they discovered their status they started the treatment and what it was like living with an HIV infection and on treatment. Furthermore, the participants shared their experiences in relation to issues of adherence to ART. Participants highlighted that before knowing their HIV positive

status they were suffering from multiple illnesses, they were always in and out of hospital due to illness. They had repeated bouts of sickness.

*“I started getting lazy going to hospital for treatment. One of the ladies who were attending the clinic came to see me, because she was not seeing me at the hospital. She requested me to go to hospital to take treatment. She told the care-givers to come and talk to me to go to hospital. My body was weak and was doing nothing at home.” (Participant 1)*

*“I saw my body becoming weak, and was in an out of the hospital. I then ask(Ed) them to test me. No, it was ok. People were saying maybe I was bewitched and it was not like that, it was AIDS. I spoke to the nurses and they said I must start with the treatment.” (Participant 4)*

Almost all participants indicated that the issue of adherence were discussed when they start the treatment. These are their responses:

*“Yes, they told me about that. If you don’t drink on time and always, the disease will come back and grow. They told me that if you leave a space, the disease will come back and grow.” (Participant 2).*

*“Yes, they did. If they tell you to come on the date they give you, you must come on that date, like today is on the 20<sup>th</sup>, and next appointment will be on the 18<sup>th</sup> of next month, so I will come back so that I must not miss any dose.” (Participant 3)*

*“Yes, the sister here at the hospital told us to take the treatment on time, if you take it at 7 o’clock; you must always take it at the same time.” (Participant 4)*

*“Yes, they told me that if you miss treatment, you will die.” (Participant 5)*

NDOH (2010) indicates that ART is a life-long treatment and requires adherence to be effective, and to prevent the development of resistant strains. According to Sithole (2013), it is indicated that an individual’s motivation, determination and the ability to manage his or her illness, available resources and support systems, understanding

the possible consequences of non-adherence and expectation of positive treatment outcomes all interact to impact on adherence.

According to the NDOH (2015:36) education on adherence to treatment starts at the beginning of the treatment cascade, when a patient is diagnosed as HIV-positive. Furthermore, adherence includes taking treatment as prescribed, keeping to appointments for test results, referrals and further investigation.

The patients' motivation to continue engaging with care regardless of eligibility for ART is influenced by their experience with the healthcare system and the attitude of healthcare providers.

#### **4.3.2.2. Missing doses of PLHIV on Antiretroviral treatment**

Of the five participants, two participants indicated that they have missed treatment before. The findings are shown below:

*“Yes, in 2011, I started getting lazy going to the hospital for treatment. One of the ladies who were attending the clinic came to see me, because she was not seeing me at the hospital. She asked me to come to the hospital to take the treatment. My body was weak and was doing nothing at home.” (Participant 1)*

*“Yes, I did miss the treatment, you know , we are males, sometimes you go far because you are working there, and people that you are working with don't understand your disease, you try to explain to them, but I ended up missing my treatment. I was not well; it was not the same when I start treatment, like I was feeling weak, as if I will fall. I stopped treatment for two months and went back to clinic to collect the treatment.” (Participant 5).*

However, the other three participants indicated that they never missed any treatment. But they had difficulties taking the morning doses.

*“No, I want to live and I don't want to die now. When I started the treatment, the one that I used to take during the day, I used to have hallucinations but now I am well.” (Participant 2)*

*“I have never missed any treatment, it is the law, and I am not supposed to miss any dose. The one during the night is difficult, if you take it, you feel dizzy but the next day, and I will come to the clinic and tell them about it.” (Participant 3).*

*“No, I never missed taking treatment. The dose in the morning is difficult because I get tired taking them. I cannot miss a treatment, I saw a lady that was taking ART with her, she stopped taking treatment for 3 months, and when she came back to clinic, she was using (a) wheelchair; she started drinking alcohol and not taking treatment. I told myself that I will not miss treatment.” (Participant 4)*

According NDOH (2012) indicates that across many medical conditions 50% or more of all patients stop taking their prescribed long term medication within the first year of initiation. Sithole (2013) indicates that this could be due to a number of reasons including the fact that patients have to submit to treatment for the rest of their lives, the number of tablets taken daily and co-infection with other chronic illnesses. In this study, two (40%) of the participants stopped or missed the treatment which correlates with the above statement.

#### **4.3.2.3. Poverty and hunger of PLHIV on Antiretroviral treatment**

The participants indicated several factors that complicate adherence to treatment, sometimes leading to non-adherence for a period, but often just making adherence more difficult. Lack of employers' and colleagues' support and lack of education about the HIV/AIDS was reported by participants during the interviews (Participant 5). Participant 1 reported feeling lazy and staying at home for more than a month without going to the hospital to collect her medication.

*Many people are weak and don't have power to work, I think giving them (a) grant or food will be ok. Many people struggle because of not having food.” (Participant 1)*

*“... I have a problem of getting food, this treatment makes you to eat a lot and I don't earn much...” (Participant 4)*

According to Sithole (2013), patients on ART indicated that food complicates adherence and can also be a cause of non-adherence. Furthermore, in a number of cases treatment with ARVs made people hungrier, but they could not afford the cost of additional food. Witpoort Hospital provides nutritional food (food supplements), such as fortified high protein supplements and other nutritional supplements recommended by dieticians. Mukherjee et al. (2006:124) state that lack of adequate food has also been associated with poor adherence to ART. This is in correlation with the responses of the participants interviewed in this study.

According to Simoni et al. (2009,192) and Kagee (2006:416) poverty can influence adherence because access to financial means to travel to and from the ART clinic, to pay for child minders during parents absence to access treatment and to attend to several, competing needs and responsibilities all come into play. For the poor and unemployed, lack of financial resources to pay for the kind of food stuffs required to be taken alongside medication may be of concern. According to the NDOH (2010:9) poverty is one of the major contributors to poor health and treatment outcomes through food insecurity in as far as HIV and TB acquisition and treatment adherence are concerned. In this study, the findings show that three (60%) participants were employed temporarily and the other two (40%) were unemployed and dependent on the grant provided by the South African government.

#### **4.3.2.4. Benefits of being on Antiretroviral treatment**

This sub-theme highlights the participants' experiences about the outcomes of being on ART. Almost all interviewees shared positive outcomes and experiences while taking ART, including an improvement in physical, social and emotional well-being, as well as a greater sense of optimism about the present and the future. Although some participants raised concerns about the possible long-term side effects of medication that could counteract the positive outcomes, many participants mentioned that being able to continue to care for their families and children was an enormously beneficial

outcome of being on ARVs, and interviewees praised ART for the positive results they noticed in their health (including weight gain and the return of physical strength).

*“I was unable to walk when I came here, and my CD4 were 120, now my CD4 is more than 300. I could not work. They boost the immune system of the body.” (Participant 2)*

*“I noticed the difference, started to gain weight and recovered from weakness and became normal again. Even people who knew me when I was sick noticed the difference.” (Participant 3)*

*“I feel very well, I’m light, able to work, before my whole body was sore...I’m well, I highly recommend these pills.” (Participant 4)*

*“I was told that I have to take treatment, I was weak and lost weight. Now, I am well and have gained weight and working and my skin is beautiful now.” (Participant 5)*

The findings in this study show that the provision of ART to people living with HIV and requiring treatment in South Africa has brought hope to people who would not have survived. It has led to improved quality of life, reduced morbidity, mortality and the number of deaths resulting from AIDS-related illnesses and has generally prolonged the lives of many people living with the virus. This correlates with the findings of all participants interviewed in this study. According to the UNAIDS (2012), there is a significant decline in the number of AIDS-related deaths by at least 24% since 2005 and in 2011 there were 1.7 million deaths reported. Li (2014:998-1010) postulates that ARVs have revolutionized the management and care of HIV and AIDS patients. In addition, new results of these studies indicate that HIV and AIDS patients can recover to some extent from AIDS stage III to HIV infection.

