Adherence: Perceptions and behaviour of patients on Antiretroviral therapy in Vhembe District of Limpopo Province, South Africa

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DECLARATION

I, Takalani Tanganedzani, declare that this dissertation entitled **“Adherence: Perceptions and behaviour of patients on Antiretroviral therapy in Vhembe District of Limpopo Province, South Africa”** is a product of my own original work, unless otherwise stated. Conclusions reached are my own and may not be attributed to any other individual or association. Furthermore, I declare that this thesis has not been submitted to this or any other university.

Signature________________________ Date_______________________________

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DEDICATION

My late father, Chief Takalani Tshivhase Christian Mmbangiseni, I dedicate this dissertation to your memory.

ABSTRACT

Background: An estimated 70% of people in Sub-Saharan Africa out of 25 million are living with HIV. HIV is a debilitating disease, however, antiretroviral treatment helps promote effective viral suppression, reduces the risk of transmission and prevents death (WHO, 2013). To ensure positive treatment outcomes, high levels of Anti-Retroviral Therapy (ART) adherence, 95%, is necessary, however, research indicates that 23% of Africans are achieving less than 80% adherence, potentially impacting negatively on prognosis.

Aim: The aim of this study was to determine adherence, explore perceptions and behaviour of patients on Antiretroviral Therapy attending Thohoyandou Health Centre, in Vhembe District, Limpopo, South Africa.

Methodology: This was a mixed method which employed both quantitative and qualitative research approaches. In quantitative, triangulation was utilised through a questionnaire and patients' file, simple random sampling was used to select 105 male and female patients aged 18-60 who are on ART at Thohoyandou Health Centre; data were collected and SPSSversion 25 was used to analyse the data through descriptive, cross tabulation and inferential statistics using Chi-square.Qualitative phase – phenomelogical research design was utilised, twenty participants were purposively sampled and individually interviewed, ATLAS. ti program was used to analyse the data collected.

Results: 67% of respondents were females, 34% of the respondents' age range was 50-60 years, 44.8% were single, 48.6% had tertiary education and 69.5% were unemployed. The self-report of ART adherence of 87.6% among patients was indicated, with 19.6% who reported defaulting ART, 14.3% admitted to missing medical appointments. The reasons for missing medical appointments were: forgetfulness, not a convenient time, patient feeling better, transportation challenges and being too sick to attend. The objective evaluation of patients' CD4 count at baseline revealed that 40.9% of patients had a CD4 count of <200c/mm3, out of 40.9% respondents (15.2%) were those aged between 41-50 years, 31.4% of respondents did not know their CD4 count for various reasons (defaulted on treatment, missed appointments). CD4 count follow-up data after six months revealed that 33% of patients had a CD4 count <200c/mm3 and 39% accounted for unknown CD4 count.

Three themes emerged from the data, namely: Knowledge of HIV were respondents presented a negaitive and positive perception of ths diagnosis; barriers to ART adherence where sub-themes included discrimination, strigma, rejection, inadequate knowledge about the diagnosis and treatment, side effects; coping strategies where acceptance, religion and social support serve as corner stones for patients. Association was examined and findings did not reveal any significant association between gender, marital status, education, occupation; however, age was significantly associated with non-adherence to ART with X2 = 3.69, df = 1, p = < .002.

Recommendations: The study recommends intensification of health education campaign against stigma, discrimination, rejection and other barriers to enhance positive attitude towards HIV patients that wil consequently stimulate adherence and alleviate the burden associated with taking treatment unswervingly. Given the high percentage of infected older respondents, government must also focus its resources to educate illiterate and older people about HIV, adherence and management in order to achieve the golden standardrate of 95% adherence. Strategies to facilitate and normalise adherence among males is indicated.

Keywords: *Acquired Immune Deficiency Syndrome (AIDS), Adherence, Anti-retroviral Therapy/Treatment (ART), Human Immunodeficiency Virus (HIV), Patients, Perceptions, Behaviour*

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LIST OF ABBREVIATIONS AND ACRONYMS

ART :	Anti-Retroviral Therapy
CD4 :	Lymphocytes Count of
CV :	Construct Validity
HBM :	Health Belief Model
HCT :	HIV Counselling and testing
HIV :	Human Immunodeficiency Virus
HAART:	Highly Active Antiretroviral Therapy
HSRC :	Human Science Research Council
ICC :	Intra-Class Coefficient
PMTCT:	Prevention of Mother to Child Transmission
PTSD :	Post Traumatic Stress Disorder
SES :	Socio-Economic Status
SSA :	Sub-Saharan Africa
SHDC :	Schools Higher Degrees’ Committee
SDT :	Self-Determination Theory
STI :	Sexual Trammitted Infections
TB :	Tuberculosis
UHDC :	University Higher Degree’s Committee

UNIAIDS: United Nations Acquired Immunodeficiency Syndrome

WHO : World Health Organisation

Rx : Prescription

CHAPTER ONE: INTRODUCTION

1. INTRODUCTION

Nearly 25 million people, 70% of all those living with HIV globally, live in Sub-Saharan Africa (SSA) (WHO, 2013). Human Immunodeficiency Virus (HIV) is a debilitating disease, however, antiretroviral treatment (ART) helps promote effective viral suppression, reduces the risk of transmission and prevents death (WHO, 2013). To ensure positive treatment outcomes, high levels of Anti-Retroviral Therapy (ART) adherence, 95%, is necessary, however, research indicates that 23% of Africans are achieving less than 80% adherence, potentially impacting negatively on prognosis (Mills *et al.,* 2006; WHO, 2013). Moratioa (2007) indicates that not complying with medication for Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV and AIDS) in South Africa has become one of the biggest problems in primary health care, causing high rates of mortality, hospitalisation, morbidity and relapse. It has become clear that non-adherence to ART needs extra attention. Maintaining high levels of adherence to ART is a challenge across settings and populations (Lingappa, 2010). This study focuses on perceptions and behaviour of patients regarding adherence to ART at Thohoyandou Health Centre.

The introduction will provide a general overview of the background of the study, problem statement, significance of the study, aims, objectives, research questions, delimitations, and definitions of selected concepts.

1.1 BACKGROUND OF THE STUDY

HIV was discovered in the human body in the year 1981 (UNAIDS, 2007). HIV emerged at different times in diverse regions, and it has been spreading unnoticed for decades, especially in sub-Saharan Africa. Between the years 1981 and 2000, the number, of those living with HIV, increased from less than 1 million to an estimated 27.5 million (UNAIDS, 2011).

The first AIDS-related deaths in South Africa occurred in late December 1982, with very limited attention to the epidemic over the next decade (UNAIDS, 2007). In the 1980s most AIDS diagnosis in South Africa were limited to gay men and blood transfusion recipients. Late 1980s, the rate of the virus presented in the heterosexual population was relatively low with only 12 cases identified in the city of Pretoria in 1986 (Sher, 1986; Karim & Karim, 2002). Even as the virus spread beyond the initially limited population, HIV and AIDS went largely unaddressed by the South African Apartheid government as it was seen to be an issue only within the black and gay communities (Karim & Karim, 2002).

With the limited knowledge regarding HIV transmission, the first response during the 1980s and 1990s was the provision of condoms and safe-sex education. In 1990 the government began to measure infection rates by collecting data from anonymous antenatal surveys. The results showed a volatile and rapid increase, suggesting that the national prevalence rate was 0.76%, which increased to 10.44% by 1995, and astonishingly to 22.4% by 2000 (UNIAIDS, 2014; WHO, 2002). The second phase of response was examining the effectiveness of antiretrovirals (ARVs). Widespread implementation of ART programs in South Africa did not occur until April 1st, 2004, all the while PMTCT programs and ARV campaigns were well underway in neighbouring country - in Botswana, by 1999 and 2001 (Adam & Johnson, 2009). By March 2005, the country’s 53 districts received treatment centres and one service point for AIDS-related care. All provinces began providing ART in hospitals and in tertiary facilities. By September 2005, after the rollout has begun, 85 000 were initiated on ART in the public health sector. By then, 199 public healthcare facilities (just over 5%) were providing ARVs for the treatment of HIV (Simelela and Venter, 2014). At the end of 2007, the WHO estimated that 460 000 South Africans were receiving treatment (WHO, 2008).

Despite the complicated history in South Africa in the fight against HIV, the past five years have largely been defined by growth and success. After the inauguration of President Jacob Zuma in 2009, together with Dr. Aaron Motsoaledi as South Africa's Minister of Health, new attention and urgency was given to the HIV situation in South Africa (Simelela, 2015). After Dr. Motsoaledi acknowledged that the past 10 years were spent "pedalling backwards", the president declared World AIDS Day 2009 as, "the day on which we start to turn the tide in the battle against AIDS" (Simelela, 2015). The effects of this charge were seen shortly thereafter; the rate of adults on ART rapidly increased from 4.9% in 2004 to 55% in 2010. Simultaneously, with the increase of coverage and continual monitoring, segments of the population that did not have adequate access to care were identified. On World AIDS Day 2011, South Africa released their third National Strategic Plan (NSP) for the years 2012 – 2016 which included a new and emphasized focus on under-reached populations, such as sex workers, men who have sex with men, and adolescents (National Strategic Plan on HIV, STIs & TB, 2012-2016).

1.2 PROBLEM STATEMENT

The World Health Organisation (WHO) (2016), estimated that at the beginning of the epidemic, over 70 million people were infected with HIV and almost 35 million of these people have since passed away. At the end of 2015, 36.7 million people were estimated to be living with HIV worldwide; 0.8% of these were adults aged 15-49 years, even though the extent of the epidemic differed among countries and regions. Sub-Saharan African countries remain the most affected people with approximately 1 in every 25 adults (4.4%) living with HIV and almost 70% worldwide. 1.1 million people passed away in 2015 worldwide due to AIDS-related illness. The South African National Prevalence report of 2012 estimated that 12.2% of the South Africa population (6.4 million people) were HIV-positive (Shisana, Rehle, Simbavi, Zuma, Jooste *et al., 2012*). The outcome of an analysis of HIV-prevalence, based on demographic variables, revealed that the overall HIV prevalence differed substantially by province. In Limpopo Province, in 2012, 9.2% of people were living with HIV. Stats SA (2017) reported that HIV prevalence of people living with HIV in South Africa "increased from an estimated 4, 94 million in 2002 to 7, 06 million by 2017". In 2017, an estimated 12, 6% of the total population was believed to be HIV positive. The infection rate is increasing rapidly, despite efforts made by government, with 2.1 million new infections in 2016 (UNIAIDS Fact Sheet, 2017). South Africa has the fastest growing rates of new HIV infection in the whole world (Maswikiti, 2011) with Limpopo Province in the seventh position with a 9.2% prevalence rate (Stats SA, 2017).

Non-compliance with medication for HIV/AIDS is a major problem in the South African primary health care, (Kagee, 2004), resulting in high rates of relapse, hospitalisation, morbidity and mortality. Adherence to ART is currently the only factor that can delay the development of virus resistance. Poor adherence to antiretroviral therapy can lead to treatment failure and the emergence of resistant viruses with eventual exhaustion of treatment options (Nechega *et. al*, 2005). Non-adherence results include "decrease of CD4+ cell count, incomplete viral suppression, continued destruction of the immune system, progression of disease, emergence of resistant viral strains, limited future therapeutic options, and higher costs for individual treatment" (Eyassu, 2015). Non-adherence to ART affects the well-being and health of patients; non-adherence may also cause increase in unnecessary clinic appointments, emergency-care visits, and hospitalizations; that impacts on the cost of medical care, money is wasted on unused medications or other therapies which are not followed (Rapoff, 2010)

The researcher is concerned about the high HIV prevalence in Vhembe district. HIV epidemic is increasing, and Thohoyandou is one of the towns with a high population and many people from other villages depend upon Thohoyandou Health Centre. HIV prevalence of 2009 in Limpopo Province was estimated at 21, 3%, while Vhembe District HIV prevalence was 14, 2% (STATS SA, 2017). Information from the operational Manager, Thohoyandou Health Centre in 2016, showed that about 320 people were diagnosed HIV positive. Although an abundance of literature exists on factors that influence adherence (Sendagala, 2010; Shubber, 2016), few studies have been published addressing adherence to ARV treatment in poor-resource settings, particularly in the Vhembe District of Limpopo Province. It is important to investigate adherence and explore the perceptions and behaviour of patients on ART in this setting. Such an understanding can provide guidance in developing interventions to increase adherence over time which would result in better treatment outcome, reduced infection and HIV transmission hence strengthening HIV prevention strategies. South Africa has made steps in scaling up ART. In this context, this study seeks to investigate perceptions and behaviour of HIV/AIDS patients regarding adherence, in Vhembe District, Limpopo Province of South Africa.

1.3 SIGNIFICANCE OF THE STUDY

The findings of this research might benefit the following stakeholders:

The study is intended to create awareness and provide a better understanding among individuals in the immediate community as well as members of the public on the subject of adherence to HIV treatement and patients’ behaviour.

Health care providers might benefit from insight into the behaviours that HIV patient's display. Health care providers might, therefore, be in a position to provide appropriate and relevant information to patients, hence, empower them with knowledge about ART adherence.

Policy makers may benefit from the findings by contributing to enhance and review HIV and AIDS treatment protocols and policies, related in-service education for medical personnel. The findings will enable them to evaluate health education plan for HIV - positive patients so as to increase the clinical management of HIV and AIDS.

Government would be able to enhance the implementation of ART adherence in South Africa and further explore ways to improve the knowledge and understanding of HIV-diagnosed patients.

This study may contribute to the pool of knowledge. Currently, the few researchers who are conducting studies on ART adherence have not used mixed research method, hence, this study will provides the basis for future studies intending to use the mixed research method approach. This study could provide a comprehensive picture of adherence to HIV medication through exploring the perceptions and behaviour of patients on ART.

1.4 RATIONALE

It has been reported that South Africa has the biggest ART programme in the whole world (The AIDS Epidemic Update, 2009). The researcher was motivated to conduct this study because optimal adherence translates to better health. The researcher also realised that adherence is a complex concept that needs attention. Studies have been conducted in South Africa, but none of them has been conducted specifically at

Thohoyandou Health Centre in Limpopo Province. Low adherence to ART is associated with higher hospitalization rates, due to the disease's progression (Melissa *et al.,* 2010). In efforts to prevent HIV spreading, the introduction of ART and its increasing availability worldwide is appreciated. Access to antiretroviral medication in the low and middle-income countries rose by 10-fold between the year 2003 and 2008 (Maswikiti, 2011; UNAIDS Fact Sheet, 2017). South Africa is reported to have the largest ART programme globally (The AIDS Epidemic Update, 2009), the consequence of which is substantial public health benefits and improved access for HIV-positive patients. With an increased awareness of mental health issues comes the benefits of healthy mental wellbeing (Maswikiti, 2011).

A major concern, however, is that not much research has been done in Limpopo to explore and understand adherence of the HIV-diagnosed patients. Several researchers have highlighted the importance of doing research on various aspects, such as the status of people living with HIV/AIDS and their ART adherence, factors and barriers to ART adherence and what interventions can be tailor-made and be efficient in this context (Dlomo, 2010; Kotzé, 2013; Sendagala, 2010). The researcher is of the idea that this study will shed light about facts that can sustain adherence and serve as a catalyst for curbing the HIV pandemic by tapping into adherence to ART and mental health.

In Limpopo few studies have been done about HIV/AIDS but not much investigating the perceptions and behaviour of the HIV-diagnosed patients towards adherence to ART treatment (Dlomo, 2010; Kotzé, 2011; Sendagala, 2010). Little is known about the perception and behaviour of patient on antiretroviral therapy in Vhembe District and the Thohoyandou area in particular. Using a mixed method approach to the current study should help to get more relevant information and better understanding on adherence by HIV patients.

1.5 AIM

The aim of the study was to investigate adherence through an exploration of perceptions and behaviour of patients, on Antiretroviral Therapy, attending the Thohoyandou Health Centre, in Vhembe District, Limpopo Province, South Africa.

1.6 OBJECTIVES

Phase 1: Quantitative

- To determine patients’ adherence to ART at Thohoyandou Health Centre;

Phase 2: Qualitative

- To explore patients’ perceptions of HIV diagnosis;
- To explore perceived barriers towards HIV medication adherence;
- To describe strategies used by HIV patients to cope with the diagnosis and ART

1.6 HYPOTHESIS

- There is high level of adherence to medication among HIV-diagnosed patients.

1.7 DELIMITATIONS

The study focused on the adherence of HIV-diagnosed patients on Anti-Retroviral therapy, at Thohoyandou Health Centre, in Vhembe District. 105 male and female respondents were recruited from all ethnic groups and whose age ranges between 18-60 years.

1.8 DEFINITIONS OF CONCEPTS

Adherence - “Means taking medication at the right time, in the right doses, in the right way” (Australian Federations of AIDS Organisation, 2009).

In the context of this study, adherence refers to taking HIV medications at the accurate time and in accordance with instructions as prescribed by health-care providers.

Acquired Immune Defeciaency Syndrome - It is the “advanced stage of HIV infection” (WHO, 2006). In the context of this study, AIDS is a disease caused by HIV, which affects the cells of the immune system by attacking and weakening such cells, leaving the body vulnerable to other infections transmitted through body fluids, such as, semen and blood”.

Anti Retroviral Treatment/therapy - is defined as a “treatment for people infected with HIV using anti-HIV drugs” (WHO, 2017). In the context of this study, ‘ART’ refers to all drugs developed to prevent and suppress Human Immunodeficiency virus from replicating.

Behaviour - “Is the way in which one acts or conducts oneself, especially towards others” (English Oxford Dictionary, 2016: 55). In the context of this study, ‘behaviour’ refers to the way in which HIV- diagnosed patients’ react/behave toward adhering to ART.

Human Immunodeficiecy Virus - The WHO (2007), defines ‘HIV’ as a “retrovirus which infects cells of the immune system by impairing and destroying their function, as the infection progresses it makes the immune system weaker, and the person becomes more exposed to infections; the most advanced stage of HIV infection is AIDS. In the context of this study, HIV is a sexually-transmitted infection as diagnosed by health-care providers.

Patient - The English Oxford Living Dictionaries (2016: 500) defines 'patient' as a "person who is receiving or have registered to receive medical treatment either in a hospital or clinic". In this study, a patient refers to any person from the age of 18-60 years who is HIV-positive, diagnosed within a period of 1 year, on treatment and is attending Thohoyandou Health Centre.

Perceptions - "Is the ability to see, hear, or become aware of something through the senses" (English Oxford Dictionary, 2016: 506). In the context of the study, 'perceptions' refer to the patients' knowledge, understanding and intepretation of HIV diagnosis and ART.

1.9 STUDY OUTLINE

The study followed a mixed method approach - a combination of Quantitative (Phase 01) and Qualitative (Phase 02). The chapters of the study are as follows:

Chapter 1: Introduction

The emphasis in this chapter is on the background, problem statement, research aim and objectives, hypothesis, delimitations, significance of the study and lastly definitions of key concepts.

Chapter 2: Theoretical Framework

This chapter gives an introduction and detailed overview of two theoretical frameworks, in which adherence is discussed in great detail. The two theories that were considered are the Self-Determination Theory (SDT) rational emotive-behaviour therapy and the health belief model.

Chapter 3: Literature Review

The chapter provides a detailed review of different literatures in order to understand adherence to ART, perceptions and behaviour of HIV-diagnosed patients. Prevalence of HIV and adherence is discussed internationally, in three African countries, in South Africa and in Limpopo Province.

Chapter 4: Methodology

This chapter addresses the research methods and research designs including the location of the study, background, population setting and characteristics and the phases of the investigation. Phases 1 involves the quantitative section, while Phase 2 focuses on qualitative data. The rresearch design, sampling, sampling method, research instruments, reliability and validity/trustworthiness, pretesting, data collection and analysis are all discussed. The ethical considerations that were applicable for the current study are outlined.

Chapter 5: Results

This section outlines in detail the study findings. Statistical findings are presented first followed by the themes and quotations from the qualitative phase. The results were presented following the objectives of the study.

Chapter 6: Discussion

This chapter provides a detailed discussion of the research results and integrate the current findings with previous studies and the theoretical framework.

Chapter 7: Limitations, Recommendations and Conclusions

This chapter is a summary of the chapters, limitations of the current study, recommendation and conclusions.

1.10 CHAPTER SUMMARY

In this chapter the researcher had provided detailed information regarding the topic of the study, the background, problem statement and rationale. The current study's aim, objectives, research question and hypothesis, delimitations, significance, definition of the concepts and the research outline were described.

CHAPTER TWO: THEORETICAL FRAMEWORK

2. INTRODUCTION

A theoretical framework is defined as the structure that holds the theories that can be used to support the rationale of the study (Welman, Kruger & Mitchell, 2005). This chapter outlines the theories that were considered relevant and appropriate in the current study. The theories which will be discussed in detail in relation to this study are the Self-Determination theory and the Health Belief Model, as the researcher was interested in understanding the adherence through exploring perceptions and behaviour of diagnosed patients on ART.

2.1 Self-Determination Theory (SDT)

This theory was developed by researchers, Edward L. Deci and Richard M. Ryan inytri The self-determination theory is a theory of human motivation and personality which utilise traditional empirical methods while employing an organismic metatheory that highlights the worth of people's evolved inner resources for personality development and behavioural self-regulation. The grassroots of this theory is the study of people's inherent growth tendencies and their unique psychological needs that are the foundation for their self-motivation and personality integration; even the conditions that nurture these positive processes.Three needs were pointed out using the process of empirical study- the needs for relativeness, autonomy, and competence - for facilitating paramount functioning of the natural properties for growth and integration, as well as for constructive social development and personal wellbeing (Ryan, & Deci, 2000).

This theory is multidimensional, comprising of cognitive and psychosocial predictors of motivation. SDT suggests that people have an inherent predisposition to be self-motivated. This inherent desire can be stimulated or slowed down by the social environment. Self-motivation has also been refered to as intrinsic motivation, autonomous regulation, and integrated or identified motivation. In this study, self-motivation talks about intrinsic motivation that will allow the diagnosed patient to soldier on (self-regulated). In adding to intrinsic motivation, SDT differentiates between other types of motivation that drive people's behaviour: extrinsic motivation (so-called controlled motivation) and introjected intrinsic. Extrinsic motivation refers to behaviours done to achieve something separate from the activity (for example, adhering to medication to suppress the progression of HIV to AIDS). Significant to SDT is intrinsic motivation*;* explained as the motivation to participate in an activity because it is entertaining, satisfying or challenging. Intrinsic motivation is significant for people who are expected to be determined with a task that they are involved in. because intrinsic motivation is out of their own wish, rather than for extrinsic reasons. Intrinsic motivation can also be incompletely intrinsic that is, when one is controlled by anxiety or guilt), also called introjected motivation (Ivanova, 2011).

Kennedy, Goggin & Nollen (2004), maintain that adherence to HIV medication is expected to improve one state of health if a patient is proactive in planning his/her treatment with the physician, by expressing his/her beliefs about treatment and possibly empowering himself/herself to make decisions concerning his/her health care. Attitudes towards adherence is expected to improve if the person believes that he or she is at liberty to choose to participate in drug therapy and because it is important to him or her. This idea on patient autonomy and its role in predicting health behaviours is described in the theory of self-determination (SDT) (Kennedy, Goggin, & Nollen (2004).

2.2 Health Belief Model

The Health Belief Model (HBM) was developed by Rosenstock in the 1950s in order to understand the failure of people to adopt preventative strategies or screening tests for early detection of disease. It is derived from behavioural and psychological theory with a foundation based on two components of health-related behaviour - the desire to avoid illness or conversely get well if already ill, and the belief that a specific health action will prevent, or cure the illness (LaMorte, 2016)

There are three major components of the HBM, namely, individual perceptions, modifying factors, and taking health action. The model makes sure that an individual takes a health-related action if that person perceives susceptibility, severity, benefits, barriers, cues to action, and self-efficacy (Orleans, 2008). HBM provides a framework for understanding psychosocial factors that may contribute to ART adherence. Adherence is taken as a desired health-related action or behaviour that can be influenced by the perceptions, beliefs, and cues in relation to the actions of an individual (Sondagala, 2010).

a) Modifying factors

Modifying factors in the health belief model includes factors that are modifiable and have some effect on the person’s adherence to ART. These include factors impacting on adherence. A single person can adhere better than a person who is married because of the freedom they might have. Economic status, communication and prior contact with the disease influence choices and decisions by individuals on health actions (Sondagala, 2010).

b) Perceived susceptibility

According to the HBM, perceived susceptibility refers to beliefs about the likelihood of getting a disease (LaMorte, 2016). A study by Chigova (2016) found perceived susceptibility was the perceptions of the HIV-positive patients that the problem of the infection is relevant and correct.

The assumption of the study was that patients whose perception of their susceptibility of HIV disease progression to AIDS is suboptimal, consequently are more likely to not fully adhere to ARV treatment. LaMorte (2016) concluded that perceived susceptibility influences patients' efforts to change their health behaviour. Adhering to ART treatment could be easy if patients perceive their own health as important, thus helping patients to understand that susceptibility to resistance strengthens the progression of HIV to AIDS.

c) Perceived severity/threat

Perceived severity/threat indicates the beliefs about the seriousness or severity of contracting an illness. It leaves a person with beliefs about the difficulties an illness can cause on his or her life in general. The combination of perceived susceptibility and severity results in perceived threat (LaMorte, 2016). Perceived severity of non-adherence is based to a great extent, on the patient's knowledge about HIV and AIDS (Oyore, 2009). This perception is likely to influence an individual to take the health action of adherence due to their experience of contact with the disease; this leads to a perceived threat of deterioration or even death.

d) Perceived benefits

Perceived benefits refer to the seriousness of the health condition and the patient's personal perceived susceptibility that can only be changed by the person's beliefs about the perceived benefits of available actions to reduce the illness (LaMorte, 2016). Individuals exhibiting optimal beliefs in susceptibility and severity are not expected to accept any recommended health action, unless they also perceive the action as potentially beneficial by reducing the threat (LaMorte, 2016). After a person has perceived the susceptibility to a serious health condition, it leads to behaviour change and adhering to medication becomes possible because of the perceived benefits. Patients' belief that they will recover from sickness and that they will be able to work again and live long to raise their children if they take their ARVs properly will influence their adherence behaviour (Hayden 2009).

e) Perceived Barriers

Perceived barriers are those against undertaking recommended behaviours. It is an individual's own evaluation of the obstacles in the way of adopting a new behaviour or continuing with the same behaviour (Hayden, 2009). Barriers to ART treatment include side effects, stigma and discrimination or individuals may lack the support of family members or friends. According to the HBM, modifying factors and cues to action, affect perception of susceptibility, seriousness, benefits, and barriers and therefore, the possibility of a person taking or not taking the recommended health action; in this instance, the action is adhering or not taking medication against HIV. Doctors and nurses play a major role in helping patients implement healthy behaviours (Sondagala, 2010).

f) Self-Efficacy

Self-efficacy is defined as "the level of a person's confidence in his or her ability to successfully perform a behaviour and it is associated with many behavioural theories as it directly determines whether a person performs the desired behaviour" (Afe, Motunrayo, Ogungbade, 2017:109). Self-efficacy expectations differ from outcome expectations; the latter is defined as a person's estimate that a given behaviour will lead to certain outcomes (Sondagala, 2010). In the current study, it is assumed that if a diagnosed patient 's level of self-efficacy is high, the more likely s/he will be able to successfully take ART.

g) Cues to Action

The cues of action motivate the decision-making process about executing the target behaviour (adherence) (Oyore, 2009). These are things that move people to change behaviour; they can be external and internal. External cues that can affect adherence to ART treatment, for example, could be an illness of a family member or a friend, advice from others, and pill-taking reminders. Internal cues include feeling fatigue, uncomfortable symptoms, or thinking about the condition of another person who is HIV-positive (Sondagala, 2010).

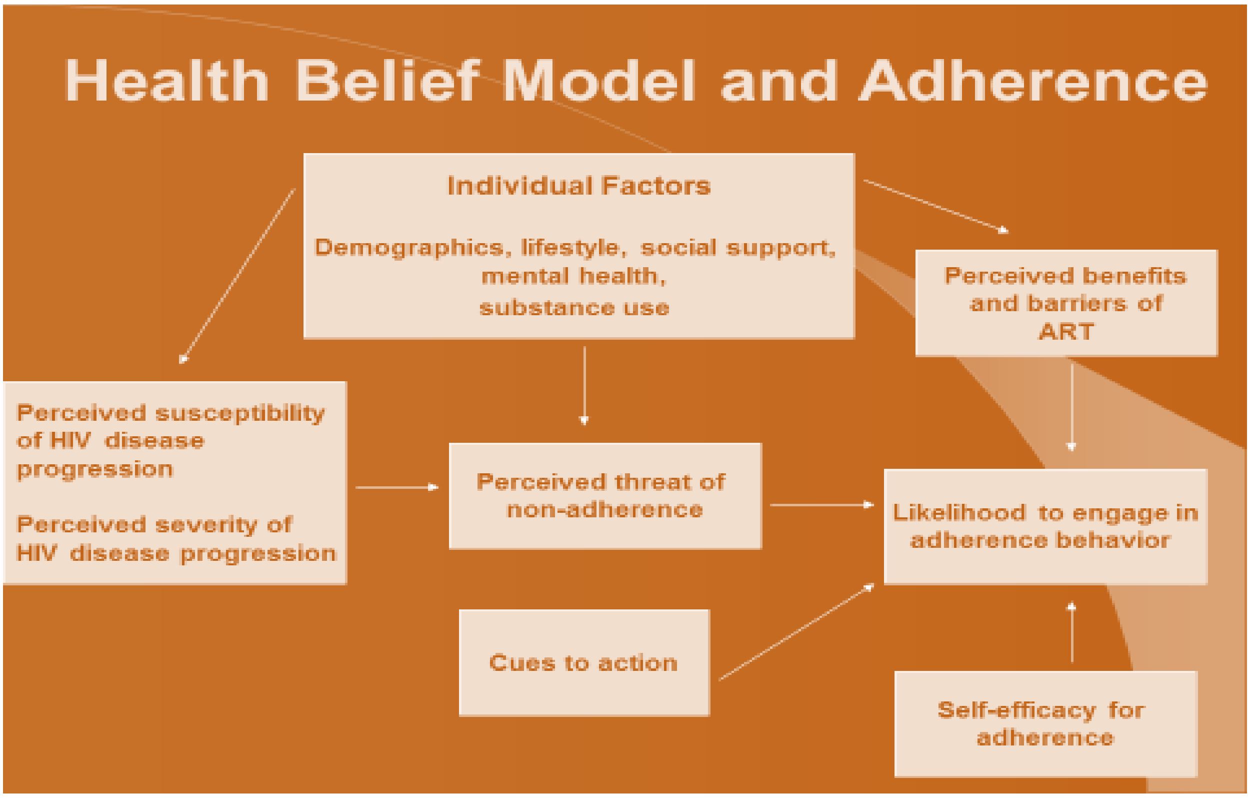


Figure 2.1 Health Belief Model, (Source: Chigova 2016)

2.3 Chapter summary

SDT and HBM theories were discussed in detail with specific focus on the corner stone concepts of the theory. The relevance of these theories to the current study was highlighted.

CHAPTER THREE: LITERATURE REVIEW

3. INTRODUCTION

A literature review provides important information regarding what has been done and what needs to be done in relation to a research problem (Fain, 2009). The process covers significant content areas related to the key research interests. While providing a review of what others have done on the topic of this study, this section reviews literature relevant to adherence, patients' perceptions and behaviour after HIV diagnosis, perceived barriers towards ART adherence, and coping strategies used by HIV patients.

3.1 OVERVIEW OF THE CD4 COUNT AND VIRAL LOAD

CD4 count is the results that come afterwards of administering HIV test, showing the levels and number of CD4counts cells presence within an individual's blood (Yeni, et al., 2002). This test helps the healthcare providers in determining the strength and weakness of the immune system. And determining the damages that had occurred in the immune system and what can possible happen in future if the antiretrovirals are not taken at all or not adherently (Ford et al., 2017; Johnson et al., 2013). After HIV diagnosis is a must that all patients who are HIV positive should take the ART in order to attain a normal range of CD4 starting from 500c/mm3 to 1,400c/mm3 (Govender, et al., 2014; Yeni, et al., 2002). Above 350c/mm3 patients are advised to take their ART treatement and adherently so, while between 200c/mm3 and 350c/mm3 is risky and patients are advised to take their ART (Dybul, Fauci, Bartlett, Kaplan & Pau, 2002; Yeni, et al., 2002). Whereas below 200c/mm3 is highly risky and patients are recommended to take their ARV's as in this state they will be vulnerable to many infectious diseases and HIV is advanced to can easily progress to AIDS (Govender, et al., 2014; Yeni, et al., 2002).

CD4 counts goes hand in hand with the viral load. Viral load is the concentration or amount of the virus in the blood as a way of showing how sick the patient is. The higher the level of viral load the higher the chances of HIV progressing from one state to another and the possibilities of the patients becoming more weaker and sickweaker and sicker (Dybul, Fauci, Bartlett, Kaplan & Pau, 2002; Tang et al., 2017; Yu et al., 2018). When the viral load is over 1000 copies/ml HIV is considered to be high, between 50-1000 copies/ml shows that there is actually no change in HIV status and ART is needed while adherence must be addressed with the patients (Dybul, Fauci, Bartlett, Kaplan & Pau, 2002; Govender, et al., 2014; Johnson et al., 2013;). Lastly below 50copies/ml it’s in undetectable/suppressed and it indicates that ART are taken adherently and they are successfully controlling the virus. The CD4 count should increases when taking ART adherently and whiles the viral load should decreases overtime when patients takes ART (Dybul, Fauci, Bartlett, Kaplan & Pau, 2002; Govender, et al., 2014).

3.1.1 The importance of ART adherence

Optimal ART of 95% is important to attaining the best outcomes when managing HIV/AIDS. ART is a long-term plan for HIV/ AIDS and requires the patient to have at least 95% adherence to prevent the emergence of drug resistance (WHO, 2006; Collins, Holman, Freeman & Patel, 2006). High levels of adherence are essential for optimal benefit of ART. ARV medication has to be taken every single day at the same time for the rest of the patient’s life for the simple fact that the disease process is chronic and ARVs manage and suppress the virus (Maswikiti, 2011; Wang et al., 2009).