#### 4.3.3. Theme 2: Social support for PLHIV on Antiretroviral treatment

This theme describes the support structures available for PLHIV on ART and the importance of having these when coping with the demands of the ART programme. Participants mentioned a variety of support needs, including: emotional support, food, family support, and support from health professionals.

In this study, it was found out that families were placed at the forefront of social, emotional, physical and economic support for ART and care. Relatives are often sources of information and encouragement on advising other members to go for HIV testing, including where to go and where to access support for HIV related care and ARVs.

*“My mother and my children know about my status and support me a lot. My neighbours know as well. The support group was there, where even the social workers used to come and talk to us but now is no longer there.” (Participant 1).*

*“I think the home is an important support system, people who are close to you need to disclose to make it easy, even if you forget the pills someone at home will remind you by asking if you’ve taken your pills.” (Participant 2)*

*“I knew my status in 2005 and my health status was not good, my sister kept on saying I must take ARVs...I asked my sister to come and sleep with me...she kept on reminding me not to forget and I told her I’ll never forget.” (Participant 3)*

*“I have no problems; my daughter supports me and my parents are a warm, my children make sure I take pills at the correct time, they ask me if I’ve taken pills, they even pack for me the ones I take when I’m at work... my daughter is with me through all hardships.” (Participant 4).*

According to the NDOH (2011), community health workers (CHWs) are significant people in providing support for PLHIV. Their roles include home visiting for further



support regarding adherence to treatment (including treatment for opportunistic infections), assisting with the various difficulties of disclosure and making arrangements for food parcels if necessary.

*“There are CHWs who do home visits so she was referred to come to my house. I was able to visit the clinic again. She motivated me because I wanted to desert taking treatment but she encouraged me to continue with my treatment.”* (Participant 1)

Almost all participants highlighted the support they got from the nurses and doctors who were rendering treatment, care and support in the ART programme.

*“Yes, sometimes I used to not sleep at night. I went to the clinic and talk to (the) nurses and they told me to continue taking the treatment. They are doing a wonderful job and I am happy with them.”* (Participant 2)

*“I do talk to them if I have a problem and I am happy with them.”* (Participant 3)

*“Yes, I do, and they are doing ok and I am happy with them. If you have a problem, the sisters have love, they don’t talk bad about us, they are nice to us.”* (Participant 4)

*“Yes, I talk to them, they assist me a lot. I call them teachers.”* (Participant 5)

This theme is an important factor in supporting adherence, and it was mentioned by most of the participants. However, ARV patients are usually shocked when they first realize they have contracted HIV, and often find it difficult to disclose to family members and community support groups and so do not receive the social support they deserve and it is shown by their responses below.

*“I did not want people to see me taking treatment. I used to take my treatment in town because of that. I am free now because we are many here who are taking treatment.”* (Participant 2)

In contrast, other participants indicated that they have a support group and used to attend on Thursdays and Fridays.

*“There are a lot of support groups here. We attend Thursdays and Fridays. My family supports me a lot. I try to assist other people. Other people believe when you talk about yourself, your experiences, and what you have went through. I told my mother, I told my brother, they all support me ...”* (Participant 3)

People affected by and infected with HIV are often subjected to discrimination and rejection by their friends, family, sexual partners and work colleagues (Evian 2011). Even though they may be motivated to adhere to their ART for personal reasons, lack of or poor support from their loved ones, or feelings of being discriminated against or stigmatised as a result of being HIV positive may negatively impact on adherence. In this study, the findings are that all five participants reported that they have disclosed to family members especially the sister and the children. This is what they had to say:

*“Yes, I have disclosed to my daughter who was born in 1993. I also told my sister. She accepted and did not have a problem.”* (Participant 2)

*“Yes, I did disclose to my sister, then my children. My sister did not have any problem and she said I must just take treatment.”* (Participant 3).

*“Yes, I spoke to my brother and my father. My father was not happy but he took me to town and we talk about it. After that he was ok with that.”* (Participant 4).

*“Yes, I told my mother and my sisters. They told me is part of life. I don’t have to think otherwise and they told me you will live like others.”* (Participant 5).

It is evident from this study that almost all the participants interviewed, reported that they received some social support from families and some engaged in community groups activities. WHO (2006:28) suggests that positive attitudes of the community towards people living with HIV play a significant role in influencing adherence. Adults on ART and receiving community based support.

According to AIDS Map (2012), it was found out that of the 19,668 patients only 6% of those receiving community based adherence support were lost to follow up as compared to 9% of those not receiving community-based adherence supports. Heyer and Ogunbanjo (2006:6-7) state that the presence of social support systems such supportive family members, friends and treatment supporters have been consistently associated with good adherence to treatment. In this study, the findings correlate with the statements given and shown in the responses above of all the participants interviewed.

#### **4.3.4. Theme 3: Knowledge of PLHIV about Antiretroviral treatment**

This theme describes the knowledge that the participants have regarding ARVs. The participants were asked questions such as whether they know about ARVs, their names, whether they know what ARVs do to the human body and any information provided regarding ARV. Almost all participants seem to have knowledge of antiretroviral treatment they are taking, even though none of them were able to call ARVs by their correct names.

*“I know that the medication decreases the strength of the virus and rendered it weak. Also assist the body not to get diarrhea.” (Participant 1)*

*“I was told that I must drink it on time at nine in the morning and nine in the evening. I am not allowed to miss treatment; they told us that if I miss treatment, the disease will come back.” (Participant 2)*

*“They assist the immune system to go up and if you cannot eat well, you start eating and gaining weight. They give you tablets to eat well, if you vomit, not to vomit.” (Participant 3)*

*“The treatment should get completed every month. You must drink the medication at the right time; you don’t have to miss the treatment.” (Participant 4)*

*“Yes, I know them. I wrote their names somewhere. They make me dream somehow, sometimes I am dizzy.” (Participant 5)*

According to Seeling, Mavhunga and Thoma (2014:268), knowledge about HIV and AIDS and the benefits of ART is regarded as crucial for accepting the offer to get tested. Furthermore, their study that looked into knowledge of the PLHIV, it was found out that knowledge was remarkable high. In addition, the knowledge of ART drug combinations, appropriate time to start ART, the benefits of taking ART regularly and possible results of not adhering to one's ART was high among all the participants. In this study, the participants' knowledge is also high and it correlates with the participants responses mentioned above. Participants were able to know the benefits of ART, appropriate time of taking ART and the issue of adherence was known. The patients' knowledge of ART is crucial in this study. It is the assertion of this thesis that if PLHIV were given information about the benefits and the side effects of ART and its impact on their wellbeing, the issues of adherence and loss to follow-up would be minimized and more people would be tested and if positive start the treatment.

#### **4.3.5. Theme 4: Attitudes of PLHIV towards Antiretroviral treatment**

This theme describes what the feelings regarding the treatment are, whether the treatment they are getting is helpful, whether the ARVs make the patients sick, why they started the treatment and whether they can advise other people to take the treatment.

All participants were positive about taking ART. The positive attitudes reported came from the participants' experiences since they started treatment.

*"I used to get ill a lot and no money. I needed money to buy food when taking the treatment and also taking care of my kids. Many people are weak and don't have power to work, giving them a grant or food will be ok." (Participant 1)*

*"As for me, I want the government to help us, since I am HIV positive, I don't have a house of myself, and I want the government to build the house for me. If I die, I want my children to have a place to stay. As for other people, I think the government must help people with money. Other people cannot get a job like me. Giving them money or a grant will help." (Participant 2)*

A major concern for almost all the respondents was that of prolonging life and all referred to it as a significant benefit of ART.