When therapy fails then the disease rapidly progress leading to ill health, dire consequences and more burden to the healthcare resources, world-wide (DOH, 2010). Adherence to ART continues to be a challenge because when patients default it limits their options (Nwokike, 2004). The chronic nature of HIV/AIDS demands commitment from patients to be prepared to take medication (correct dosage, minding the specified time and in a particular way taken concurrently with food or after eating) for the rest of one's life (Peltzer et al., 2010). The Department of Health ensures that there is sufficient pre- and post-testing counselling; given the burden, the process seems overwhelming (Holstad, Pace, De & Ura, 2006). Numerous factors can affect how adherent a patient is and mental health is at the core, including psychosocial, cultural, healthcare provider, and diagnosed person's own factors. Studies also maintain that the supply of ART in the society may hinder some people from pursuing ART because privacy and confidentiality are not protected and consequently they default (Fredlund & Nash, 2007; Peltzer et al., 2010); too many pills may also lead to relapse (Wang et al., 2008); studies have also identified that social and psychological support serve a critical component in encouraging patients to continue to adhere to their medication (Holstad et al., 2006; Nachega, 2004).

Beer et al., (2012) note that a high level of adherence to antiretroviral therapy is essential to achieve sustainable viral suppression and better clinical outcomes in HIV-diagnosed patients. Other studies have supported this idea that higher levels of ART adherence is linked with improved, immunological and good clinical outcomes, and also adherence has been found to be the most attainable way to determine outcomes from HIV-diagnosed patients; (Matchtinger & Bangsberg 200o; WHO, 2006). ART adherence is one of the major concerns in the public health sector and it is critical for people living with HIV or AIDS; for its effectiveness, HIV patients has to adhere to prescribed ART medications. Adherence to ART it is far more than just taking the pills, it is a lifestyle of living healthy, exercising and eating healthy food. Adherence is also a form of a process and HIV patients are expected to be an active member in the same process (Mills 2011; Nachega, 2004; Sunpath et al., 2011). Health-care providers also believe that ART adherence is more than taking one's medication, it also includes diet, and or executing lifestyle changes.

3.2 ADHERENCE, HIV AND AIDS IN SOUTH AFRICA

In South Africa, various studies have been conducted on HIV/AIDS. Bhat et al., (2004) found 37,5% of poor adherence to ART; Nachega, Stein, Lehman, Hlatshwayo, Mothopeng, Chaisson and Karstaedt (2004) has established 95% level of ART adherence in Soweto; Peltzer et al., (2010) they all- got 82.9% level of adherence from newly initiating ART patients at one of the 3 public hospitals in KwaZulu-Natal; Laurent et al., (2002) has established 87.9% level of adherence among HIV-diagnosed patients on high antiretroviral therapy from a 18-months follow-up study; Oyugi et al., (2004) revealed91%-94% of adherence in HIV antiretroviral therapy in a resource-limited setting; Harries et al., (2001) collaboratively emphasised that there is poor adherence to ART treatment in sub-Saharan Africa including, here in SA (Gill et al., 2005). According to Wood et al., (2007) in SA many studies have been conducted pertaining to HIV and adherence to ART, however, results always show a low level of adherence being attained from these previous studies and there are many barriers to ART adherence.

3.2.1 Adherence to ART

Adherence to ART has become a major concern, as it can cause treatment resistance if individuals take their medication inappropriately. It is very important that all patients understand the importance of adherence to ART before initiating treatment. Assessing patients understanding, empowering patients and giving full information regarding ART's lifelong treatment should be done during the first visit (Eyassu, 2015). If healthcare professionals fail toobserve their primary role of helping patients who are infected with HIV, it may lead to the development of multidrug resistance that may lead to increase in mortality and morbidity from HIV infection (Orell, Bangsberg, Badri & Wood, 2003). For ARVs to be effective, it requires at least 95% level of adherence. Adherence to ART improves the quality of patient's life as the viral load declines and the CD4 counts increases, if the treatment is effective (Eyassu, 2015).

Adherence to ART involves taking all the prescription in the correct quantities, taking the pills at the right time and ensuring that the treatment is taken according to the healthcare practitioner's instruction; some treatment needs to be taken on an empty stomach while others need to be taken with food and it is very important for patients to eat the right food that goes well with the treatment (Muthiani, 2010). Antiretroviral treatment is the golden standard for HIV and AIDS treatment in the modern world. It is not a cure but prolongs the life of infected people by many years. The treatment consists of drugs that have to be taken every day for the rest of a person's life (Eyassu, 2015). The main role of antiretroviral treatment is to keep the level of HIV in the body at a low level; it minimises any weakening of the immune system and allows it to recover from any damage that HIV might have caused already. A systematic review compared adherence to ART treatment among patients in North America and Sub-Saharan Africa; for the latter, 77% patients achieved adequate adherence, while the former achieved 55% (Singh *et al*., 2006).

It was estimated that 5.6 million people were HIV positive in South Africa, while 310 000 died of AIDS-related diseases, (UNAIDS, 2010). Nachega *et al.,* (2004) reported 95% level of adherence among patients on ART in Soweto. HIV prevalence in South Africans between the ages of 15 and 49 was 17.8% in 2009. Another study conducted at Ithembalabantu clinic in Umlazi, KwaZulu-Natal found 79% of ART adherence (Dlomo, 2010), while a study conducted in a rural area in South Africa reported 37.5% poor adherence to ART (Bhat *et al*., 2010). Adherence to ART varies from place to place across South Africa, and contrbuting factors are, among others, sociocultural, economic, and demographic in nature. In addition, social, historical, and geographic contexts also influence the adherence rates to ART programmes (Gilbert & Walker, 2009), especially in the context of rural South Africa.

3.2.2 ART and treatment failure

Antiretroviral treatment failure is defined as an HIV-positive patient who is experiencing virological failure, which can occur due to poor medication adherence, drug resistance, poor medication absorption, inadequate dosing, and drug reactions (WHO, 2015). A person's virological state is measured through a viral load blood test. If the results show that a person's blood contains betweenb 1,000 to 5,000 copies of the HIV virus per millilitre, they are said to be experiencing virologic failure (AIDS Info, 2015). High adherence, defined as taking the prescribed medication 95% or more of the time, is necessary for a greater chance of virological suppression; a state when the virus is controlled within an individual's system (WHO, 2013). If a person is able to achieve longstanding suppression, their immune system can restore functionality and will likely avoid the progression of HIV to AIDS (WHO, 2013).

The National Institute of Health's AIDS Info (2015) outlined three stages of HIV infection: 1) acute infection 2) chronic infection and 3) AIDS. Acute infection, the earliest stage, is when the virus multiplies rapidly and destroys the immune system's CD4 cells. The chronic infection stage is asymptomatic and is when the virus continues to multiply in the body, although at a much slower rate than in the acute phase. Without regular treatment, the virus usually advances to the AIDS stage in 10 to 12 years. AIDS is diagnosed when a person has a CD4 count of less than 200 cells/cubic millimetre and/or they have one or more opportunistic infections (that is, pneumonia or tuberculosis). Without treatment, a person with AIDS will generally live three years following their diagnosis.

3.2.3 Missed medical appointments

Missing medical appointment can be detrimental to the patients because it automatically means that the patient will not be taking treatment. Regardless of the fact that HIV treatment is free, transport costs are major problems for people on ART causing them to miss medical appointments (Michel & Matlakala, 2013). In a study conducted by Kaplan-Lewis & Percac-Lima, (2013) on HIV patients reported forgetfulness as one of the reasons for missing appointments with health practitioner. Similarly, Zeleke (2012) found that forgetting/unable to attend an appointment for refill were some of the reasons leading to poor adherence. The first step in adherence to ART is attending follow-up appointments. There are many reasons why patients fail to keep medical appointments with health care providers.

3.3 ASSOCIATION BETWEEN DEMOGRAPHIC FACTORS AND ART ADHERENCE

There are several factors that are related with non-adherence to HIV medication. Adherence is understood as a self-motivated behaviour influenced by conditions of related factors that change over time. To counteract non-adherence, demographic factors must be discussed. as these factors may yield poor adherence outcomes in South Africa. Kennedy, Goggin, and Nollen (2004), state that adherence to HIV medications is linked with a number of demographic variables such as gender, age, marital status, highest education level, and occupation.

Gender

In the growing literature on factors associated with antiretroviral adherence, a consistent relationship between gender and adherence has not been found. While several studies have failed to show a significant association between gender and antiretroviral adherence (Wagner, 2002), some studies show that women are less adherent than men. Most studies that found no association between gender and adherence is limited either by small numbers of women participants or by the use of self-report, which has been shown to overestimate adherence. Another possible explanation for inconsistency in the relationship between gender and adherence is that this relationship may have been confounded by unexamined social or behavioural factors. Some studies show that women adhere better, especially those committed to taking care of children (Abdissa, 2013). On the contrary, some studies have found that gender influences adherence to ART (Abah *et al.,* 2010; Eyassu, 2015). Sendagala (2010) reported that there was no association between gender and respondents' adherence levels. Similarly, a study conducted by Nyambura (2011) in Kenya found no association between adherence to ART and gender.

Age

Age may influence adherence. Older adults are generally considered to be at greater risk of medication non-adherence due to factors such as medication complexity, side effects, cost, and cognitive decline (Brooks et al, 2012). Dowshen (2011) found that the leading reasons for non-adherence among the youth were of insurance, in addition to social and psychological factors. Other factors that contribute to non-adherence among the youth included inconsistent daily routine, fear of disclosure, simply forgetting, adverse effects of the medication, and not understanding the need to take medication when one feels well. Some studies found that elderly people are said to adhere less although adherence to HIV medication increases with age (Abdissa (2013). A study conducted by Negash (2011) on HIV in Addis Ababa in Ethopia reported no significant association between age and ART adherence level. Similarly, Sendagala (2010) found no association between adherence and age. The ASSA model estimates that there were 6.5 million people in South Africa living with HIV/AIDS on 1 July 2002. Of these, over 6.1 million (95, 1%) were in the age group, 18-64 years. This is also the age group which is most likely to form part of the labour force (WHO, 2002).

Marital status

Marital status can be a protective factor which, as a result, might lead to high levels of adherence. A study done at Kwa Thema clinic in Gauteng Province found no association between marital status of respondents and adherence to ARV treatment (Melaku et al, 2016). Similarly Sendagala (2010) found no association between adherence to ART and marital status. Eyassu (2015) found that there was no significant association between marital status and ART adherence, however, a study conducted by Mugoh, Kabiru & Mwaniki (2016), found that marital status was significantly associated with ART adherence with monogamously married and polygamous married respondents more likely to have optimal adherence as compared to widowed or widower respondents.

Education level

People living with HIV who have low educational levels show poor treatment adherence. Poor literacy and general lower levels of education impact negatively on some patients' ability to adhere (Nakiyemba, 2004). Higher educational level is associated with better adherence; high education level increases patients' adherence to ART, because it becomes easy to understand and follow instructions from the health-care providers (Eyassu, 2015). In the study of Sendagala (2010), the majority of respondents had low education levels with (n=179; 69.6%) primary education level; there was no association found between adherence to ART and education levels.

Occupation

It is not clear what effect socioeconomic factors has on adherence to antiretroviral therapy (ART) among patients in low- and middle-income countries. A systematic review by Peltzer & Pengpid (2013) found a positive trend among components of socio-economic status (SES) (income, education, occupation/employment) and adherence to antiretroviral therapy. The review, however, found inconclusive support for a clear association between SES and adherence among patients infected with HIV/AIDS in low- and middle-income countries. The association between SES and adherence may differ depending on the cultural/economic/geographic context of the countries. In a study conducted by Sumbi (2010) in Nyeri Provincial Government Hospital in Kenya, occupation was found to be a factor with employed patients as a group exhibiting poorer adherence levels than self-employed and unemployed patients. Sow, Coume, Ka, Gaye, Fall, Toure, & Traore (2012) indicated that low level of adherence was found among unemployed respondents, however, there was no significant differences between adherence to ART and occupational status of people living with HIV and AIDS. In a study by Mthembu, & Van Wyk (2014) there was a high sample of unemployment with 75.5% (n=40) males, and 87% (n=114) females, however, the results show no significant association between adherence to ART and employment status.

3.4 PATIENTS' PERCEPTIONS OF HIV DIAGNOSIS

The diagnosis of HIV has been found to be traumatic, comprising of feelings of depression and isolation, fear of disclosure, denial, vulnerability and poor psychological adjustment (Kelly, Alderdice, Lohan and Spence, 2012). Studies have revealed prenatal screening to be suitable to many women, although recently there are few studies that are trying to understand the distinctiveness of being diagnosed with the infection of HIV, from the viewpoint of pregnant women (Kelly, Alderdice, Lohan and Spence, 2012). Many women believe that they could not be infected with HIV or it is impossible for them to be HIV-positive since HIV happens to other people. After being diagnosed with HIV, most women found themselves being pushed into a state of otherness. The diagnosis of HIV also symbolises an assault on one's body, which for some time was taken for granted (Kelly, Alderdice, Lohan and Spence, 2012)

According to Renesto, Falbo, Souza, and Vasconcelos (2014) when patients are diagnosed with HIV, they perceived their lives as at a turning point that the disease is capable of destroying their lives and their relationships and making it so hard to adjust in the society. This goes together with the need to deal with doubt and suffering, knowing that the disease is incurable; this adds a weight of moral judgment and fear to hide the fact at all cost in order to continue to be accepted by the society. Christopoulos, Massey, Lopez, Hare, Johnson, Pilcher, Fielding, Dawson-Rose (2013) add that patients' perceptions of HIV differ with the risk, namely, those who have no information regarding their infection, those who expected the diagnosis, and those who reported feeling being betrayed by their partners handle the disease differently.

Several patients mentioned that they were shocked as a results they are unable to accept the diagnosis; others refer to being unable to have any emotional response at all. The way patients perceive HIV diagnosis has an influence on ART adherence and various factors which influence adherence (Christopoulos, Massey, Lopez, Hare, Johnson, Pilcher, Fielding, Dawson-Rose, 2013).

3.4.1 Patient's knowledge about HIV and ART medication

HIV is found in all body fluids like semen, blood, pre-seminal, saliva, breast milk, nervous system tissue and spinal fluid, even though only blood, semen, and breast milk has been shown to transmit HIV to others. Exposure to infected fluids leads to the risk of contacting the infection (Davidson, 2002). The common method of HIV transmission includes: using sexual toys and objects with an infected person, having unprotected or condom-less vaginal, oral and anal sex, especially with high-risk groups, like injection-drug abusers. This population is likely to contract HIV and healthcare workers who can accidentally prick themselves with an infected needle (Mandal, 2017). There is a risk when sharing needles with other drug users and patients who are likely to be HIV-positive; those who get tattoos or body piercing or using improperly-sterilized devices, from an infected mother to her baby before or during birth. Transmission may also occur via breast milk during lactation. If the mother is treated with anti-HIV medications, the risk of transmission is low; getting a surgical operation with unsterile instruments that may have been used on HIV-positive individuals, via transfusion of blood contaminated with HIV. This is very rare these days since blood is screened for HIV before being transfused, and being exposed to blood, organs or products of an infected person (Mandal, 2017).

According to Mulelu (2016), knowledge and understanding of the diagnosis of HIV and AIDS helps in adherence of ART. It was found that most of the participants have knowledge about the ART they are taking, even though all of them could not be able to call the ART using the correct names. In a study of Haffejee, Ports and Mosavel (2016), many participants were able to differentiate between HIV and AIDS and were knowledgeable about the transmission of HIV from unprotected sexual intercourse, sharing of needles and or razor blades with infected persons.

According to Kibicho & Owczarzak (2011) patients may have misconceptions about the importance of absolute adherence and as a result self-tailor own antiretroviral regimens. Even when patients are aware that taking medication is important, few may understand why it has to be taken at an appointed time and why an exact drug or combination of drugs or the reasons for daily dosage. Patients may also not take medications as prescribed because of problems of reading prescription label instructions, identifying pills, or understanding how to take medications (Kibicho & Owczarzak, 2011).

A study conducted by Nachega, Lehman, Hlatswayo, Mothopeng, Chaisson and Karstaedt (2005) found that knowledge scores among HIV positive people attending clinical care was 86%. Their knowledge was evaluated in terms of cause, mode of transmission and progression of HIV. The knowledge gained through the media and during counselling sessions at health facilities was well understood by HIV patients. Among patients taking HIV medication, a high level of knowledge regarding HIV medication and its importance in controlling the infection was observed. Another study done by Murray, Semrau, McCurely, Thea, Scott, Mwiya, Kankasa, Bass, and Bolton (2009) conducted among Zambian urban women found that lack of information regarding HIV and its medication was associated with non-adherence; with the absence of adequate information about HIV and its medication, when patients feel better, discontinuing with the medication is easy with the rationale that one has been cured.

3.5 PERCEIVED BARRIERS TO ART ADHERENCE

In South Africa there is a high production/ availability of HIV medication but attaining high levels of adherence remains a concern. This section discusses the barriers to HIV medication.

3.5.1 Discrimination, Stigma and Rejection

Stigma was identified as one of the major barriers to ART adherence (Negash, 2011; Van Dyk, 2011). ART treatment is a life-long process bur sometimes, once a person starts taking ART treatment, social stigma may completely disturb the patient’s adherence levels. A study conducted on Zambian women described stigma in different ways: fear of being laughed at, shyness, fear of being embarrassed or others knowing their status, and fear of being identified as a prostitute (Murray, Semrau, McCurely, Thea, Scott, Mwiya, Kankasa, Bass & Bolton, 2009). Stigma is one of the main reasons why ARV users hide their HIV status; they hide taking medication in front of friends, colleagues and others. Van Dyk (2011) in her study found out that 75% of ARV-users stated that stigmatisation is a problem in their communities and that a culture of non-disclosure still exists because their communities are not open to HIV and ARV talk. According to Bauleth, (2013), stigma and discrimination are believed to contribute to some of the HIV patients’ fears, the stigma is caused by lack of knowledge, types of sexual behaviours, as well as fear of death and disease. In the study of Bauleth, (2013) some of the participants accepted that they have not disclosed their HIV status because they are afraid of rejection and discrimination. Some of the participants indicated that they are afraid to talk about their illness with their neighbours and families or take their treatment in front of their friends because they are afraid of what they will say or suspect.

Discrimination is said to occur when people are singled out in a way that results in them being treated unfairly and unjustly on the basis of their belonging or being perceived to belong to a particular group. Where stigma exists, people are reluctant to get tested or get involved in education and preventative measures. Much of the stigma concerning HIV has been found to be associated with lack of understanding of the disease, myths about how HIV is transmitted, fear, shame and blame (Moratioa, 2007). Internalised shame indicates the extent to which the experience of rejection and financial insecurity has been turned inward and includes feelings of being set apart from others who are well and blaming oneself for the illness. Social isolation signifies a feeling of aimlessness, incorporating feelings of loneliness, inequality with others, and uselessness. Three dimensions of self-esteem have been indicated are potentially influenced by stigmatisation in this analysis: self-esteem, personal control and body image. Fife and Wright (2000) hypothesise that the individual’s perception of stigmatisation accounts for significant differences in the impact of the illness on the self. Baghazal (2011) has reported that many HIV patients experience stigma and discrimination from the community, their family and even from the hospital; this causes the patients to distance themselves from getting HIV care and start getting their treatment from clinics which is far from their community than risking been seen in a nearby clinics. Female patients become afraid that their male partners might abandon them if they disclose their HIV status to them, they are afraid of the resultant violence. Even though there is high level of stigma and discrimination, this can be overcome by support from family and friends and by motivation and acceptance of one’s HIV status.

3.5.2 Psychological factors

Psychological factors associated with adherence include psychological distress, stress associated with adherence and depression. The severities of anxiety and depression have significant influence on adherence to HIV medication. Patients exhibiting symptoms of some psychological disorder, such as depression, are less likely to assert themselves in adhering to medication regimens that in some cases require a stringent ability to follow complex instructions from a medical professional (Kagee, 2004). According to Mokwele & Strydom (2017), HIV and AIDS is a chronic illness that requires life-long adherence to treatment, therefore an adequate amount of attention needs to be dedicated to the psychological dimensions of care and support needs of community caregivers to encourage ART adherence of patients. It is found that people living with HIV and AIDS encounter a number of stressors that impact their mental health. Psychological stressors is manifested differently from one patient the other.

Patients who are facing the blunt of the emotional impact of being HIV-positive through substance abuse, depression and suicidal ideation, are also less likely to be ready to adhere (Nordqvist et *al.,* 2006). Depressed patients also, usually harbour feelings of hopelessness towards their future, therefore, adhering to medication with the hope of future health is unlikely (Simoni, Frick, Lockhart & Leibovitz, 2002). The emotional and the cognitive sequelae of depression may inhibit the patient’s ability to concentrate and remember important details such as the time recommended for the medication. Depressed individuals may also lack the physical and mental energy necessary to maintain high levels of adherence, thus requiring the help and support of others. Appetite changes are usually associated with depression; consequently patients may find it difficult to adhere to special dietary instructions related to antiretroviral regimens

(Simoni *et al.,* 2002). Abdissa (2013) found that symptoms of severe anxiety were associated with non-adherence. Psychological distress has also been found to be a risk factor for poor adherence. Depressed mood has frequently been linked with poorer adherence to ART and general pessimism about the future (Kennedy, Goggin, and Nollen, 2004).

A study conducted by Moratioa (2007) in Kalafong hospital on HIV and AIDS patients, found depression to be one of the barriers patients mentioned to accepting their HIV-positive status and also is a barrier in having a positive view on life. Depression is the strongest predictor of non-compliance with antiretroviral medication. Feelings of hopelessness and negativity decrease ones' ability to look after oneself. Kibicho & Owczarzak (2011) mention that patients who suffer from psychological or mental health disorders like depression, fail to cope with the demands of ART and HIV. Other patients refuse to take medications because they do not want to challenge their HIV diagnosis. International Centre for Reproductive Health and Coast Province General Hospital (2004) added that patients with psychiatric illness and depression might find it difficult to adhere to treatment. Patients who are at an advanced stage of HIV might have HIV-disease-related conditions such as AIDS dementia, which might stop them from caring for themselves and taking their medications correctly and all the time; they might also suffer from residual confusion, later an episode of meningitis or encephalitis. Depression in patients living with HIV is associated with reduced adherence to ART (Mathebula, 2014).

According to Yehia *et al.,* (2015), patients who are on ART identified with some mental illness, such as schizophrenia, Post-Traumatic Stress Disorder, anxiety and depression. Patients suffering from depression often feel apathetic and some start to not care if they die or live. Previous research has illustrated that people living under stressful conditions, frequently engage in poor-health practices, which ultimately increases their risk to disease and disease progression. Life stresses can interfere dramatically with people's ability to function. Numerous studies have shown that the onset of depressive episodes is etiologically linked to stressful life events (Leserman *et al.,* 2002).

3.5.3 Treatment-related factors

A study by Abdissa (2013) points out that the number of ARVs pills per day, the regularity of dosage, and the type of ARV regimen were not related to adherence to ART. Abdissa noted that there was a difference in adherence by patients who are taking their medication once or twice a day, and patients taking three ARV pills per day. Even though there was no suggestion recognised in these variables in relation to treatment in the study setting, the current availability ARV medications has contributed to a decrease in the number of pills and the regularity of dosage. This can possibly, indirectly, encourage adherence. The change in ARV medication was found to affect ART adherence. Patients who change their medications are likely to report poorer adherence than patients who never changed their treatment. Nkomo (2014) adds that treatment-related factors which encourage adherence require prescription of regimens that are simple to take, with the least side-effects, medication which does not have food limitations and prevention of drug stock-outs. Amongst a number of the factors that were seen to affect adherence were problems related to the number of pills, size of pill, side-effects, food limitations as well as dosing times which had significant influence on adherence.

Johnson, Johnson and Neilands (2007) note in a study conducted in the USA that patients on ART medication deliberately missed their medications in order to avoid the side effects from the treatment. Missing of medication has been found among patients with inadequate understanding of how the medication works, those who had poor interactions with health-care providers, those who have not disclosed their HIV status to family members and friends and those with significant intrusiveness of the HIV treatment on their lives. In the study of Moratioa (2007) all participants reported that they are experiencing side effects from the medication. Side effects including lethargy, nausea, diarrhoea; vomiting, lower abdominal pains and painful feet, increase patients' reluctance to adhere. Even though some participants report that they cannot manage the side effects, some participants reported continuing with medication despite side effects, but altered frequency and took the medication randomly. The number of pills that patients have to take daily and their side effects have been identified as a barrier to adherence to ART. The pill burden was reported to be physically taxing, confusing and emotionally consuming (Baghazal, 2011). The counselling received on how to manage side effects did not make it better when the reality occurred (Moratioa, 2012; Simoni, Frick, Pantalone & Turner, 2003). Southern African HIV Clinicians Society (2012) adds that side-effects remain the commonest reason patients stop (default) treatment.

3.5.4 Disclosure of HIV status

Disclosure of HIV status refers to opening up about one's diagnosis of HIV. Disclosure is an important factor influencing adherence. Fear of rejection or discrimination may prevent people living with HIV from disclosing their status to family members and friends, thereby losing out on social support. Patients may not want to take their medications in the presence of colleagues at work or family members at home and so choose to skip that particular dose of medication (International Centre for Reproductive Health Coast Province General Hospital, 2004). Disclosure is a difficult decision for people living with HIV; patients carefully weigh their decision about disclosing their HIV status to their families and community because it is followed by a major changing consequence such as labelling, stigma, and belittlement (Kwanisai, 2014).

Fear of disclosure of HIV status for some patients led to difficulties obtaining and using treatment correctly. People living with HIV are afraid of being fired from work if their employers found out they are using ARVs, therefore, they hide their medication which leads to missing or delaying doses (Mathebula, 2014). Reasons for non-disclosure include fear of rejection, isolation or abandonment, stigmatisation, lack of social support, separation or divorce, and even prosecution (Olley *et al.,* 2004). Disclosure of HIV-status opens up the potential for stigma. Stigma manifests in several ways, broadly grouped into physical and social isolation/exclusion (Cao *et al.,* 2006), which leads to decreased adherence. Stigma is associated with social rejection, internalised shame, social isolation, financial insecurity and decreased self-esteem. Social rejection pertains to individuals' perception that they are discriminated against at work and in society generally; this includes the perception that others have less respect for them, do not act as though they are competent, avoid them, and appear to feel awkward in their presence.

3.5.5 Inadequate knowledge

Patients with low literacy levels may not completely understand their disease, its challenges and complications. Patients may not comprehend instructions provided (International Centre for Reproductive Health Coast Province General Hospital, 2004). Knowledge about HIV disease is believed to prolong life of people living with HIV, hence, lack of or inadequate knowledge about HIV may affect adherence to ART (Nakiyemba, 2004). In a study conducted by Kambale, (2013) in Palapye clinics, patients reported lack of knowledge regarding ART regimen and also forgetting to take their medication at the prescribed time. The finding correlates with the findings by Mathebula (2014) who found that most participants reported lack of knowledge when it comes to their treatment regimen.

Religious prophets and traditional medicine is commonly used by HIV-treatment-naïve outpatients in facilities in South Africa. Some of these people promote non-adherence on the belief that they have healing powers against HIV. It has been reported that some churches claims that faith-healing can cure HIV and AIDS; some patients are misinformed by churches about their illness, leading to the transmission of the diseases to other family member, reduced CD4 cell count and eventual death (Michael and Matlakala, 2012).

3.5.6 Forgetfulness

Mulelu (2016), state that forgetfulness can be manifested when a patient attends social functions on weekends or is always away from home. Eyassu (2015) identified forgetfulness as the most common reason for not adhering to ART. Kibicho & Owczarzak (2011) mention various reason for forgetting to take the treatment, such as interruptions in the daily routine, running out of medications and patients may also forget to take their medication when dosing time does not fit with their daily schedule (Azia, Mukumbang, and Van Wyk, 2016).

Facts and studies on barriers to ART adherence

Being HIV-positive to some people is perceived as some sort of a curse; some patients after discovering their status, prefer to hide it until a later stage, when they are ready to disclose, then they inform their loved ones. Mothers or caregivers who are infected with HIV struggle with the diagnosis alone, in secret (Mellins, Brackis-Cott, Dolezal & Abrams, 2004). Mills et al., (2006) conducted a meta-analysis in 72 high-income countries and 12 low- and middle- income counties, comprising of five African countries and found that barriers to ART optimal adherence include fear to admit one's positive HIV status, complex medication, being absent, and failure to remember to take medication. In addition, social, historical, and geographical contexts have an effect on the level of adherence (Gilbert & Walker, 2009); Socio-economic constraints and interruption in the supply of medication, insufficient knowledge about HIV/AIDS and stigma obstructed optimal adherence (Kempf et al., 2009).

Studies conducted in Zambia looking at the determinants of ART adherence found that lack of social support, depression, discrimination and the inability to speak openly about one's HIV status, food insecurity, health service- related factors, medication and side effects were acknowledged as barriers to ART adherence (Dahab et al., 2008; Murray et al., 2009; Kip et al., 2009).

Nordqvist, Sodergard, Tully, Sonnerborg & Lindbald (2006) note that in an Australian sample, out of the 270 HIV-infected patients who were not adhering to ART, the most common reason that was provided related to being afraid of the side effects. Defaulting is also as a result of fear of disclosing own status and many miss doses leading to lower rates of adherence (Musheke et al., 2012). Some HIV patients fear being discriminated by other people once they find out that they are HIV positive, however, causes of these fears stem from disclosure and rejection, losing loved ones, death, transmitting HIV to a partner, change in quality of medical care, changes in the manner of obtaining HIV medication and lastly HIV progression (Kylma, Julkunen & Lahdevirta, 2003).

The following are some of the patient-related factors that other researchers have found and agree may lead HIV patients to stop taking their medication - non-disclosure, adjustment to the diseases, failure to understand and accept the diagnosis, travelling far away from home maybe due to work or visiting relatives, staying too far from the hospital/clinic, some patients preferring to receive ART far away from home as a way of hiding their diagnosis; too sick to attend the medical appointment; relocation or transfer to their nearest clinics; running out of ART medicines and patients not seeing that it is problematic, being hospitalized as a result of HIV progressing to AIDS; all these reasons weaken the immune systems (Chesney, 2000; Chesney, Morin & Sherr; Smit et al., 2006; Tweya et al., 2018).

3.5.7 Lifestyle barriers

A study done by Chesney, Morin and Sherr (2000) indicated that people living with HIV who use substances are often unwilling to comply with long and complex regimens and they know how to access medical help and receive less preventative treatment. The study further states that HIV-positive patients', who live negligible lifestyles, use substances and have lower socioeconomic status, are at at a higher risk of future non-compliance (Chesney, Morin and Sherr, 2000). Southern African HIV Clinicians Society (2012) has revealed that alcohol use causes a major problem with adherence to ART treatment, even though the use of substances differs with patients in accordance with the availability of the substances and peer pressure. Kibicho & Owczarzak (2011) add that HIV-patients engage in risky behaviours, such as, substance abuse that can affect their ability to adhere to medication, cause isolation, and reduce the effectiveness of ART. International Centre for Reproductive Health Coast Province General Hospital (2004) mentioned that patients with high alcohol intake or drug use have problems adhering to ART. Abdissa (2013) notes that adherence to ART is less for people with psychiatric illness, and individuals who use alcohol and drugs.

Azia, Mukumbang, and Van Wyk (2016), found that evidence that one is feeling better was identified as one of the challenges influencing non-adherence for some participants. In the same study one of the participants testified that after commencing treatment, health improved and she stopped taking medications and carried on with socializing with friends as she used to before initiating treatment. In this study, participants mention that alcohol and smoking, negatively affected adherence to treatment.

3.6 Coping strategies used by HIV diagnosed patients

Coping is a very comprehensive notion which includes many behavioural, cognitive and affective responses; various coping strategies have been identified. This section presents a brief discussion of some of the coping strategies that HIV-diagnosed people use, namely, acceptance, seeking social support, and joining religious organisations.

3.6.1 Acceptance of HIV status

Acceptance suggests that people acknowledge the reality of the situation and try to deal with the stressful situation. Accepting HIV-positive status is explained as the awareness to recognise the influence that HIV will have on one’s life. People who are HIV-positive might not, certainly achieve acceptance of their status immediately after being diagnosed, but gradually develop a sense of acceptance when time progresses. Acceptance is frequently conceptualised as a secondary control or accommodative way of coping. Acceptance can be in the form of passive, resigned or even fatalistic acceptance which is related with negative effects and faster disease progression in people living with HIV. Healthy acceptance eventually empowers the people living with HIV, to deal with the challenges of the illness in a genuine and practical way (Kotzé, 2011).

3.6.2 Social support

Kambale (2013) explains that in preparation for patients to initiate treatment, it is important that patients get support from their relatives, and friends. A study conducted in Palapye clinics reported that social support was found to be important for adolescent patients in the study. Adolescents who participated in the study who were accompanied by their direct relative; siblings, mother, or an aunt were found to adhere better than those who come alone and those accompanied by their grandmother (Kambale, 2013). Social support from relatives and the community plays a big role in patients' life when facing problems with taking their HIV medication, treatment follow-up, and also addressing any multifaceted psycho-social needs for people living with HIV. A study conducted by Abdissa (2013) in Addis Abada found out that social support is in relation with disclosure, and the presence of social support in taking HIV medication was found to be significantly associated with ART adherence. Rankin (2015) reported that having formal or informal social support is a way of resilience in older HIV-positive adults. Social support also refers to special relationships, association with recreational activities, and support groups for HIV-positive adults.

3.6.3 Religion

Religion and spirituality are two ways that some HIV-positive older adults use to cope with their HIV diagnosis. A person practices spirituality to understand his or her own world, away from concrete and earthly concepts. Being spiritual does not automatically mean a person ascribes to a specific religion. In a qualitative study by Rankin (2015), participants were asked to describe how religious or spiritual beliefs helped them to cope with their disease. All of the participants stated that having faith was very useful for them in coping with HIV and AIDS, even though many did not take part in structured religious services due to feeling uncomfortable with being in a traditional church setting (Rankin, 2015).

Moratioa (2007) suggests that church attendance, religious practices and spiritual beliefs play an important role in improving the health of an individual in general. Hope and faith in a higher power gives inspiration, help patients to make sense of their world, gives validity to people, and act as a foundation for daily decision-making. People usually believe their spiritual belief systems to cope with adverse conditions. Moratioa (2007) identifies two types of religious coping, namely, positive religious coping and spiritual struggle. Positive religious coping includes actions that are focussed at seeking a close relationship with God as well as the belief that there is a larger meaning to one’s life. On the other hand, spiritual struggle includes conflicts, doubts and the questioning of one’s faith, religious relationships and God. While positive religious coping has been linked with positive psychological outcomes in people living with HIV, spiritual struggle has been linked with negative psychological outcomes. Kotzé (2011) notes that religious coping can also have a social support element, for when people are using religious coping they often go to religious meetings for fellowship with other believers or seek religion-based counselling

2.7 Chapter summary

This chapter discussed literature on the patients’ adherence to ART, association between demographic factors and adherence to ART, patients’ perceptions of HIV diagnosis and coping strategies used by HIV patients. It concluded by discussing the theoretical framework. The next chapter will discuss the methodologies used in this research.