*“I was unable to walk when I came here, and my CD4 were 120, now my CD4 is 300, I could not work.” (Participant 2)*

*“My concern is, “when am I going to get healed?” When the tablet for healing is going to come? I am ok at the moment, I can work for myself and the treatment is ok.” (Participant 3)*

*“I am concern about what food to eat? And sometimes there is no money to buy food. Treatment is ok; it is helping me a lot.” (Participant 4)*

*“I used to get sick a lot and no money. I needed money to buy food when taking treatment and taking care of my kids.” (Participant 1).*

Almost all participants indicated that they can advise other people to take treatment. The findings are indicated below:

*“Yes, I saw it by myself, taking treatment has helped me to live, gave strength and I am able to work at home now.” (Participant 1)*

*“Yes, I can advise them to take treatment. At the moment I do tell them to go to hospital or clinic to test. I am not ashamed of my condition; I can tell anyone that I am HIV positive.” (Participant 2)*

*“Yes, if the person can come to me, I can see the person who is sick with HIV. I can talk to that person to go to clinic to test.” (Participant 3)*

*“Yes, HIV, I know HIV, if someone does not want to test and I see that person, I can talk to him that I am also HIV positive and tell him to go to Hospital for testing, even if he does not ask for help.” (Participant 5)*

Sellam (2014:98) indicates that prejudice and stigmatization refers to a specific attitude which is a combination of hostile feelings, negative emotions and hostile behavior towards others.

Many personal attributes such as commitment, positive self-esteem, motivation and ability to deal stress and adaptability have been indicated by the participants in this study. Almost all participants were motivated to live and continue taking their treatment as required.

#### **4.3.6. Theme 5: Unemployment and economic support of PLHIV on Antiretroviral treatment**

This theme describes the unemployment and economic factors that support the participants. Questions such as whether they are earning an income and whether there are any existing economic services helpful for PLHIV were asked, to understand the participants economic support factors. Furthermore, unemployment plays an important role in whether patients are able to adhere to their treatment regimens or not. It relates to factors such as transport and food costs that patients incur when they attend clinic in order to take their medication well (NDOH 2010).

Two of the five participants interviewed were unemployed and the other three participants were employed temporary, working piece jobs as they call it.

None of the women interviewed were in a relationship due to issues of lack of trust. Financial difficulties were reported almost by all participants. Their responses are indicated below:

*“Many people are weak and don’t have power to work, I think giving them a grant or food will be ok. Many people struggle because of not having food to eat.” (Participant 1)*

*“I think the government should give us a grant for the disease.” (Participant 3)*

*“About the grant, we must be assisted. It is difficult if the tablets are finished and you don’t have money for transport to the hospital.” (Participant 5)*

According to Yoder et al. (2009), many patients experienced financial problems which meant they encountered problems in obtaining appropriate food and paying for transportation to the nearest facility to collect their medication.

Hardon et al. (2007) indicated that patients struggled with transport and user fees, long waiting times, lack of food, side effects from medication and stigma. The findings in this study show that three (60%) were employed, even though in 'piece jobs' and two (40%) were unemployed and dependent on the social grant. All participants interviewed struggled financially. A study by Ware (2009) also found that scarcity of resources was a constant problem for adherence and patients had to beg, borrow or otherwise struggle to fund for transport to obtain their monthly medication.

#### **4.4. SYNTHESIS OF THE STUDY**

The objective of the study was to gain understanding of the participants' experiences, knowledge and attitudes in their own words. The information was sought through the use of interviews conducted with five participants. The issues reported by the participants affecting adherence as their lived experiences were unemployment and economic support, lack of knowledge of the employers and colleagues and also laziness of some of the participants.

Factors reported by participants as promoting and supporting adherence are: being able to live better and able to see their children grow, support from their families and friends and a good quality of life. The information, motivation and behavior (IMB) model of adherence emphasizes that for adherence to happen one has to receive relevant information, getting motivated by the outcome and change behavior. There is always a benefit for changing one's behavior about the consequences of one's action. The respondents reported that they were given relevant information about the benefits of ART and about the danger of not taking the medication correctly as recommended. They were taught that the treatment would enable them to continue having a good quality of life, give them the opportunity to support their families.

#### **4.5. CONCLUSION**

In this chapter, the participants' background information was presented. Their experiences were divided into five themes and were defined and described. The following chapter will discuss the results, recommendations to other researchers for further research and to the authorities for implementation. It will also make conclusions of the research.



## **CHAPTER 5**

### **DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1. INTRODUCTION**

The previous chapter presented all the data and findings of the study. In this chapter the researcher discusses a summary of the findings, conclusions and recommendations for both health authorities and for further research opportunities. These are discussed in relation to the objectives of the study as set out at the beginning. The researcher also outlines the identified strength and weaknesses of the study.

#### **5.2. SUMMARY OF FINDINGS ACCORDING TO THE OBJECTIVES**

The main aims of the study were to investigate knowledge, attitudes and experiences of people living with HIV who are on ART at a public health clinic in Limpopo.

##### **5.2.1. OBJECTIVE 1: KNOWLEDGE OF PEOPLE LIVING WITH HIV TOWARDS ANTIRETROVIRAL TREATMENT**

The first objective of the study was to investigate the knowledge of patients on ART the findings showed that the patients know ART, what it does in the human body, even though all five (100%) were unable to correctly pronounce the names of the ARVs. This is also supported by the information, motivation and behavior model which suggest that personal, behavioral and environmental factors largely determine one's actions according to Munthli, Mvula and Maluwa-Banda (2014). Having a good knowledge and understanding of the benefits the patients can derive from adhering to ART may encourage the patients to take their treatment as required.

All five of the participants interviewed (100%) shared positive outcomes and experiences while taking ART, including an improvement in physical, social and emotional wellbeing as well as greater optimism about the present and the future. This knowledge is crucial for patients to appreciate the importance of the ART and the

required adherence for it to work optimally and produce positive outcomes. Although participants raised concerns of possible side-effects of medication, all of them (100%) mentioned that being on ART has enabled them to continue to care for their families and children and has been a great benefit. All indicated that they will never stop taking the treatment.

### **5.2.2. OBJECTIVE 2: ATTITUDES OF PEOPLE LIVING WITH HIV REGARDING ANTIRETROVIRAL TREATMENT**

All five of them (100%) reported feeling much better after taking the treatment and yielded better results. Participant said they trusted the nurses and felt that they were listened to, respected and given a chance to ask questions.

According to Sellam and Flower (2014), attitudes originate from human cognition and are closely linked and influenced by perceptions. Beaulieu et al. (2014) also reports that people's attitudes, change of behavior and optimal adherence depend on the knowledge, information, feelings and emotions they possess and this is supported by theoretical model used in this study, which indicates that inaccurate information plays an important role in negatively affecting adherence.

According to Mayberry and Osborn (2014), the IMB model of adherence, medication adherence is determined by the extent to which an individual is informed about his/her regimen, is motivated to adhere, and possesses the necessary behavioral skills to adhere in a variety of situations. Furthermore, according to Fisher and Amico (2008), adherence information includes accurate knowledge about the regimen, potential side effects and drug interactions. In addition, adherence motivation is a function of personal and social motivation to adhere and personal motivation to adhere to regimen reflects an individual's attitudes about adherence and is based on one's beliefs that medication is helpful and not taking medication as prescribed would have undesirable consequences.

However, having the accurate knowledge or information about the treatment, the motivation and skills necessary to change the behaviour, is not a green light to optimal adherence but there are still factors such as disclosure of the status, the beliefs, experiences and the family and community support system, access to the health facility, reliable transport system and money can have an effect on whether the patient adheres to his or her treatment.

The personal attributes such as positive self-esteem, commitment, ability to deal with stress and motivation are important in optimal adherence. In this study, all the participants have benefited from ART in a variety of ways, such as enhancing quality of life and fulfilling family obligations.

All participants reported that they are happy about the programme, about the staff in the facility and about ART. However, challenges are still there and need the ART programme to address them in order to strengthen adherence and treatment outcomes.