CHAPTER FOUR: METHODOLOGY

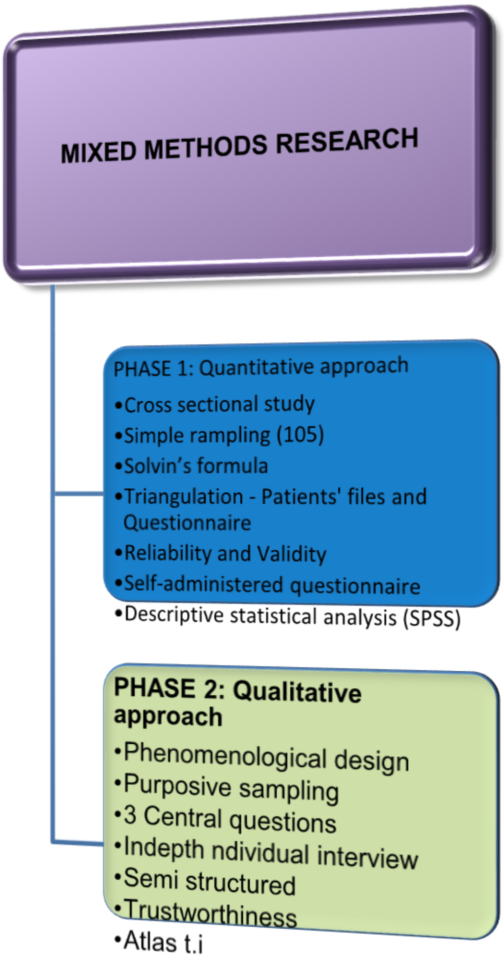
4. INTRODUCTION

The choice of a methodology is guided by the objectives of the study as well as the time and resources available to conduct it. Discussions on methodology outline and justifiy the strategies used in the study. This section introduces the research methodology, research design, population and setting, sampling, research instrument, validity and reliability, trustworthiness, pre-testing, data collection, data analysis and ethical consideration.

4.1 BACKGROUND ABOUT THE PROJECT

This study is nested within a project investigating HIV/AIDS in the northern part of South Africa: how it is transmitted, acquiring drug resistance, adherence to treatment, on coviruses, blood pathogens, and host genetics. The project has been running since 2015 with ethical clearance from the University of Venda SMNS/15/MBY/23/0710 and Ref: 4/2/2 from the Department of Health.The research team is looking at antiretroviral treatment outcomes, the development and transmission of resistant viruses in adults and children, and the prevalence, risk factors and genetic variants of cancer-associated viruses such as HBV, HHV8 and HPV. In order to understand how viruses develop resistance once treatment is initiated, persons who are about to start antiretroviral treatment were recruited and are being followed up while they are under ARV treatment. The goal is to find out if resistant viruses are being transmitted. The results of the project will help in determining whether HIV-resistant variants are being transmitted; whether individuals failing first- and second-line treatments are infected with viruses bearing resistant mutants. This information may be useful in understanding the impact of the Highly Active Antiretroviral Therapy (HAART) rollout in Limpopo Province and the prevalence of other-related viruses. In general, the data that is generated may impact policies on the management of HIV/AIDS.

In the current study the researcher investigated adherence through an exploration of perceptions and behaviour of patients on Antiretroviral Therapy attending the Thohoyandou Health Centre, in Vhembe District, Limpopo Province, South Africa. A summary of methodology is presented in figure 4.1 below.



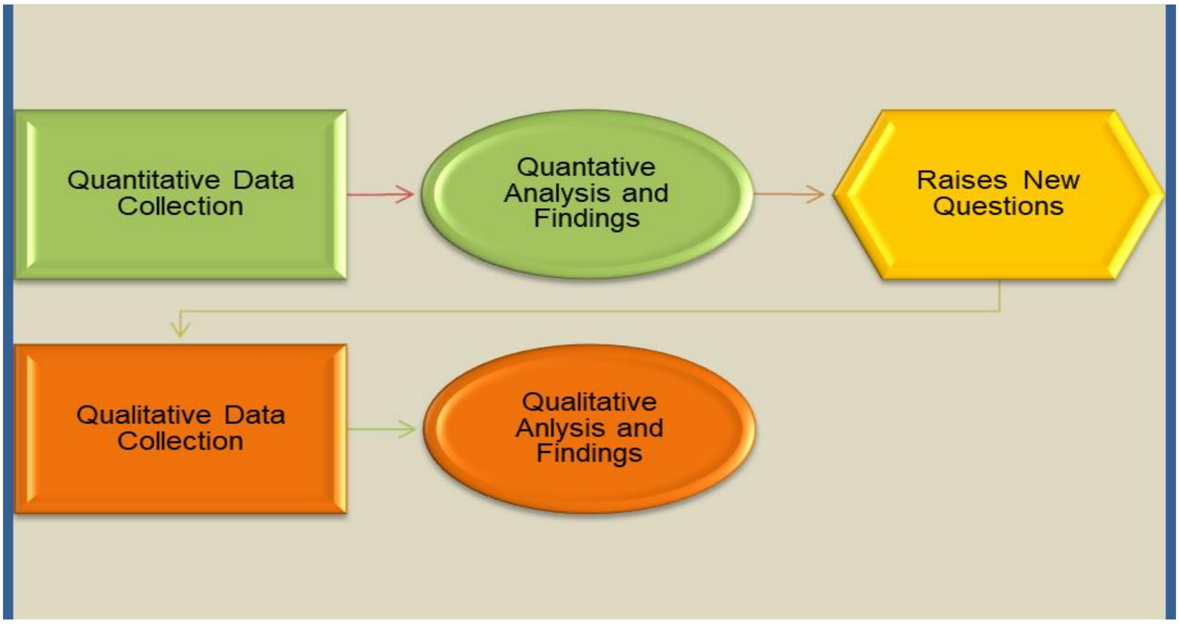


Figure 4.1 – Methodology Framework

4.2 RESEARCH APPROACH

According to Babbie and Mouton (2001) a research approach is the methods which are used in the process of fulfilling a research plan, as well as the underlying principles and assumptions underlying their use. Gray (2009) defines a research approach as the analysis, general philosophy and justification of theories for an exact method to use in research.

In this study the researcher used a mixed method research approach - a combination of qualitative and quantitative approaches. Quantitative approach is defined as a way of investigation into social and human problems, by testing a theory comprised of variables, calculated with numbers and analysed with statistical procedures to determine if the predictive generalisation of the theory is true (Fouche, Delport, & De Vos 2011). The quantitative approach is relevant in getting appropriate information and to identify adherence to ART treatment among HIV-diagnosed patients. The qualitative research approach is a general research approach in social research which focuses on the inside perspective of social action (Babbie and Mouton, 2008). The qualitative approach was helpful in understanding the perceptions of HIV-diagnosed patients towards adherence to HIV medication.

Researchers Hurmenrita-Peltomaki and Numela, (2006) found that an advantage of mixed method research is that it increases validity in the findings of the study. They further added that studies that use mixed method research gain in-depth and broader understanding of the phenomenon than the studies that do not use both quantitative and qualitative research approaches. Every method has its own shorffall; mixed method research offers a way to strengthen the study by counterbalancing one method’s shotfall with the strength of the other method. The study is therefore being divided into two phases namely; phase one Quantitative and phase two Qualitative approaches.

4.3 LOCATION OF THE STUDY

The study was conducted at Thohoyandou Health Centre located in the Vhembe District, Thulamela Municipality of Limpopo Province in South Africa. Limpopo is South Africa's northernmost province which lies within the great curve of the Limpopo River. Its capital city of Polokwane has four languages - northern Sotho 52 %, Tsonga 24.0%, Venda 16.7% and Afrikaans 2. 3 %; it has a population of 5 404 868 (South Africa Info, 2015). Vhembe District contributes 22.1% of the population in Limpopo Province and has three (3) hospitals, eighteen (18) health care centres and one hundred and twenty-six (126) clinics. Thohoyandou Health Centre is located in Block G in Thohoyandou Location, Limpopo. It is a government/public organisation which offers primary health care facilities providing HIV, AIDS and TB-related treatment, care and support services. The centre offers HIV counselling and testing (HCT) and test patients’ CD4 count. The centre is an established, recognised antiretroviral (ARV) treatment initiation and on-going treatment site. Patients who require medical attention are referred to Tshilidzini Hospital. Centres offer the following services: fortified porridge to malnourished children, support for TB, HIV and AIDS patients, run monthly support groups for TB, counselling on prevention of mother-to-child transmission (PMTCT), attend to chronically ill and HIV-positive people, provide home-based care services for sick people, care for vulnerable family members, assessments and referrals for people with mental-health problems, offer counselling, referral for support for survivors of abuse, rape and domestic violence, offer treatment for opportunistic infections and maternity services for pregnant women, which includes short-term admissions for up to 6 hours post-delivery. It opens 24 hours a day, 7 days a week and its services are offered free of charge. During a personal interview with the centre’s Manager it was indicated that 320 newly diagnosed HIV patients were seen in 2016 and that the number is rising.

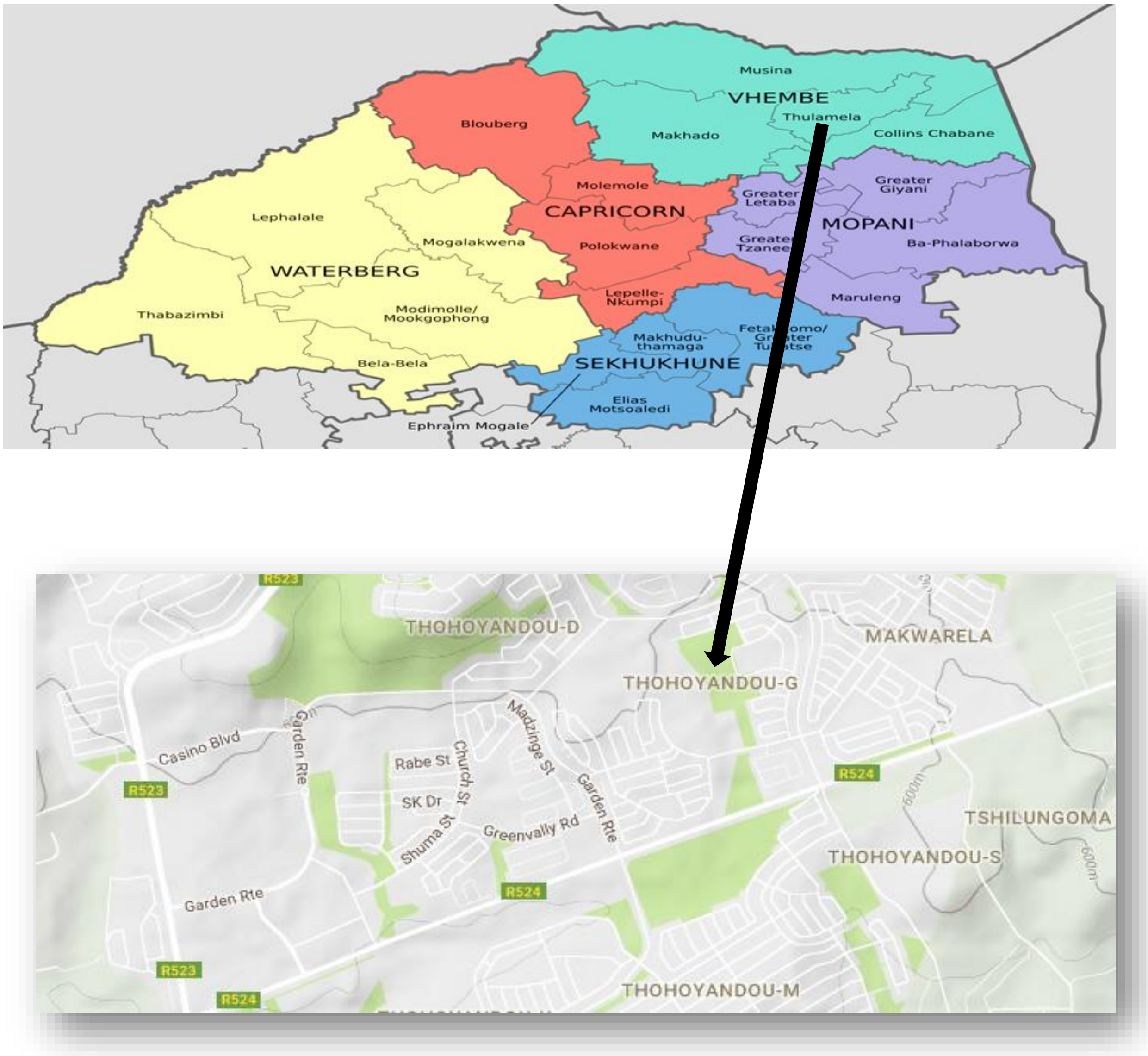


Figure 4.2: *Maps Show Limpopo province and Thohoyandou Health Centre, Block G Thohoyandou Location (Source: Info4africa, 2017*)

4.4 POPULATION

The term ‘population’ is used to refer to every personrepresented in a research. This means that every person who share similar characteristics which were set by the researcher to be required in a population. Babbie (2008) similarly clarifies the point that a population involves the nature of what or whom is being studied and consist of the most distinctive units of analysis and individual people. In this study, the population for the quantitative study comprised of patients who are diagnosed with HIV and are receing ART at Thohoyandou Health Centre, both males and females aged from 18-60 years, and from all ethnic groups.

4.5 PHASE 1: QUANTITATIVE APPROACH

4.5.1 Research design

A research design is the strategy of exploring in order to get answers to research questions, (Kerlinger & Lee, 2000). The design focuses on collecting detailed information about a phenomenon being studied (Brink, 2006). A cross sectional research design was used because it collects data from people sharing the same characteristics and it takes place at one time point. The design provided the researcher with an opportunity to look at various characteristics at once and also assisted to provide useful information about the behaviour of HIV-diagnosed patients (Creswell, 2003; Burns & Grove, 2005). This research design was appropriate to attain appropriate information and to describe and identify information about ART adherence and behaviour among HIV-diagnosed patients.

4.6.2 Sampling

Sampling method and procedure

Sampling means the systematic selection of a group of participants (Leavy, 2006). A sample consists of elements of the people well-thought-out for inclusion in the study, or it can be regarded as a subsection of measurements drawn from a population in which the researcher is interested in (De Vos *et al*., 2005). Respondents for the quantitative phase were selected using simple random sampling, which is a probability sampling technique that ensures that everyone has an equal chance of being choosen to be part of the study. Probability sampling methods were developed to make sure that there was a certain degree of accuracy in the estimation of the populations' parameters, hence reducing sampling mistakes (Burns & Grove 2005). For the current study, simple random sampling techniques was utilised to select respondents. Every patient who attends Thohoyandou Health centre was eligible to be selected and the researcher used the register to select the individuals who met the criteria, after which respondents were selected randomly from that list to form a sample for this study.

Sampling size

Lawrence (2011) outlines that the sampling size is the group of participants who the researcher selects from the larger population to make generalizations about the entire population. For the purpose of this study, a total of 105 patients (both male and female) were selected from Thohoyandou Health Centre to constitute the sample size. The sample size was calculated using Slovin's formula where n is the participants sample size; n is the total number of the population at Thohoyandou Health Centre and e is the accepted level of error (Almeda, Capistrano, & Sarte, 2010). In this study e is 0, 08

$n=N/ (1+ (Ne^{2}))$

$n=320(1+ (320x0, 08^{2}))$

$n=320(1+ (320x0, 0064))$

$n=320(1+2, 048)$

$n=320/3, 048$

$n=104, 9868766404$ OR $n= 105$

Inclusion criteria

Respondents who formed part of the study were HIV-positive patients on ART between the ages of 18-60 years, females and males. Patients who were diagnosed and enrolled in the ART treatment within a period of 1 year at Thohoyandou Health Centre. Patients in this category who gave their informed consent were included in the study.

Exclusion criteria

HIV patients who refused to start ART, patients below the age of 18 and above 60, patients who are very ill and patients who were unable /unwilling to give informed consent were excluded from the study. Patients who were mentally unstable (that is, patients who have been declared by medical doctors to be mental ill).

4.5.3 Research instrument

Welman, Kruger and Mitchell (2005), define a research instrument “as an instrument that the researcher uses to collect data”. In order to get a subjective and objective picture about ART adherence, the researcher triangulated data collection methods through the use of, patients’ file and a questionnaire.

Patients’ records review

Patients’ records refer to systematic files that are used to store information regarding patients’ medical history including their care over time, information about the pateints’ CD4 counts, viral loads and medication type that had been prescribed and were/are continuously being used by the patients (Judson & Harrison, 2010). In this study patients records/file were also used to collect information regarding each patient’s CD4 count for objective assessment of adherence to ART. Baseline data of CD4 count was recorded upon recruitment and after six (6) months each patient's CD4 count was recorded again.

Questionaire

A questionnaire was used to collect data. A questionnaire is a printed self-report form designed to elicit information that can be obtained through written responses (Creswell, 2003). Since this is a nested study from a bigger research project, the questionnaire for this study composed of two sections with closed-ended questions for information on, namely, demographic information using six (7) questions and adherence using thirteen (14) questions. Sections 1 address the demographic information (gender, age, marital status, highest education level, occupation, religion and ethnicity), section 2 deals with ART adherence (assesses if patients are taking their medication; if they are adhering to their medical appointment with their healthcare practitioners, and if defaulting their ART adherence, the reasons for missing their medical appointment). The ART adherence questionnaire was adapted from a study conducted on HIV baseline patients at the University of Virginia (http://globalhealth.virginia.edu/). Respondents answer 'yes' or 'no' to questions relating to ART adherence. The instrument was developed by experts in the HIV/AIDS project under the institute for Global health and Infectious Diseases in Virgina, USA. The advantage of a questionnaire is that it is relatively cheap (less costly), there is no interviewer bias, ensures respondent anonymity, data yielded is easy to analyse and it is easy to administer (Burns & Grove 2005). The instrument was translated from English to Tshivenda so that respondents could understand better since the dominant population in Vhembe district are Tshivenda-speaking people. A team of experts in Psychology was tasked to scrutinise the instrument in order to assess its relevance and suitability to the current population and some adjustments were made to ensure that the questions were suitable.

4.5.4 Validity and reliability of the study

Reliability translate to the fact that numerical results that a study reproduces do not vary because of characteristics of the measurement's process (Golafshani, 2003). Joppe (2000) maintains that validity determines whether the research truly measures that which it is intended to measure or how truthful the research results of the study are.

The researcher checked for internal consistency, that is the degree to which every test item measures the same construct with regard to adherence items; Cronbach's alpha of .96 was used for this study. The base line study in Virginia found the test-retest reliability which was calculated as an intra-class coefficient (ICC) an ICC>0.7 and considered Cronbach's alpha >0.80 as an acceptable Construct Validity (CV) CV ≥0.70 which was similar to the current population.

4.5.5 Entry negotiation

Permission and ethical clearance from the University of Venda's Higher Degrees Committee to access participants were sought before conducting the study (reference number SMNS/15/MBY/23/0710 and Ref: 4/2/2 from the Department of Health). The researcher was helped by the nurses from Thohoyandou Health Centre to talk to patients about the study. The researcher approached patients when they came to collect their medications, patients were given all information about the study and were also provided sheets with written information about the research, aims and objectives, the researcher and the supervisor. Participation in the study was voluntarily and all patients who were willing to participate were given consent forms to sign.

4.5.6 Pre-testing

According to De Vos *et al.,* (2005), a pre-testing “is a mini-version of a full-scale study or a test done in preparation of the actual study”. The process is required to discover possible mistakes in measurement procedures (including instructions, time limits and wording of questions) and in the operationalization of independent variables; it was also needed to find unclear or ambiguous items in a questionnaire. Ten respondents were carefully chosen from the Thohoyandou Health Centre with the same characteristics as those of the main study in order to test the relevance of the questions. Those who formed part of the pilot testing did not form part of the main study. During the pre-testing, ten respondents were given questionnaires. Modifications were done to include all dialects since Thohoyandou Health Centre serves multitudes of people from different municipalities who aso speak different dialects of the same TshiVenda language.

4.5.7 Data collection

Welman *et al.,* (2005), explain that data collection “is the collecting and preparation of information from different sources”. Data were collected through structured self-administered questionnaires. The researcher gave the respondents questionnaire to fill and was present during the time that the respondents were completing the questionnaires in order to carify any misunderstandings or to answer any questions. Data were collected at the Thohoyandou Health Centre and it took about 20-30 minutes to fill the questionnaire. Data collection was done in a private room. The researcher assisted those iliterate respondents by asking questions and filling the questionnaire on their behalf.

4.5.8 Data analysis

Data analysis “is the procedure that consists of breaking up data into manageable themes, patterns, trends and relationships” (Babbie &Mouton, 2001). Data were analysed using SPSS version 25. A descriptive statistical analysis was used used to provide a frequency distribution table and percentages of respondents according to the selected characteristics. The descriptive method is used to report the distribution or spread of a sample or population across a wide variety of variables. The aim of this method is to produce a scope of the characteristics of such distributions through frequencies, measures of central tendency and measures of dispersion (De Vos *et al.,* 2011); cross tabulation was used to examine relationships within data and chi-aquare was used to examine the association between demographic factors and non-adherence.

4.6 Phase 2: Qualitative approach

4.6.1 Research design

Gray (2009, 178) describe a research design as “the main plan for the collection, measurement and analysis of data”. Usually the design defines the purpose of the study and the types of questions being addressed, the methods to be used for collecting data, approaches to choosing samples and how the data are going to be studied.

The study used a phenomenological design which is defined as a qualitative research design that is appropriate to study humans’ experiences from their point of view. Phenomenological design focuses on a person’s perception of the meaning of an event or meaning of their lived experience of a phenomenon or concept for several individuals. It tries to understand people’s perceptions and understanding of a particular situation (De Vos *et al.,* 2005). Phenomenological research design helped to provide a better understanding of the adherence to medication and the perceptions of HIV-diagnosed patients.

4.6.2 Population

Gray (2009) maintains that population is the entire number of participants that are going to form part in a research study. Babbie and Mouton (2001), add that a population is the theoretically specific total number of study participants. The study comprised of patients from Thohoyandou Health Centre who are diagnosed with HIV and have been receiving ART for a period of one (1) year, both males and females from all ethnic groups, within the age range of 18-60 years.

4.6.3 Sampling

Babbie and Mouton (2001), define ‘sampling’ as a technique in which participants are carefully chosen for the purpose of research. The researcher used non-probability, purposive sampling to select the participants. De Vos *et al.,* (2005), point out that purposive sampling is the kind of sampling that is based completely on the researcher’s judgment, based on participants’ characteristics or quality that is relevant for the purpose of the study. Twenty (20) participants were selected based on the results from the quantitative study. The patients targeted were those who were adherent, partially adherent and those who do not miss medical appointments with the healthcare practitioners. The reason to have the different categories was to ensure that the partcipants represented patients who are adhering, partiay and those who are strugging to adhrere to the ART.

4.6.4 Research instrument

Welman, Kruger and Mitchell (2005), define research instruments as the tools or implements that the researchers have that make it possible for them to carry out the research. The researcher used an interview guide. The interview guide comprised of five demographic questions, an ice breaker about initiation of ART, 3 questions formulated from objectives with probes aimed at getting information about patients' perceptions of their HIV diagnosis, barriers towards adhering to HIV medication and the coping strategies used by HIV patients. Questions in the interview guide were translated from English to Tshivenda. In cases where participants needed clarification, the researcher clarified the point. The researcher took notes and also used an audio-recorder to record the interview.

4.6.5 Pre-testing

Gray (2009) maintains that pretesting helps the researcher to gain or collect appropriate data from the participants. Its purpose is to test if the research instrument is effective, and it also helps the researcher to identify if there are any changes that needed to be made which may imply changing questions or phrasing them differenty. Pre-testing assists a researcher to gain an understanding about the questions, in order to eliminate those that are irrelevant; it assists the researcher to see if the purpose of the research will be achieved. During pre-testing, three participants were interviewed, and the interviews were audio-recorded and evaluated for consistency. After pre-testing, participants were asked to give feedback with regard to clarity of the questions and time allocated to answer all the questions in the interview guide. The participants did not experience any difficulty in answering questions but pointed out that the different dialects needed to be addressed and the rephrasing of some questions. The researcher made the following changes in the interview guide with the help of the supervisor:

The word “vhudipfi” was used interchangeably with “vhupfiwa” to accommodate dialects.

Please tell me about when you first started taking ARV. Please tell me about when you were first told about taking ARTs. The researcher decided to revise the questions to read: “When did you start taking ARVs?

The researcher added a last question to give patients the opportunity to add any information that are they considered important by asking the following question: “Is there anything else you think may be important for me to know that we haven’t talked about?”

4.6.6 Data collection

Welman, Kruger and Mitchell (2005) define data collection as the collection and preparation of information from various sources. The researcher used semi-structured interviews to gain a detailed picture of participants’ beliefs about, or perceptions or accounts of adherence to antiretroviral treatment (Smith, Hareé & Van Langenhoven 1995: 9-26). The researcher obtained permission from the participants and informed participants about the nature of the research and the purpose of the study. The interviews were conducted at Thohoyandou Health Centre in a private room to maintain privacy. All participants were interviewed in Tshivenda, since almost all people living with HIV and were attending Thohoyandou Health Centre are Tshivenda speaking. The interviews were conducted for an average of 45 minutes and were recorded using an audio recorder and notes were taken during the interview. To make sure that participants understand the questions and to make sure they answer comprehensively, several probes were incorporated during the interview.

4.6.7 Trustworthiness of the study

Trustworthiness of the study is an assessment of the truthfulness in the outcomes of data in qualitative research; it measures the quality of data to avoid the problem of researcher's bias on data (Babbie & Mouton, 2002). Trustworthiness is a process to test validity and reliability of qualitative research. It also refers to a demonstration that the data stated is sound and that the arguments made are based on the result and are strong (Bowen, 2009). To ensure trustworthiness of the study, the researcher applied the following assumptions of the qualitative paradigm, proposed by Lincoln and Guba, in De Vos *et al.,* (2011:419-421).

4.6.7.1 Credibility

The aim of credibility is to demonstrate that the inquiry was conducted in a manner to ensure that the subject has been accurately identified and described. Credibility is the relevance between what the researcher transcribed and the information collected from the participant. The researcher ensured that the data were interpreted correctly to increase credibility by referring back to the audiotaped and the transcribed data (Babbie & Mouton, 2010). Credibility was attained through the following steps:

- Prolonged engagement- The researcher engaged the participants to check that data reflected what they meant.

- Persistent observation- The researcher tried to interpret the data in different ways, in conjunction with the process of constant and tentative analysis. Searching for multiple influences and what is significant and not necessary to the study.

- Member checks- Checking the information of the study- both the data and its interpretation. The aim of this was to detect any unintentional errors and mistakes made by the participants, correcting the obvious errors and adding volunteer information from the participants (Babbie & Mouton, 2010).

4.6.7.2 Transferability

Transferability is the degree to which the findings can be useful to other settings or with other participants. A qualitative researcher can increase transferability by bringing together adequate and detailed explanation of the study and using suitable methods so that they can allow judgements about transferability by the reader. Data collected from participants was used in a way that it was transferable to other areas in the field of HIV and AIDS, hence, another researcher can use the information from this study to conduct the same study in other area.

4.6.8 Data analysis

According to Burns and Grove (2005), data analysis is a process conducted to minimise, organise and give sense to the collected data. The researcher used Atlas. ti software, a computer-aided program which is a powerful workbench for qualitative data analysis that is particularly used when conducting a large study that has large sections of text, visual and audio data (Smit, 2002). The texts were analyzed and interpreted using codes and annotating activities. This means that the data collected can be presented in diaphragms (Smith, Flowers & Larkin, 2009; Pietkiewicz & Smith, 2012). The researcher had followed the following steps when anaylsing the data:

Step 01: The researcher had to search for all the themes that were emerging from the transcriptions, systematically, through the use of Atlas ti program.

Step 02: The researcher then serched to find the connections within all the themes that were identified within each of the transcription and went through all of them carefully, one by one. and each theme was coded using Atlas ti by going through all the participants' transcription.

Step 03: Lastly the researcher had to look for the patterns into which the themes were emerging, with the aim of finding the major themes. The identified themes were grouped into a table dividing them as whole and then into two portions in order to develop subthemes (Breakwell, 2004; Pietkiewicz & Smith, 2012). Data were interpreted using ATLAS.ti 8.3.16. It helped the researcher to uncover and systematically analyse complex phenomena hidden in semi-structured data. The program provides tools that allow the researcher to locate codes and annotate findings in primary data material, to weigh and evaluate their importance, and to visualize the often-complex relations between them. This program helped the researcher to make meaningful analysis using the transcript document.

4.7 Ethical considerations

Institutional ethics

Institutional ethics were considered by first presenting the proposal to the Department of Psychology and the School of Human and Social Sciences Higher Degree's Committee. Then the proposal was submitted to the University's Higher Degrees Committee (UHDC) for approval and lastly to the University's Research Ethics Committee for ethical clearance. Ethical clearance was issued under project No: SMNS/15/MBY/23/0710.

External ethics

The requests for permission to access a public health facility in Vhembe District were approved from the Department of Health at the provincial office in Polokwane - Ref: 4/2/2. The permission to conduct a study at Thohoyandou Health Centre was obtained then the letter of rereference was used to gain entry to the operational manager of the Centre.

The researcher applied the following ethical issues to the participants:

No harm to participants

Babbie and Mouton (2002) caution that social research should never injure the people being studied since subjects can be harmed psychologically in the course of the study. The researcher, hence, made efforts to avoid any kind of harm to the participants and also informed participants beforehand about the emotional impact that the study could have, so that they knew what to expect from the research.

Confidentiality

According to Babbie (2007) confidentiality refers to an agreement between the researcher and participants that the information provided will not be made available to any other person who is not involved in the study but could only be divulged to the supervisor. To maintain confidentiality, the researcher separated the participants names from the data provided.

No deception of participants

Babbie and Mouton (2001) note that participants should not be misled. Information must not be deliberately misinterpreted or withheld by the researcher from participants to secure their participation when they could otherwise possibly refuse. The researcher did not deceive the participants in any manner. The researcher provided comprehensive information to the participants regarding the nature and content of the study.

Informed consent

Babbie and Mouton (2010) advise that written consent forms must be given to participants that explain the nature of the research, the goal of the investigation, the expected duration for participants' involvement, the procedures which will be followed, the possible risks involved and that participation is voluntary, that participants are free to discontinue, at any time. Informed consent was obtained by giving participants written informed consent forms, informing them of the purpose of the study. When the participants voluntarily agreed to participate, they signed the informed consent to confirm that they are willing to take part in the research study.

4. Chapter summary

This chapter has outlined the research methods. The study employed a mixed method approach which is a combination of quantitative and qualitative research methods. The next chapter presents the results of the study.

CHAPTER FIVE: RESULTS

5.1 INTRODUCTION

This chapter outlines the summary of the findings of the study. One hundred and five (105) respondents from Thohoyandou Health Centre participated in phase 1 of the study, twenty (20) participants participated in phase 2 of the study. Data were analysed using the Statistical Package for Social Sciences (SPSS) version 25 and Atlas ti version 7. The results include demographic profile, adherence of HIV-diagnosed patients, and perceptions and behaviour of patients on ART and 100% response rate was obtained. The results of this study are divided into two phases, quantitative data analysis and the qualitative data analysis.

5.2 PHASE 1: QUANTITATIVE PHASE

5.2.1 Demographic information

Table 5.1 Demographic factors with the frequencies (n) and percentages (%)

Demographic Characteristics	Frequency (n = 105)	Percentage (%) (n=105)
Gender		
Male	36	34.3%
Female	69	64.7%
Age (in years)		
18-30	10	9.5%
31-40	24	22.9%
41-50	35	33.3%
51-60	36	34.3%
Marital status		
Single	47	44.8%
Married	35	33.3%
Widowed	17	16.2%

Divorced	06	5.7%
Highest level of education		
No education	11	10.5%
Primary	16	15.2%
Secondary	17	16.2%
Matric	10	9.5%
Tertiary	51	48.6%
Occupation		
Unemployed	73	69.5%
Employed	26	24.8%
Student	05	4.7%
Religions		
Islam	02	1.9%
Hinduism	01	0.9%
Christianity	90	85.7%
Traditional	03	2.8%
Christianity & Tradition	09	8.5%
Ethnicity		
Black	98	93.3%
White	1	1%
Coloured	3	2.9%
Indians	3	2.9%

Summary of the findings in Table 5.1 shows that out of 105 respondents, 64.7% were females. The majority of respondents were aged between 51-60 years at 34.3% and single category accounted for 44.8%; 48.6% of respondents attained tertiary level education. Many of the respondents were unemployed at 69.5% and Christians accounted for 97.1%.

5.2.2 Objective 1: To determine patients' adherence to ART at Thohoyandou Health Centre

Self- report of adherence

Respondents at 87.6% reported that they were adhering to medication whiles 12.4% reported not taking ART.

Baseline CD4 count at ART initiation with Age

Table 5.2 Baseline CD4 count at ART initiation

Age	***Count & Percentage (%)***	**<200c/mm3**	**200-350c/mm3**	**>350c/mm3**	**Unknown**	**Total**
18-30 Years	*Count*	05	01	01	03	**10**
	Percentage (%)	4.7%	0.9%	0.9%	2.8%	**9.5%**
31-40 Years	*Count*	08	03	04	09	**24**
	Percentage (%)	7.6%	2.8%	3.8%	8.5%	**22.9%**
41-50 Years	*Count*	16	02	06	11	**35**
	Percentage (%)	15.2%	1.9%	5.7%	10.4%	**33.3%**
51-60 Years	*Count*	14	06	06	10	**36**
	Percentage (%)	13.3%	5.7%	5.7%	9.5%	**34.3%**
Total	***Count***	**43**	**12**	**17**	**33**	**105**
	Percentage (%)	**40.9%**	**11.4%**	**16.1%**	**31.4%**	**100%**

The finding of the current study reveals that 40.9% of the respondents from Table 5.2 CD4 count is below 200c/mm3, 31.4% of the respondents did not know their CD4 count, 16.1% had CD4 count greater than 350c/mm3. 11.4% of the respondents had their CD4 count ranging between 200-350c/mm3, 15.2% of respondents aged 41-50 years had most of their CD4 count below 200c/mm3 was the highest amongst all age groups.