### **5.2.3. OBJECTIVE 3: EXPERIENCES OF PEOPLE LIVING WITH HIV TOWARDS ANTIRETROVIRAL TREATMENT**

This research has revealed a numbers of experiences of people living with HIV and AIDS such as good knowledge of ART, positive attitudes towards ART and some concerns about the ART programme. Yoder et al. (2009:70) indicates that experience results in knowledge and understanding gained either individually or as a group or society through day-to-day living.

The most immediate form of experience reported by all participants was a personal experience, the body of knowledge gained individually through encountering situations and events in this HIV/AIDS journey of life. Challenges such as a lack of knowledge by employers, poverty and unemployment were reported as some of the barriers to optimal adherence. The researcher observed during clinic visits, that written information and materials about adherence and treatment guidelines and protocols to reinforce adherence are available in the clinic. The participants interviewed were generally happy with the outcomes of treatment. Some participants

complained about side-effects early during the treatment and the demanding nature of ARV regimens. Almost all participants experienced problems during the early days of the treatment and there were advised to stick to treatment.

#### **5.2.4. OBJECTIVE 4: ECONOMIC FACTORS THAT SUPPORT PEOPLE LIVING WITH HIV**

Social and economic factors may combine to yield poor adherence outcomes in South Africa. In addition, many patients studied experienced financial constraints for food and transportation to the nearest facility to collect medication, long waiting times, poverty and hunger, lack social support, side effects and lack of appropriate counseling. All these factors undermine the adherence to antiretroviral treatment (Kagee 2006:415)

It is crucial to note that in this study three (60 %) of the participants reported having no problems adhering to their treatment whilst two (40%) agreed and admitted having stopped ART for more than a month prior for these interviews which is in essence non-adherence to treatment as it was prematurely stopped. The findings show that there is generally poor adherence to treatment regimes in this study.

Hardon et al. (2006) conducted a study in Tanzania, Uganda and Botswana concludes that costs of food and transport to and from the clinic serve as a deterrent to ART optimal adherence. Transport costs and money for food were reported to be a burden for almost all respondents and a treatment-related increase in appetite posed an additional challenge especially because most of the respondents are not employed and depend on the government grant and “piece jobs”. However, the government provides some nutritional support if needed in the form of nutritional supplements provided by the dieticians in the clinic and also a grant in the form of monetary value on a monthly basis depending on the status of the patients.

### **5.2.5. OBJECTIVE 5: SOCIAL FACTORS THAT SUPPORT PEOPLE LIVING WITH HIV**

According to Roura et al. (2009:48), social support is believed to affect adherence behaviors both directly (e.g. through positive reinforcements and encouragement) and indirectly (through variables that compromise adherence such as stress, anxiety and depression). Mukherjee et al. (2006:124) posit that social support comes in the form of emotional support from family, friends and peers as well as from social interactions in the community, including with health care providers. In addition, these factors have been found to have a great potential to impact on adherence to treatment.

Furthermore, family support and religious beliefs about illness and medication may influence motivation and adherence. Factors such as unemployment, difficulty taking medication at work and dependency on social grants were reported as having negative bearing on adherence. It is reported in this study that two (40%) were unemployed and dependent on the social grants but had managed to be adherent with medication despite the unfavorable circumstances.

In this study, almost all participants acknowledged the support they received from their immediate family members such as parents, partners and children. In addition, some stressed the importance of support from support groups in their communities. It emerged that almost all participants interviewed tended to have a good attitude towards their lives and good adherence to ART.

From the study it emerged that a great many social factors play a significant role in determining whether patients adhere to their treatment or not. This is supported by Heyer and Ogunbanjo (2006:8), who suggest that personal, behavioral and environmental factors largely determine one's actions.

### **5.3. WEAKNESSES AND STRENGTHS OF THE STUDY**

The study has some weaknesses and strengths that come out of the findings.

#### **5.3.1. The weaknesses of the study**

- 1) Selection bias may have occurred as only those patients who were on ART treatment at the time of data collection were included. The research was conducted among people living with HIV and who are on ART; but only those attending the Witpoort Hospital Wellness Clinic, in the Lephalale Local Municipality and who are six months and above on ART were included in the study. Those that were HIV positive and on ART but for less than six months and those who were lost to follow-up at the time of data collection were excluded. The findings of this study are not representative of other locations in the Lephalale Municipality.
- 2) The use of open-ended questions in a qualitative study gives much discretion to researchers and participants. It was also observed that the presence of the researcher can potentially influence the behavior and findings of participants especially males. In this research only one male participant agreed to participate; this can compromise research findings.
- 3) The interviews were conducted at the Wellness Clinic in the dietician consulting room for the convenience of both the interviewer and participants. The interviewers were viewed as staff members and these could lead to over-reporting of adherence to appease the researcher.

#### **5.3.2. The strengths of the study**

- 1) The study was able to meet all the objectives as outlined in the beginning which was to explore and investigate the knowledge, attitudes and experiences of people living with HIV and on ART at a public health clinic in Limpopo.
- 2) The study focused mostly on the exploration of factors that influence adherence and non-adherence. The role and the impact that family and social support,

unemployment, food and knowledge of ART have on the optimal adherence of these patients was studied in detail.

#### **5.4. RECOMMENDATIONS FOR FURTHER RESEARCH**

- This study was conducted in a rural area, it is recommended that the similar study should be conducted in an urban area; then one would be able to compare and contrast the rural and urban area findings.
- Social and economic support is an important factor in achieving optimal adherence. It is recommended that the role of social and economic support in adherence should be explored with the aim of developing improved implementation strategies.

#### **5.5. RECOMMENDATIONS STEMMING FROM THE FINDINGS**

The research involved the exploration and investigation of the knowledge, attitudes and experiences of people living with HIV and on Antiretroviral Treatment (ART) at the Witpoort Hospital Wellness Clinic.

- 1) The findings suggest that patients are experiencing problems and challenges in their efforts to attain optimal adherence. Conclusions by the researcher were made that these might be some of the challenges and factors causing patients to become lost to follow-up. It was shown through interviews of the participants that transport and food costs, lack of proper counseling, poverty are some of obstacles to optimal adherence. ART programmes need to find ways to confront these constraints.
- 2) Treatment programmes also urgently need to find ways to reduce waiting times for ART patients coming for refills and take into consideration the work schedules of ART users.
- 3) Pharmacists and nurses can play an important role in this follow-up care. Their involvement can also reduce the workload of doctors. To provide good quality

care, all auxiliary health workers should be trained to recognize clinical signs of treatment failure, such as emergent opportunistic infections, and to provide adequate adherence support. It is recommended that task shifting from pharmacists to auxiliary health workers should be explored.

- 4) Adequate counseling services are needed at health facilities or in communities in both the initiation and continuation phases of ART to help patients cope with the side effects of ART, identify and confront the social constraints to adherence, and address the financial problems that ART patients face. Training programmes for counselors and people taking ART are limited. It is recommended that adequate counseling should be explored with the objectives of developing implementation plans and strategies.
- 5) Programmes for ART adherence counseling exist in South Africa and could be used more fully. More specifically, adherence support programmes need to find ways to help ART patients to remember to take their pills on time, for example through alarms on mobile phones, or through using popular radio programmes as a prompt. Adherence support could recognize the potential role of children in adherence support, and provide them with adequate information on ART, for example through school education programmes, to empower them in their role as treatment supporters. Who then becomes a treatment supporter?

## **5.6. CONCLUSION**

The aim of this study was to investigate the knowledge, attitudes and experiences of people living with HIV and on ART at the Witpoort Hospital, Limpopo Province. It is envisaged that the findings of this study will help the health care professionals and the Provincial Department of Health to develop intervention strategies and programmes that will help in identifying those patients at risk of non-adhering to treatment and those that need support for optimal adherence. The most commonly reported experiences on ART in this study were inability to take treatment at work, being just too lazy to go to clinic for follow-up visits and forgetting to take the treatment. It also emerged that a lack of HIV and AIDS knowledge of the employers and colleagues contributed to some participants not adhering to their treatment.