Latest CD4 count after at least 6 months with Age

Table 5.3 Latest CD4 count after ART initiation

Age	***Count & Percentage (%)***	**<200c/mm3**	**200-350c/mm3**	**>350c/mm3**	**Unknown**	**Totals**
18-30 Years	*Count*	06	02	01	01	**10**
	Percentage (%)	5.7%	1.9%	0.9%	0.9%	**9.5%**
31-40 Years	*Count*	07	02	03	12	**24**
	Percentage (%)	6.6%	1.9%	2.8%	11.4%	**22.9%**
41-50 Years	*Count*	12	05	03	15	**35**
	Percentage (%)	11.4%	4.7%	2.8%	14.2%	**33.3%**
51-60 Years	*Count*	10	06	07	13	**36**
	Percentage (%)	9.5%	5.7%	6.6%	12.3%	**34.3%**
Totals	***Count***	**35**	**15**	**14**	**41**	**105**
	Percentage (%)	**33.3%**	**14.2%**	**13.3%**	**39%**	**100%**

The findings show that 39% of th patients’ CD4 count was unknown, 33.3% of responendets had a CD4 count which was less than 200c/mm3, 11.4% of patients within the age range 41-50 years had less than 200c/mm3 and the highest rate of 14.2% accounting for unknown CD4 count.

CD4 Count at baseline and 6 months after ART initiation

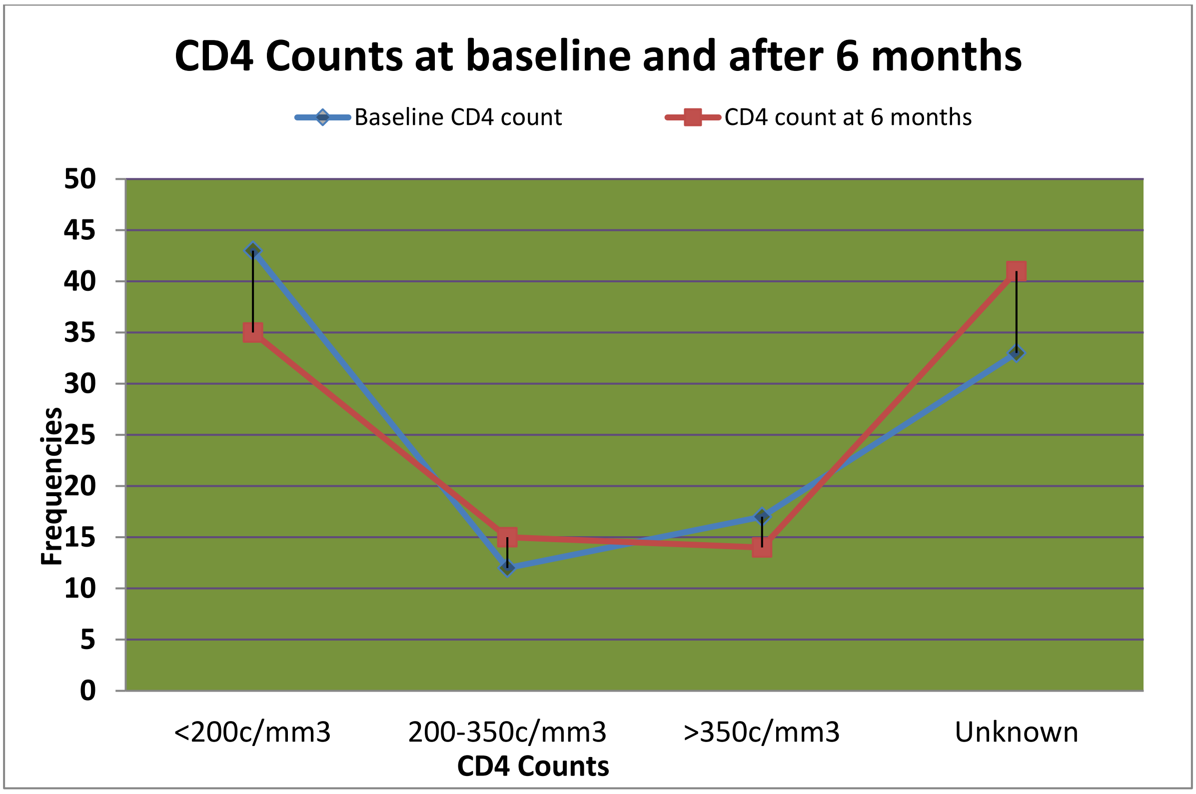


Figure 5.1 CD4 counts at baseline and after 6 months of ART initiation

The findings revealed that at the baseline, 40.9% of the respondents' CD4 count was below 200c/mm3 while after six months 33.3% accounted for less than 200c/mm3 respectively, 11.4% of the respondents had the CD4 count of 200-350c/mm3 at baseline which increased to 14.2% after six months, 31.4% of the respondents' CD4 count was unknown at baseline, and astonishingly after six months 39% accounted for patients who did not know their CD4 count.

5.4 ART ADHERENCE (N=105)

Table 54: ART adherence

	Frequency	Percentage %
Are you currently taking ARV		
Yes	92	87.6%
No	13	12.4%
Have you ever defaulted ART		
Yes	21	19.6%
No	84	78.5%
Have you ever missed appointment		
Yes	15	14.3%
No	90	85.7%

The majority of the respondents, 87.6% reported to be taking ART while 12.4% indicated they were not taking ART, 19.6% revealed that they have defaulted to take ART and 14.3% indicated that they have missed a medical appointment.

Table 5.5 Reasons for missing appointments in the past six months (n=105)

The table below consists of nine statements which were some of the reasons for respondents to miss their appointments with their healthcare providers for HIV medical care in the past six months.

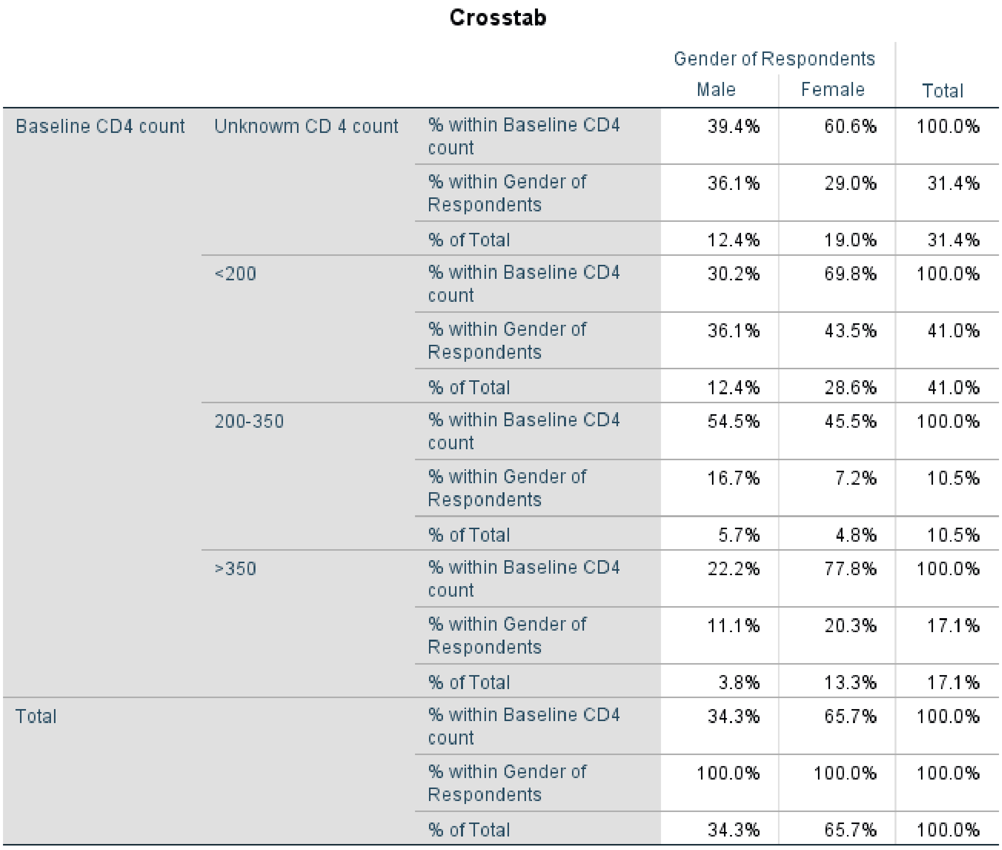
Table 5.5 – Reasons for missing appointments in the past six months

Reasons for missing appointment	Frequency (n*)	Percentage (%)
I forgot about the appointment	5	4.8%
Appointment not at a convenient time for me	4	3.8%
I was feeling better so I did not go	4	3.8%
I had other commitments	4	3.8%
I overslept	3	2.9%
I was too sick to attend	2	1.9%
I was in the hospital at the time	2	1.9%
Less preferred health care provider of	1	1%
I could not get transportation	1	1%

**Numbers are overlapping (respondents could report more than one reason)*

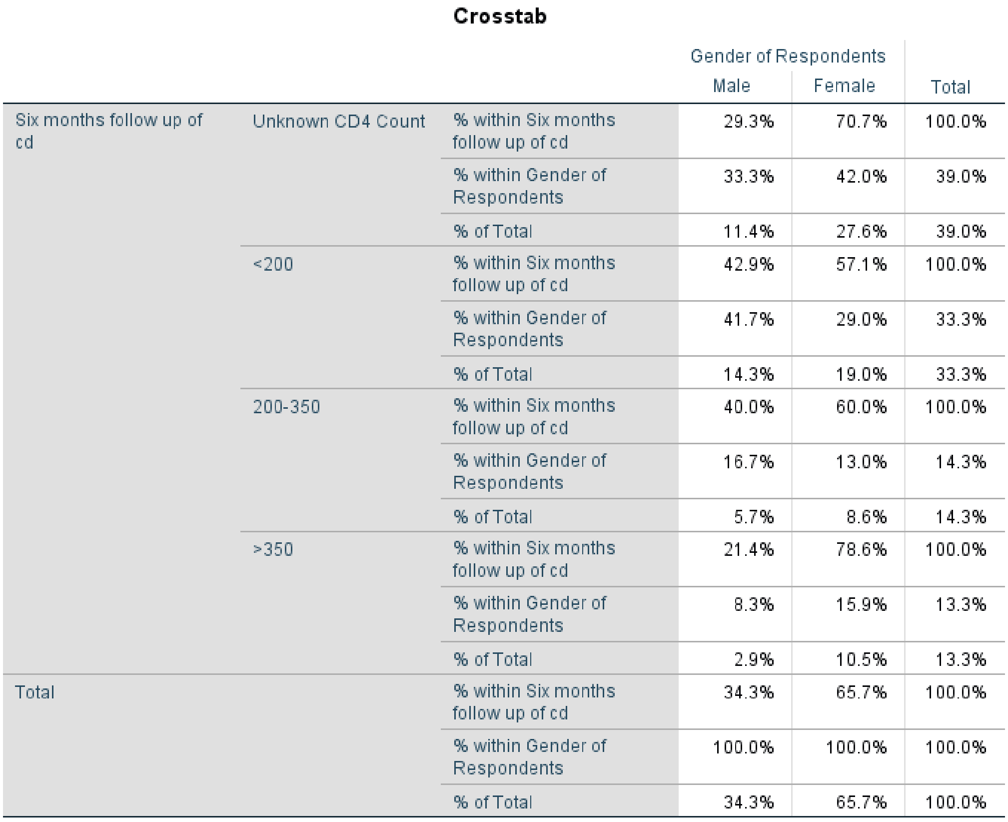
The findings show that 4.8% who missed their medical appointment forgot about the appointment, 3.8% indicated that the appointment was not at a convenient time, 3.8% had other commitments, 3.8% were feeling better and decided not to go for the appointment, 2.9% overslept, 1.9% of patients were too sick to attend, 1.9% were in the hospital at the time, 1% indicated that the appointment was not with the health care provider of their choice and 1% could not get transportation.

Table 5.6 Gender and adherence at baseline and follow-up



Crosstab

			Gender of Respondents		Total
			Male	Female	
Baseline CD4 count	Unknowm CD 4 count	% within Baseline CD4 count	39.4%	60.6%	100.0%
		% within Gender of Respondents	36.1%	29.0%	31.4%
		% of Total	12.4%	19.0%	31.4%
	<200	% within Baseline CD4 count	30.2%	69.8%	100.0%
		% within Gender of Respondents	36.1%	43.5%	41.0%
		% of Total	12.4%	28.6%	41.0%
	200-350	% within Baseline CD4 count	54.5%	45.5%	100.0%
		% within Gender of Respondents	16.7%	7.2%	10.5%
		% of Total	5.7%	4.8%	10.5%
	>350	% within Baseline CD4 count	22.2%	77.8%	100.0%
		% within Gender of Respondents	11.1%	20.3%	17.1%
		% of Total	3.8%	13.3%	17.1%
Total		% within Baseline CD4 count	34.3%	65.7%	100.0%
		% within Gender of Respondents	100.0%	100.0%	100.0%
		% of Total	34.3%	65.7%	100.0%



Crosstab

			Gender of Respondents		Total
			Male	Female	
Six months follow up of cd	Unknown CD4 Count	% within Six months follow up of cd	29.3%	70.7%	100.0%
		% within Gender of Respondents	33.3%	42.0%	39.0%
		% of Total	11.4%	27.6%	39.0%
	<200	% within Six months follow up of cd	42.9%	57.1%	100.0%
		% within Gender of Respondents	41.7%	29.0%	33.3%
		% of Total	14.3%	19.0%	33.3%
	200-350	% within Six months follow up of cd	40.0%	60.0%	100.0%
		% within Gender of Respondents	16.7%	13.0%	14.3%
		% of Total	5.7%	8.6%	14.3%
	>350	% within Six months follow up of cd	21.4%	78.6%	100.0%
		% within Gender of Respondents	8.3%	15.9%	13.3%
		% of Total	2.9%	10.5%	13.3%
Total		% within Six months follow up of cd	34.3%	65.7%	100.0%
		% within Gender of Respondents	100.0%	100.0%	100.0%
		% of Total	34.3%	65.7%	100.0%

Baseline findings show that 36.1% of males had <200c/mm3 CD4 count while after six months 41.7% of male patients had <200c/mm3 CD 4 count, on the contrary, 43.5% of females accounted for <200c/mm3 at baseline and 29% after six months. Additionally, at baseline males who had >350c/mm3 CD4 count were 11.1% at baseline and 8.3% after 6 months; for females 20.3% accounted for CD4 count of >350c/mm3 and 15.9% after six months respectively.

5.3. PHASE 2: QUALITATIVE PHASE

5.3.1 INTRODUCTION

This section outlines the qualitative findings of the study in line with the objectives of the study. Data was interpreted using ATLAS.ti which is a computer program used in the qualitative data analysis. To protect the identity of the participants, codes were used to distinguish participants who were involved in this study. The research findings are presented using themes and sub-themes identified. Verbatim quotes from the interviews are used to substantiate the themes and sub-themes.

Table 5.7: Characteristics of the participants

No	Age	Gender	Education	Occupation	Duration living with HIV
1	21	Female	Secondary	Unemployed	6-12 months
2	25	Female	Primary	Employed	2years
3	31	Male	Secondary	Unemployed	2 years
4	33	Female	Secondary	Unemployed	6-12 months
5	32	Female	Matric	Unemployed	6-12 months
6	36	Male	Tertiary	Unemployed	>4 years
7	31	Female	Secondary	Unemployed	6-12months
8	50	Male	Primary	Employed	>4 years
9	47	Female	No Education	Unemployed	>4 years
10	40	Female	Primary	Unemployed	6-12 months
11	44	Male	Matric	Unemployed	6-12 months
12	49	Female	Matric	Employed	6-12 months
13	55	Female	Secondary	Unemployed	6-12 months
14	57	Female	Tertiary	Unemployed	More than 6 years
15	59	Male	Matric	Unemployed	3-12 months
16	60	Male	Primary	Unemployed	>4 years
17	52	Male	Matric	Unemployed	>4 years
18	52	Female	Matric	Employed	<12 months
19	51	Female	Primary	Unemployed	>4 years
20	50	Male	Matric	Unemployed	>24 months

The total number of participants interviewed were twenty. Out of the participants, seven were male and thirteen were female. The age of the participants ranges between 21-30 (two participants), 31-40 (five participants), 41-50 (five participants), and 51-60 (eight participants).