## LIST OF SOURCES

Abdool Karim, S.S. and Abdool Karim, Q. (2010). HIV/AIDS in South Africa. Second edition. Cambridge.

AIDSinfomap. 2012. *Community-based support, aids retention, adherence and Treatment response*. Available at <http://www.aidsmap.com>. (Accessed on 10 July 2014).

AIDSinfonet. (2012). *How much adherence is enough?* Available at [http://www.aidsinfonet.org/fact\\_sheets/view/405#FATIGUE](http://www.aidsinfonet.org/fact_sheets/view/405#FATIGUE) (Accessed on 10 July 2014).

Amico, K.R., Toro-Alfonso, J. and Fisher, J.D. (2005). An empirical test of the Information, Motivation and Behavioral Skills Model of Antiretroviral Therapy Adherence, *AIDS care* 17(6).

Atav, S., Senir, D. and Darling, R. (2015). Turkish and American Undergraduate Students' Attitudes Toward HIV/AIDS Patients: A Comparative Study,. *Nursing Forum*

AVERT. (2011). *HIV and AIDS treatment*. Available at <http://www.avert.org/aidssouthafrica.html> (Accessed on 20 May 2014).

Babbie, E. and Mouton (2001). *The Practice of Social Research*. Oxford University Press. Cape Town.

Babbie, E.R. (2010). *The practice of social research*. Belmont: Wadsworth, Cengage Learning.

Beaulieu, M., Andrien, A. and Potvin, L. (2014). Stigmatizing attitudes towards people living with HIV/AIDS: validation of a measurement scale. *BMC Public Health*, 1246.

Berg, H.E. (2015). The Effect of Familial Support, Socioeconomic Status and Stigma on Adherence to Antiretroviral Therapy Among Women in Hartford CT: A Qualitative Approach.

Brink, H.L. (1996). *Fundamentals of research methodology for health professionals*. Knwyn: Juta.

Bucciardini, R., Fragola, V. and Abegaz, T. (2015). in: *Care of Adult HIV Patients Initiating Antiretroviral Therapy in Tigray, Ethiopia: A Prospective Observational Cohort Study*,. *PLoS one*, 136-146.

Calitz, A., Strydom, T. and Roux, H. (2014). Factors that affect social workers' job satisfaction, stress and burnout. *Social Work*, 153-169.

Collins, K.M.T., Onwuegbuzie, A.J. and Jiao, Q.G. (2006). Prevalence of mixed methods sampling designs in social science research. *Evaluation and Research in Education* 19(2): 83-101.

Corbin, J. and Strauss A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks. CA: Sage publications.

Creswell, J.W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks. CA: Sage publications.

Crotty, M. (1998). *The foundations of Social Research: meaning and Perspective in Research process*. London. Sage Publications.

Cummings, B., Gutin, S.A. and Jaiantilal, P. (2014). The Role of Social Support Among People Living with HIV in Rural Mozambique. *AIDS Patient Care and STDs*, 602-612.

Denscombe, M. (2014). *The good research guide: for small-scale social research projects*. UK: McGraw-Hill Education.

De Paoll, M.M., Mills, E.A. and Gronningsaeter, A.B. (2012). The ARV roll out and the disability grant: A South African dilemma? *Journal of the International AIDS Society* 15(1):6.

Dewing, S., Mathews, C. and Lurie M. (2015). Predictors of poor adherence among people on antiretroviral treatment in Cape Town, South Africa: a case-control study. *AIDS Care*, 342-349.

DiMatteo, M., Haskard-Zolnierok, K.B., and Martin, L. (2012). Improving patient adherence: a three-factor model to guide practice. *Health Psychology Review*, 74-91.

Dunbar-Jacob, J., Schenk, E. and McCall, M. (2012). 12 Patient Adherence to Treatment Regimen. *Handbook of Health Psychology*, Psychology Press, 271.

Eaton, J.W., Meziar N.A., and Stovee J. (2014). Health benefits, costs, and cost-effectiveness of earlier eligibility for adult antiretroviral therapy and expanded treatment coverage: a combined analysis of 12 mathematical models. *The Lancet Global Health*, 379 (9822). 23-34.

Emamzadeh-Fard, S., Fard, S.E., and Koosha, P. (2012). *Infect Discord Drug Targets*. Adherence to anti-retroviral therapy and its determinants in HIV/AIDS patients: A Review.

Evian, C. (2011). Primary HIV clinical care for adults, children and pregnant women, 5th Edition. Melville, Johannesburg: Jacana Media.

Fisher, J. and Amico, K.R. (2008). The information, motivation, and behavioral skills model of ART adherence to Antiretroviral Therapy, *Health Psychology*, 25(4).

Ford, P. (2014). Nurse initiated and managed anti-retroviral treatment: An ethical and legal analysis in South Africa. Wits University, Johannesburg. p24. Available at <http://hdl.handle.net/10539/14413>. (Accessed 4 November 2015).

Fox, M.P. and Rosen, S. (2015). Adult Patients on Antiretroviral Therapy in Low-and Middle-Income Countries: Systematic Review and Meta-analysis 2008-2013, *JAIDS*, 98-108.

French, H., Greef M. and Watson, M. (2015). HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting. *AIDS Care*, 27(8), 1-5.

Geissbuhler, A., Safran, C. and Buchan, I. (2013). Trustworthy reuse of health data: a transnational perspective. *International Journal of Medical Informatics*, 82(1). 1-9.

Gengerg, B.L., Lee, Y. and Rodgers, W. (2014). Four types of barriers of adherence to antiretroviral therapy are associated with decreased adherence over time. *AIDS and Behaviour*, 85-92.

Gioia, D.A., Corley, K.G. and Hamilton, A.L. (2013). Seeking qualitative rigor in inductive research notes on the Gioia methodology. *Organisational Research Methods*, 16(1). 15-31.

Hardon, A.P., Akurut, D, Comoro, C., and Ekezie, C. (2007). Hunger, waiting time and transport costs: Time to confront challenges to ART adherence in Africa. *AIDS care* 19(5). 658-665.

Harter, C.C. (2002). Women, leadership, and the academy: Anecdotes and observations. In P.T. Mitchell (Ed.). *Cracking the wall: Women in higher education administration* (pp. 21-27). Washington, DC: The College and University Personnel Association.

Henn, M., Weinstein, M. and Foard, N. (2006). *A Short Introduction to Social Research*. London: Sage Publications.

Heyer, A. and Ogunbanjo, G.A. (2006). Adherence to HIV antiretroviral therapy Part I: A review of factors that influence adherence. *South African Family Practice*, 48(8):5-9.

Hoang, D., Ding, A.T. and Groce, N. (2015). Knowledge and Perceptions of HIV-Infected Patients Regarding HIV Transmission and Treatment in Ho-Chi-Minh City, Vietnam. *Asia-Pacific Journal of Public Health*, 27(2). Sage Publications. 746-757.

Hogerzeil, H.V.M. (2013). Promotion of access to essential medicines for non-communicable diseases: practical implications of the UN political declaration. *The Lancet*, 381(9867). 680-689.

Holtzman, C.W., Brady, K.A. and Yehia, B.R. (2015). Retention in Care and Medication Adherence: Current Challenges to Antiretroviral Therapy Success,. *Drugs*, 75(5). 445-454.

Hulley, S.B., Cummings, S.R. and Browner, W.S. (2013). *Designing clinical research*. Lippincott Williams & Wilkins.

HSRC. (2012). Plenary Session 3, 20 June 2013. HIV/AIDS in South Africa: At last the glass is half full.

Available at: <<http://www.hsrc.ac.za/en/media-briefs/hiv-aids-stis-and-tb/plenary-session-3-20-june-2013-hiv-aids-in-south-africa-at-last-the-glass-is-half-full>>

IRIN/Plus News, (2012). South Africa, Revamped AIDS Council makes its debut, 9 October.

Irvine, A., Drew, P. and Sainsbury, R. (2013). Am I not answering your questions properly? Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews, *Qualitative Research*, 13(1). 87-102.

Jean, K., Moh, R. and Danel, D. (2014). Decrease in sexual risk behaviours after early initiation of antiretroviral therapy: a 24-month prospective study in Cote d'Ivoire, *Journal of the International AIDS Society*. 17(1). 20-35.

Jones, P.S. (2009). *AIDS treatment and human rights in context*. New York: Palgrave Macmillan.

Kagee, A. (2006). Adherence to antiretroviral treatment in the context of national rollout in South Africa: Defining a research agenda for psychology. *South African Journal of Psychology* 38(2):413-428.

Kaposhi, B.M., Moqoqi, N. and Schoopflocher, P. (2015). Evaluation of antiretroviral treatment programme monitoring in Eastern Cape, South Africa. *Health Policy and Planning*, 30(5). 547-554.

Khalili H., Rohani, R., and Seyedalnaghi, S. (2012). *Adherence to Antiretroviral Therapy among Iranian HIV and AIDS patients*. *Curr. Clin. Pharmacy*, 2012 May, 7(2): 111-5.

Laloo, U.G. and Pillay S. (2008). Managing TB and HIV in Sub-Saharan Africa. *Current HIV/AIDS Reports*, 5(3). Springer Publishers. 132-139.

Leach-Lemens, C. (2010). *Loss to follow-up high in South African public sector ARV programmes*. Available at <http://www.aidsmap.com> (Accessed on 15.10.2012).

Li, E.H. (2014). Antiretroviral and medication errors in hospitalized HIV-positive patients. *Annals of Pharmacology*, 998-1010.

Lupu, A.L. (2014). The Role of Acting Participants, Definitions, and the Determining Factors of Adherence to Treatment from Two Perspectives. *Postmodern Openings*, 7(1). 75-88.

Lyimo, R.A., De Bruin, M. and Van der Boogaard, J. (2012). Determinants of antiretroviral therapy adherence in northern Tanzania: a comprehensive picture from the patient perspective. *BMC Public Health*, 12(1). Biomed Central Ltd. 716.

Maartens G., Cotton M., Wilson D., Venter F., Meyers T. and Bekker L. (2012): The handbook of HIV medicine, 3<sup>rd</sup> Edition. Oxford University Press, Southern Africa.

Mabasa, N. (2013). Available at: <<http://www.polity.org.za/article/sa-norman-mabasa-address-by-the-limpopo-health-mec-at-the-provincial-budget-vote-for-the-department-of-health-limpopo-legislative-chamber-lebowakgomo-23042013-2013-04-23>>

Machlup, F. (2014). *Knowledge: its creation, distribution and economic significance, Volume I: Knowledge and knowledge production*. Princeton University Press.

Mathebula, T.J. (2014). *Reasons for Default Follow-Up of Antiretroviral Treatment at Thekganang ARV Clinic*. Pretoria: University of Pretoria.

Mayberry, L.S. and Osborn, C. (2014). Empirical validation of Information, Motivation and Behavioural Skills Model of Diabetes Medication Adherence: A Framework for Intervention. *Diabetes Care* (37). 1246-7263.

Mayosi, B.M., Lawn, J.E. and Van Niekerk, A. (2012). Health in South Africa: changes and challenges since 2009. *The Lancet*, 380(9858). 2029-2043.

Medley, A., Bachanas, P. and Grillo, M. (2015). Integrating prevention intervention for people living with HIV into care and treatment programs. A Systematic Review of Evidence, JAIDS.

Mertens, D.M. (1998). Research methods in education and psychology: Integrating diversity with qualitative and quantitative approaches. London. SagePublications.

Mukherjee, J.S., Ivers, L., Leandre, F., Farmer, P. and Benforouz, H. (2006). Antiretroviral therapy in resource-poor settings. Decreasing barriers to access and promoting adherence. *Journal of Acquired Immune Deficiency Syndrome* 1 (43): S123-126.

Munthli, A., Mvula, P.M. and Maluwa-Banda, D. (2014). Knowledge, attitudes and practices about HIV testing and counselling among adolescent girls in some selected secondary schools in Malawi, *African Journal of Reproductive Health*, 17(4). 60-68.

Nchendia, A.I. (2012). *Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape*. Cape Town: University of the Western Cape.

NDOH. South African National Department of Health. (2003). *Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa*. Pretoria: NDOH.

NDOH. South African National Department of Health. (2004). *National Antiretroviral Treatment Guidelines*. Pretoria: NDOH.

NDOH. South African National Department of Health. (2009). *National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa*. Pretoria: NDOH.

NDOH. South African National Department of Health. (2010). *National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa*. Pretoria: NDOH.

NDOH. South African National Department of Health. (2010). *National HIV Counselling and Testing (HCT) Policy Guidelines*. Pretoria: NDOH.

NDOH. South African National Department of Health. (2015). *Clinical guidelines for the management of HIV & Aids in adolescents and adults*. Pretoria: NDOH.

NDOH. South African National Department of Health. (2011). *National strategic plan for HIV and AIDS, STIs and TB (2012-2016)*. Pretoria: NDOH.

NDOH, South African National Department of Health. (2013). *Clinical guidelines for the management of HIV & AIDS in adolescents and Adults*. Pretoria: NDOH

NDOH, South African National Department of Health. (2014). *Clinical guidelines for the management of HIV & AIDS in adolescents and Adults*. Pretoria: NDOH

Nsanzimana, S., Prabhu, K. and McDermott, H. (2015). Improving health outcomes through concurrent HIV program scale-up and health system development in Rwanda: 20 years of experience. *BMC medicine*, 13(1). 216.

Peltzer, K., Ramlagan, S., Jones, D., Weiss, S. M., Fomundam, H. and Chanetsa, L. (2012). Efficacy of a lay health worker led group antiretroviral medication adherence training among non-adherent HIV-positive patients in KwaZulu-Natal, South Africa: Results from a randomized trial. *SaharaJ: Journal of Social Aspects of HIV/AIDS*, 9(4), 218-226. doi: 10.1080/17290376.2012.745640

Perez, A., Holt, N., Gokiart, R., Chanoine, J.P., Legault, L., Morrison, K., Sharma A. and Ball, G. (2015). Why don't families initiate treatment? A qualitative multicentre study investigating parents' reasons for declining paediatric weight management. *Paediatrics & Child Health*, 20(4) 179-84.

Robinson, O.C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide, *Qualitative Research in Psychology*, 11(1). 25-41.

Ross, E.L., Weinstein, M.C. and Schackman, B.R. (2015). Clinical role and cost effectiveness of long acting antiretroviral treatment. *Clinical Infectious Diseases*, 57(5). 1159.

Rosen, S., and Ketlhapile, M. (2010). Cost of using a patient tracer to reduce loss to follow-up and ascertain patient status in a large antiretroviral therapy program in Johannesburg, South Africa. *Tropical Medicine and International Health* 15(1): 98-104.



Roura, M., Busza, J., Wringe, A., Mbata, D., Urassa, M. and Zaba, B. (2009). Barriers to sustaining antiretroviral treatment in Kisesa, Tanzania: A follow-up study to understand attrition from the antiretroviral program. *AIDS Patient Care and STDs* 23(3):203-210.

Russell, B. and Eisenberg, J. (2012) 'The Role of Cognition and Attitude in Driving Behavior: Elaborating on Affective Events Theory' In: Ashkanasy, N. M., Zerbe, W.J. & Hartel, C.E.J. (eds). *Research on Emotion in Organizations, Volume 8: Experiencing and Managing Emotions in the Workplace*. UK: Emerald Group Publishing.

Saleh, A.M. (2012). Exploring factors influencing adherence to antiretroviral therapy among adult people living with HIV on antiretroviral therapy in Zanzibar (Tanzania). A Case of Mnazi Mmoja Hospital Care and treatment Centre. Kit Royal Tropical Institute. Tanzania.

Sandelowski, M. (1995). Focus on Qualitative Methods. Sample Size in Qualitative Research. *Research in Nursing and Health* 18:179-183.

SASSA. South African Social Security Agency. National Department of Social Development. (2011). *you and your grant*. Available at <http://www.sassa.gov.za>. (Accessed on 10 September 2014).

Seeling, S., Mavhunga F. and Thoma, A.B. (2014). Barriers to access to antiretroviral treatment for HIV-positive tuberculosis patients in Windhoek, Namibia. *International Journal of Mycobacteriology*, 3(4). 268-275.

Sellam, D. and Flower, F.L. (2014). A study on stigma towards people living with HIV/AIDS in perambalur district, *Star. Soc. Work.* 2(5). 98.

Sileo, K., Kintu, M. and Chanes-Mora, P. (2015). "Such Behaviors Are Not in My Home Village, I Got Them Here": A Qualitative Study of the Influence of Contextual Factors on Alcohol and HIV Risk Behaviors in a Fishing Community on Lake Victoria, Uganda, *AIDS and Behavior*, Springer Publishers. New York.

Simoni, J., Amico, K.R., Pearson, C. and Malow, R. (2009). Overview of adherence to antiretroviral therapies, in *HIV/AIDS: Global frontiers in prevention/intervention*, edited by C. Pope, R.T. White and R. Malow. New York: Routledge.

Sithole, B.M. (2013). Factors that influence treatment adherence for people living with HIV and accessing antiretroviral therapy in rural communities in Mpumalanga. University of South Africa. Pretoria.

Starace, F., Fisher, J.D., Massa, A. and Amico K.R. (2006). Adherence to Antiretroviral Therapy: An empirical test of the information-motivation-behavioral skills model. *Health Psychology*, 25(2). 153.

Stats SA. Statistics South Africa. (2011). Mid-year population estimates. Available at: [www.statisticssa.gov.za](http://www.statisticssa.gov.za). (Accessed on 31.10.2015).

Stricker, M., Fox, S. and Baggaley, R. (2014). Retention in care and adherence to ART are critical elements of HIV care interventions. *AIDS and Behaviour*, 18(5). 465-475.

Thompson, M.A., Aberg, J.A. and Hoy J.F. (2012). Antiretroviral treatment of adult HIV infection. *JAMA*, 308(4). 387-402.

Tsonis, M. (2012). Interrelated processes toward quality of life in survivors of childhood cancer: A grounded theory. *The Qualitative Report*, 17(45). 1-18.

UNAIDS and WHO. (2010). AIDS epidemic update. Geneva.

UNAIDS. (2012). Report on Global AIDS Epidemic: Geneva. Available at: <http://www.unaids.org/en/media/unaids/documents> (Accessed 9 May 2014).

UNAIDS/WHO. (2010). Report on global AIDS Epidemic. Joint United Nations programme on HIV/AIDS (UNAIDS).

UNAIDS. (2012). *The global AIDS epidemic – key facts*. Available at <http://www.unaids.org>. (Accessed 30 May 2014).

Van Boekel, L.C. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review. *Drug and Alcohol Dependence*, 131(1). 23-35.

Van Loggerenberg, F., Gray, D. and Gengiah, P. (2015). Qualitative Study of Patient Motivation to Adhere to Combination Antiretroviral Therapy in South Africa, *AIDS Patient Care and STDs*, 29(5). 299-306.

Van Zyl, G.U., Frenkel, L.M. and Chung, M.H. (2014). Emerging antiretroviral drug resistance in sub-Saharan Africa: novel affordable technologies are needed to provide resistance testing for individual and public health benefits. *AIDS*, 28(18). 1643-2648.

Vun, M.C. (2014). Achieving universal access and moving towards elimination of new HIV infections in Cambodia. *Journal of the International AIDS Society*.17(1). 18905.

Wamoyi, J., Mbonye, M., Seeley, J. and Bimungi, J. (2011). Changes in sexual desires and behaviours of people living with HIV after initiation of antiretroviral treatment: Implications for HIV prevention and health promotion. *BMC public health* Vol11. Available at <<http://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-11-633>> (Accessed 30 June 2013).

Ware, N.C. (2009). Explaining adherence success in Sub-Saharan Africa: An ethnographic study: *PLoS Med* 6(1).

Warner, L.M.R. (2013). Interactive effects of social support and social conflict on medication adherence in multimorbid older adults. *Social Science & Medicine*, 87(1). 23-30.

Wasti, S.P., Simkhada, P., Randall J., Freeman J.V. and van Teijlingen E. (2012). Factors influencing adherence to antiretroviral treatment in Nepal: A mixed method study. *PLoS one*. 5(7) 35547

Weiser, S., Wolfe, W., Bangsberg, D., Thior, I., Gilbert, P., Makhema, J., Kebaabetswe, P., Dickenson, D., Mompati, K., Essex, M. and Marlink, R. (2003).

Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Clinical Science Journal of Acquired Immune Deficiency* 34(3):281-288.

Weiser, S.D., Tuller, D.M. and Frongillo, E.A. (2010). Food insecurity as a barrier to sustained antiretroviral therapy in Uganda. *PLoS one*. 5(4). 1.

WHO, World Health Organization, (2006). Interim WHO clinical staging of HIV/AIDS and case definitions for surveillance.

WHO. World Health Organization. (2010). *Guidelines on antiretroviral treatment. 2010*. Available at <http://www.who.int/>. (Accessed on 15 August 2014).

WHO. World Health Organisation. (2013). *The World Health Report 2013: Primary health care (now more than ever)*.

Wilson, D., Maartens, G., Cotton, M., Venter, F., Bekker, L.G. and Meyers, T. (2002). *Handbook of HIV medicine. Southern Africa: Oxford University Press*. Available at: <http://www.businessdictionary.com/definition/attitude.html>. (Accessed 9 May 2014)

Yoder, P., Mkhize, S.P. and Nzimande, S. (2009). *Patient Experiences in Antiretroviral Therapy Programmes in KwaZulu-Natal, South Africa*. Durban, South Africa: Health Systems Trust and Calverton, Maryland, USA: Macro International Inc.

## **ANNEXURE A: INFORMED CONSENT FOR PARTICIPANTS**

You will be asked to participate in interviews for the study research. The researcher would like to hear about your knowledge, attitudes and experiences of your ARV treatment. The reason why the researcher would like to gather this information is to improve the existing services. The researcher will not record your name anywhere and no one will be able to link you to the answers you give.

There will be one interviewer. The interview is confidential, with no correct or incorrect answers. You are allowed to refuse answering any questions that makes you feel uncomfortable. The interview will last around 30 minutes – one hour. The interviewer will be asking you a few questions and request that you are as open and honest as possible in answering these questions. If the interviewer ask you a question which makes you feel sad or upset, we can stop and talk about it.

A tape recorder will be used to record information you're giving the interviewer. All the information and records about your answers will be kept confidential, only the researcher will have access to this information. Your decision to participate is voluntary. You have the right to withdraw at any given point. You will only be identified by a code number and the information will be destroyed after the study has been conducted and the results written up. No direct benefits will be given to you, but your contribution will benefit others in the future by helping to improve support for people receiving ARV treatment. If you have any concerns or problems after the interview. You are welcome to contact the researcher at the following details:

Mulelu Rodney - Cell: 072 794 9825 - Email: Mulelur@yahoo.com

## ANNEXURE B: INTERVIEW GUIDE FOR PARTICIPANTS

Participant No: \_\_\_\_\_

### Instructions

Interviews will only commence after having read the informed consent and information sheet and the participant understood and consented to be interviewed.

### SECTION A: Demographic information

#### 1. Gender

Male	
Female	

#### 2. Age

Younger than 30 years	30 - 39 years	40 years and older

#### 3. Marital Status

Single	
Married	
Divorced	
Separated	
Widowed	

#### 4. Current place of residence

Seleka	
Thabo Mbeki	
Libu	

### 5. Place of residence in a Rural or Urban area

Urban	
Rural	

### 6. Educational level

None	Primary	Secondary

### 7. Home Language

Sepedi	
Tswana	
Zulu	

### 8. Current employment status

Employed	Not employed

### 9. Main source of income

Salary	Pension after having been medically boarded	No income

## SECTION B: Investigate the knowledge that PLHIV have on ART

1. What do you know about antiretroviral therapy?
2. What ARVs do to a human body in your own words?
3. What are the names of ARVs you are taking?
4. Were you provided with information regarding ARVs? What information? Is the information helpful? Why?

### **SECTION C: Identify attitude of PLHIV towards Antiretroviral Treatment**

1. What are your feelings towards taking ARVs?
2. Do you think they help? Do people against ARV's? Why they are against it? Will it cure them? Does it make them sick?
3. Why did you decide to start on ARVs?
4. Can you advise other people to take the treatment? Why?

### **SECTION D: Identify experiences of PLHIV of Antiretroviral treatment**

1. Before you started the treatment, how was life?
2. How long after you discovered that you are HIV positive did you start the ARVs?
3. When / where did you first hear of ARVs? How did you react at that stage? Were you happy / unhappy? Why?
4. What is your experience on ART? Are you better or worse than before you start the treatment?
5. How did you get started on taking ARVs? How easy or difficult was it? Explain why?
6. How do ARVs affect you as a person?
7. Was the issue of adherence discussed when you started the treatment?
8. How do you understand 'adherence' in your own words?
9. Why is adherence important when taking ARV's?
10. Did you ever miss or stop taking your medication? E.g. have you ever missed a dose in the last week or a month?
11. What do you think is the cause of this?
12. What is the most difficult dose of the day?
13. How did you feel when you missed a dose?

### **SECTION E: Identify economic factors that support PLHIV**

1. Are you earning an income at the moment? How? If not how do you spend your days?
2. Who provides the main financial support at home?



3. Do you have electricity at home? Tap water? TV? Radio? A car?
4. Are the existing economic and social services helpful for people living with HIV and AIDS?

**SECTION F: Identify social factors that support PLHIV**

1. Have you told anyone about your HIV status, for example, friends, children, spouse (sexual partner) and parents?
2. How did she/he react?
3. Who else are you willing to disclose to?
4. Who is supporting and assisting you not to forget treatment and reminding you to go to clinic for follow-up?
5. Do you belong to a support group in your community?
6. If you have a problem with ARVs, did you ever speak to somebody or your nurse or a doctor about your problem? Were they helpful?
7. From your experience, what do you think people on ARVs need in terms of support that will be helpful to them?
8. What do you think about your nurse and your doctor? Are you happy with them? Why?

**Thank you for your time**

**ANNEXURE C: REQUEST PERMISSION TO CONDUCT RESEARCH: LDOH**

Witpoort Hospital  
Lephalale  
0555  
02 September 2013

The Research Manager  
Department of Health  
Polokwane  
0700

Dear Sir / Madam

**RE: REQUEST PERMISSION TO CONDUCT RESEARCH: STUDENT NUMBER:  
362-1-9835**

I, Rodney Azwinndini Mulelu, Identity Number: 7211106204080, Pearsal number: 90840909, hereby wish to apply for a permission to conduct research study in the Wellness (ARV) clinic at Witpoort Hospital. I'm currently working for Department of Health – Limpopo based at Witpoort Hospital as an Assistant Director: Dietetics and I'm studying towards a Master's degree in Social behavior in HIV and AIDS with UNISA.

My study is entitled "**Knowledge, attitudes and experiences of people living with HIV and on antiretroviral treatment at a public health clinic, in Limpopo Province, South Africa**". I will be interviewing 5 to 10 people taking ARVs at Witpoort Hospital. I'm enclosing my copy of the research proposal and the interview guide. I'll appreciate your timeous response as your permission is one of the requirements for ethical approval of my proposal.

Thanking you in advance.

Kind Regards

---

Mr. Rodney Azwinndini Mulelu

**ANNEXURE D: REQUEST PERMISSION TO CONDUCT RESEARCH: UNISA**

Witpoort Hospital  
Lephalale  
0555  
04 September 2013

Ms. Elize Koen

**SUPERVISOR**

UNIVERSITY OF SOUTH AFRICA (UNISA)  
PRETORIA  
0001

Dear Sir / Madam

**RE: REQUEST FOR RENEWAL PERMISSION TO CONDUCT RESEARCH:  
STUDENT NUMBER: 362-1-9835**

I, Rodney Azwinndini Mulelu, Identity Number: 7211106204080, Pearsal number: 90840909 hereby wish to apply for a permission to conduct research study in the Wellness (ARV) clinic at Witpoort Hospital. I'm currently working for Department of Health – Limpopo based at Witpoort Hospital as an Assistant Director: Dietetics and I'm studying towards a Master's degree in Social behavior in HIV and AIDS with UNISA.

My study is entitled "**knowledge, attitude and experiences of people living with HIV and on antiretroviral treatment at a public health clinic, in Limpopo Province, South Africa**". I will be interviewing 5 to 10 people taking ARVs at Witpoort Hospital.

I'll appreciate your timeous response as your permission will allow me to continue with my research on time.

Thanking you in advance.

Kind Regards

---

Mr. Rodney Azwinndini Mulelu

## ANNEXURE E: APPROVAL TO CONDUCT RESEARCH: UNISA



Department of Sociology  
College of Human Sciences

2014/MASBS/17/Student  
2014/MASBS/17/Student

06 February 2014

**Proposed Title:** Knowledge, attitudes and experiences of people living with HIV and on antiretroviral treatment at a public health clinic in Limpopo, South Africa

**Principle investigator:** Mr Mulelu R (Student number: 36219835)

**Reviewed and processed as:** Class approval (see paragraph 10.7 of the Unisa Guidelines for Ethics Review).  
**Approval status recommended by reviewers:** Approved

The Higher Degrees Committee of the Department of Sociology in the College of Human Sciences at the University of South Africa has reviewed the proposal and considers the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted for the candidate to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa.

In addition, the candidate should heed the following guidelines,

- To complete and sign a Supervisor-Student Agreement form, which is a code of conduct guiding the research process,
- To start the research study only after obtaining the necessary Informed Consent,
- To carry out your research according to good research practices and in an ethical manner,
- To maintain the confidentiality of all data collected from or about research participants, and maintain safe procedures for the protection of privacy and when storing such data,
- To work in close collaboration with the assigned Supervisor and to ensure the way in which the ethical guidelines as suggested in the reviewed proposal has been implemented in your research,
- To notify the Committee immediately in writing if any change/s is proposed to the study and await approval before proceeding with the proposed change,
- To immediately notify the Committee in writing if any adverse event occurs.

Regards,

Dr. Chris Thomas  
Chair: Department of Sociology  
Tel: 0027 (0)12 429 6301



# ANNEXURE F: APPROVAL TO CONDUCT RESEARCH: LDOH



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila

Ref:4/2/2

Mulelu R.  
University of South Africa  
P.O.Box 392  
UNISA  
0003

Greetings,

**Re: Knowledge, attitudes and experiences of people living with HIV and on antiretroviral treatment at a public health clinic in Limpopo, South Africa**

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. 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.

Head of Department

Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700  
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: <http://www.limpopo.gov.za>

The heartland of Southern Africa — development is about people