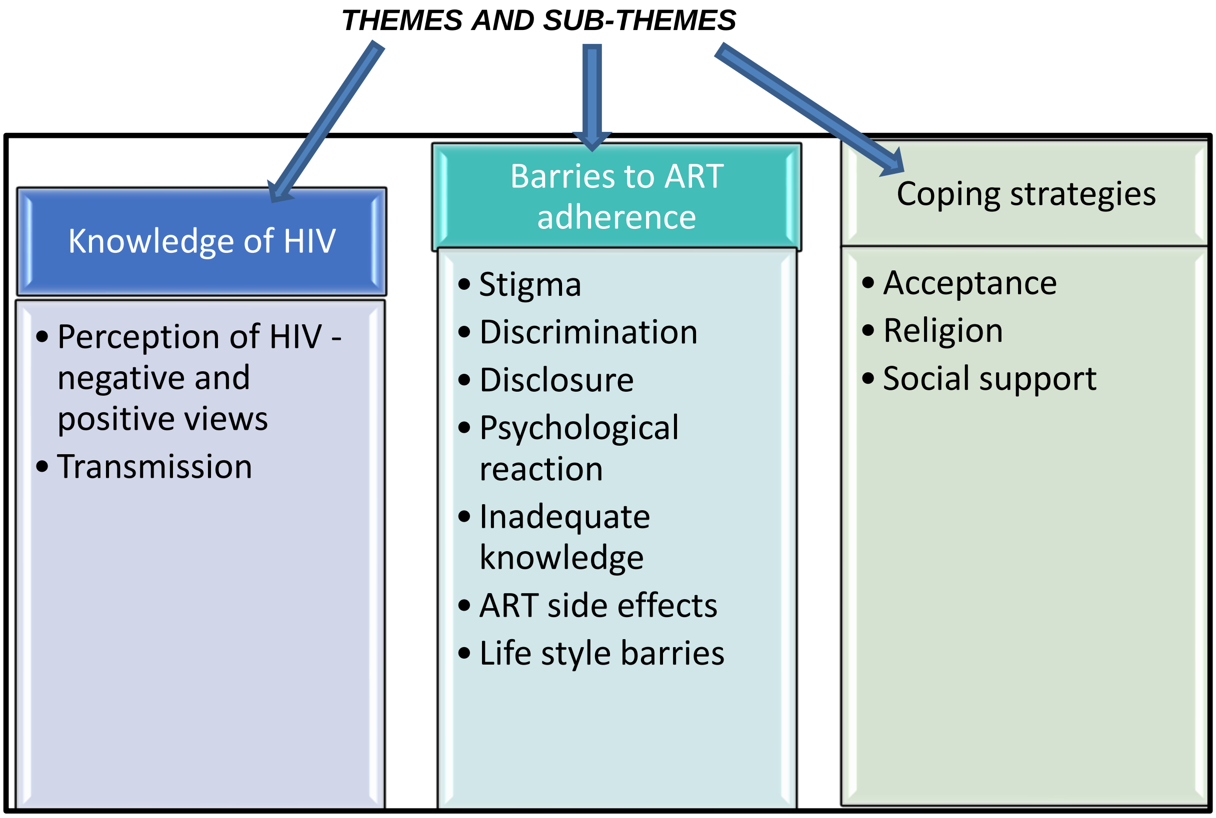


Figure 5.2: Themes and sub-themes

5.3.1 Objective 1: To explore patients' perceptions of HIV diagnosis

Theme 1: Knowledge about HIV diagnosis

➢ **Perception of HIV diagnosis – negative and positive views**

Most participants described HIV as a lifelong disease that cannot be cured. Below are statements to illustrate participants' views:

"I understand that it is a lifetime disease and you should always take treatment all the time, is bad and scary".

Participant 2 (Female, age 25)

"Ahh, people show that this disease of HIV does not kill, what kills is diabetes, if a person obeys the instructions from the nurses a person can live longer".

Participant 6 (Female, age 36)

"It's a dangerous disease because it goes to the blood streams"

Participant 7 (Female, age 31)

"…HIV is a disease which does not heal but when you're pregnant you can be able to protect your unborn child"

Participant 10 (Female, age 40)

"HIV is a virus which affects the body and it cannot be cured, it can only be controlled by taking care of oneself and using protection when having sex and also by taking medication according to the prescription, and by avoiding using substances like alcohol and cigarette".

Participant 20 (Male, age 50)

➢ Transmission of HIV

Most participants seem to understand and have knowledge of how HIV is transmitted. This finding is supported by the following statements:

"HIV is transmitted through unprotected sexually intercourse with someone who is HIV positive, or by sharing a used razor with someone who is HIV positive".

Participant 3 (Male, age 31)

"HIV is can be transmitted by touching someone's blood who is HIV positive while you have a cut in your body or by having unprotected sexual intercourse with someone who is HIV positive, but it cannot be transmitted by washing someone's clothes".

Participant 8 (Male, age 50)

"(laughs), okay, HIV is a virus which is caused by many things like touching someone's blood who is HIV positive when I have a cut, or by having sexual intercourse with someone who is HIV positive".

Participant 9 (Female, age 47)

"HIV is transmitted through sexual intercourse, or maybe you come across someone bleeding and you help without protecting yourself and maybe I am HIV positive or the other person is HIV positive".

Participant 11 (Male, age 44)

5.3.2 Objective 2: To explore perceived barriers towards ART adherence

Theme 2: Challenges associated with ART adherence

People living with HIV experience challenges in adhering to ARV medication such as stigma, disclosure, psychological reaction, lack of knowledge, lifestyle barriers, and side effects of the medication.

- **Stigma and discrimination**

Most participants reported the fear of stigma and discrimination that hinders adherence in the presence of those whom patients don't trust. The following are some of the responses:

"Fear of stigma, I am afraid of being discriminated because I am HIV, most people end up hiding and it makes us live not freely, they don't treat me the same way as everybody else".

Participant 12 (Female, age 49)

"People living with HIV are afraid of being discriminated if people could find that they are HIV, I am afraid to take my pills if there is a person I don't trust, I would rather skip or take it late because I don't want to be judged".

Participant 9 (Male, age 47)

- **Disclosure**

Some participants seem to have disclosed their status to someone they trust, hoping that those whom they trust will not tell other people but the majority reported to have kept their HIV status a secret.

"I have told only one person I stay with, I cannot tell my children because I'm afraid they might not accept it and I struggle to take ART when they are in the room".

Participant 4 (Female, age 33)

"Yes, my mother and my little brother just in case I get sick they will be able to take care of me but taking meds in the presence of other people will not work".

Participant 13 (Female, age 55)

"My friend knows my status but telling everybody is not as simple although I might be missing support".

Participant 14 (Female, age 57)

- **Psychological reactions**

Most participants reported that they experience psychological stress and depression related to HIV status, ART and additional life stressors.

"I sometimes feel depressed because I do not understand how I got infected, treatment for HIV is a huge responsibility and for life which is burndensome".

Participant 5 (Female, age 32)

“*I feel very depressed and betrayed because I know my partner was not faithful”*

Participant 14 (Female, age 57)

- **Inadequate knowledge**

Few participants mentioned that they lack full understanding of the diagnosis of HIV which is a challenge.

“Lack of information, I even tried traditional medication and I got very sick”.

Participant 16 (Male, age 60)

“Lack of knowledge about the importance of treatment. I once stopped taking my medication and I have seen the consequences”.

Participant 13 (Male, age 55)

“I used not to give myself time to know about this disease. I do not understand because my wife is HIV negative and I was faithful all the time and my wife confessed of cheating with two different people and we also have a 2 year old baby girl and she is also HIV negative, I am still very confused how HIV is”.

Participant 19 (Female, age 51)

- **Side effects of HIV medication**

Most participants stated that side effects was the biggest barrier leading to non-adherence to the HIV medication.

“The treatment was not treating me very well. After taking the medication I used to feel like there is something eating me in my stomach. I had to eat again so that the pills will be in between, but today my medication was changed”.

Participant 1 (Female, age 21)

“The treatment is giving me rush. After taking the treatment I scratch myself”.

Participant 18 (Female, age 52)

“The only challenge that I have been experiencing is, when I urinate I feel pain and I have consulted and given pills but the problem still remains and it started after I agreed to take ART”.

Participant 6 (Male, age 36)

“When I started taking treatment, I started having rush all over my body”.

Participant 10 (Female, age 40)

“hmmm at first I used to be dizzy at night I could not even want anyone to talk or wake me up, it was like I was losing my mind and this feeling lasted for a week then after that I had a rush my whole body and even under my legs and I was told at the clinic that it might be the effects of the medication and I was given a medication to use then the rush was gone”.

Participant 12 (Female, age 49)

- **Forgetfulness**

Few participants mentioned forgetfulness as a barrier for not adhering to ART.

“I do not have children to remind me when it’s time to take my medication. So I forget”.

Participant 2 (Female, age 25)

I adhere to my medication but at times I skip because I forget or at time when I am tired”.

Participant 3 (Male, age 31)

- **Lifestyle barriers**

Some participants mentioned lifestyle as a barrier to adherence to HIV medication

5.7.1. Recovery

"Most people when they feel better they stop taking their medication, I do that as well"

Participant 4 (Female, age 33)

5.7.2. Alcohol use

Alcohol, sometimes when I get drunk in such a way that I am truly drunk, I might sleep and forget to take the treatment".

Participant 17 (Male, age 52)

"Alcohol, I used to drink a lot and forget to take my medication but now I do not drink anymore".

Participant 8 (Male, age 50)

5.3.3 Objective 3: To describe coping strategies used by HIV patients

Theme 3: Coping strategies used by people living with HIV

Coping strategies were identified, namely:

- **Acceptance**

Most participants indicated that they have accepted their HIV status. This was illustrated by the following statements:

"I have accepted my status and I am coping better than when I was still too worried about my diagnosis".

Participant 4 (Female, age 33)

"*Accepting has helped me to cope with my staus…"*

Participant 16 (Male, age 60)

"Accepting that I am sick and telling my grandson has helped me because he reminds me every day".

Participant 7 (Female, age 31)

- **Religion**

Some participants indicated that being religious has offered an opportunity of support. The statements below illustrate this thus:

"I got support from church, the pastor prays for me but I will never stop taking the medication because I believe only medication can help me".

Participant 16 (Male, age 60)

"I spent most of my time with my family and also at church, so when I feel down I pray".

Participant P (Female, age 40)

"(*sigh) I don't have any professional support, I am always happy but when I feel down I go to church and church helps me cope".*

Participant 4 (Female, age 33)

- **Social support**

Most of the participants mentioned that family offers support and very few participants get support from the drop in Centre located near home.

"I only got support from my family and they are helping me to accept my status".

Participant 2 (Female, age 25)

"I get all the support from my brother and without him I was not going to cope"

Participant 20 (Male, age 50)

"I have family support and that is what is enabling me to cope with this deadly desease".

Participant 8 (Male, age 50)

"I attend a support group at a Zwoitwa Drop in Centre to cope with my status"

Participant 18 (Female, age 52)

5.3 Chapter Summary

In this chapter the researcher presented the findings of phase one and two of the study. Quantitative fresults were presented starting with demographic information, followed by tables and figures that answers to the objectives as analysed by SPSS. Phase two presented verbatim quotations as analysed by ATLAS ti based on three main themes and sub-themes.

CHAPTER SIX: DISCUSSION OF FINDINGS

6.1 INTRODUCTION

This chapter focuses on the discussion of the findings of the quantitative and qualitative results. The aim of the study was to investigate the perceptions and behaviour of patients on Anti-Retroviral therapy towards adhering to HIV medication. Little is known about achievable levels of antiretroviral treatment (ART) adherence in rural areas. The discussion will be presented according to objectives, previous studies will be used and intergration of the theoretical framework.

6.2 OVERVIEW OF THE FINDINGS

In developing countries adherence is a major challenge and in order to attain the golden standard, 95% adherence rate is required for optimum ART treatment to effectively minimise virology failure and resistance to ART (Lima, Harrigan, Murray, Moore , Wood , Hogg, 2008). In order for patients to enjoy maximum benefits of ART, commitment to take to treatment correctly as prescribed is essential.

6.3 PHASE 1: QUANTITATIVE PHASE

6.3.1 Demographic information

Gender

The findings of this study revealed that the majority 67.7% of respondents were female. These findings were similar to a study conducted amongst staff and HIV patients at public healthcare institutions in the Frances Baard District by Herbert (2013), which revealed a higher percentage of females in his study at 66%. Female seem to initiate ART more than males. Out of 112 respondents in the study of Chigova (2016), majority of female (56.3%; n=63), this shows that more females attend follow-up visits for refills. Dlomo (2010) study of people living with HIV and AIDS on ART in

Durban, a higher number of females than males formed part of the study, females are more likely to attend voluntary counselling and testing services and seek healthcare than males.

Age

In this study, the age of respondents ranged from 18-60. The most infected group in the study were respondents between 51-60 with 34% followed by 33.3% in 41-50 age group. This may be because older people are more willing to check their HIV status than younger people. STATS SA (2017) indicated that approximately one-fifth of South African women in their reproductive ages (15-49 years) are HIV positive. HIV prevalence among the youth aged 15– 24 has declined over time from 7, 3% in 2002 to 4, 6% in 2017.

Marital status

With regard to marital status, the study findings revealed that 44.8% of patients were single followed by married people at 33.3%. Contrary to the current study, (Negash, 2011), found that out of 355 patients, 43.9% of Ethiopian patients were married. The possibility that single people may have multiple partners might highten the rates of infection and single people lack stable relationships resulting to high risk of infection. This study further indicated that even married participants constitute a high percentage which might be because of infidelity. Zeleke (2012), reported that the Ethiopian Demographic and Health Survey documented that widowed and divorced respondents are much more likely to be HIV positive than those who are married and single (Central Statistics Agency, 2012: 236). However, on the contrary, Zeleke's study revealed that the majority of respondents were married (43.3%) followed by single (23.4%). The literature show that various studies find varying outcomes.

Highest education level

The current study revealed that 48.6% of patients has tertiary level education followed by 16.2% with secondary level education. On the contrary, Musasa (2011) found that the majority of respondents had a secondary school education (61%), and only a few held tertiary level education at (2%). However, Negash (2011) found opposing results whereby the majority of participants only had attended primary school. Eyassu (2015) found that high levels of education increased patients’ adherence to ART because patients with high a level of education can easily understand and follow instructions. It is also evidence that literature shows varying findings across.

Occupation

In the current study, the majority of 69.5% respondents were unemployed, while 24.8% were employed. Similarly, Nsimba, Irunde & Comoro (2010) found that out of 138 females, 37% of respondents were unemployed, 35% were business women and 28% were civil servants. The current study is also consistent with Bauleth, (2013) who found that those infected were unemployed. Financial problems were cited as one of the problems for participants default takingr treatment and not keeping the follow-up visit. Crospondingly, Chigova (2016) found that 49.1% of the respondents were employed and 50.9% were unemployed. These findings indicate that both employment and unemployed people are infected, although unemployed people seem to have high rates. Chigova (2016), reported that respondents cited work commitments as a reason that make them miss ARV doses, whereas other respondents cited not getting time off from as a hinderance to colect ARVs.

6.3.2 Objective 1 - To determine patients' adherence to ART at Thohoyandou Health Centre

a) Self- report of adherence

The current study revealed self-report adherence of 87.6% less than the ideal standard required. On the contrary Mills et al., (2006) found 77% which is way less than the required level. In 27 studies from 13 African countries; Gesesew, Ward, Woldemichael, Mwanri (2017) found that 82% of respondents were adhering to ART; Dlomo (2010) reported that 79% of respondents in his study never missed their medication; Negash (2011) reported similar results, whereby 73.5% of respondents adhered to ART; Logie, et al., 2018 found that about 83% took their ART, therefore the adherence rate is different globally. Various studies agree that self-report adherence seem to be over-exargerated.

The medical evidence of adherence though baseline and followup in the current study revealed a different picture regarding patients' adherence to ART. Baseline information showed that 40.9% had <200c/mm3 CD4 count, out of the 40.9%, 15.2% were patients aged 41-50 years; 11.4% accounted for patients with 200-350c/mm3 CD4 count while 16.1% had >350c/mm3 CD4 count. Ominously was the 31.4% of patients whose CD4 count was unknown for reasons ranging from defaulting and missing medical appointments. Additionally, follow-up after 6 months revealed an increase on the percentage of pateints whose CD4 count was unknown accounting for 39%; this is an increase from baseline which negatively implies that many patients might have defaulted within the period of 6 months.

On a positive light, baseline revealed 40.9% of patients falling <200c/mm3, follow-up shows that only 33.3% of patients accounted for <200c/mm3; this is an indication that those who take ART improve CD4 count and positively influence and stabilise own health; 14.2% accounted for those whose CD4 count was 200-350c/mm3 as compared to 11.4% at baseline, this implies that there are improvements for patients who adhere to ART.

b) Gender and adherence at baseline and follow-up

Baseline findings show that 36.1% of males had <200c/mm3 CD4 count while after six months 41.7% of male patients had <200c/mm3 CD 4 count, on the contrary, 43.5% of females accounted for <200c/mm3 at baseline and 29% after six months. Additionally, at baseline males who had >350c/mm3 CD4 count were 11.1% at baseline and 8.3% after 6 months; for females 20.3% accounted for CD4 count of >350c/mm3 and 15.9% after six months respectively. This implies that adherence to males is less compared to females. On the other hand, both males and females' CD4 count of >350c/mm3 did not improve.

The HBM theory, postulates that patients are more likely to adhere to ART treatment if they view themselves vulnerable to HIV and also after considering the gravity of the diagnosis and side effects if not taking ART (Jones & Bartlett, 2010). Similar findings where the CD4 counts of respondents continued to decrease have been discussed (Braunstein *et al.,* 2011; Ohene & Forson, 2009; Tran *et al.,* 2013). This implies that patients struggle to take ART as prescribed. Similarly, Mountain *et al.,* (2014) found that some patients had <200c/mm3 of CD4 count at initiation of ART (Braunstein *et al.,* 2011; Gesesew, Ward, Woldemichael, Mwanri, 2017; Yu *et al.,* 2018). Consistent with studies conducted in China and Kwazulu-Natal, it was found that 84.5% of the respondents had CD4 counts which was less than 350c/mm3 & 10% of the respondents had CD4 counts which was 350–499c/mm3 respectively (Yu *et al.,* 2018;

Tang *et al.,* 2017). In the current study, many patients still remain with CD4 count of <200c/mm3 although self-report reached the golden standard, consequently, most patients remain vulnerable to additional infections; higher rates of admissions in the hospital which will continue to add a burden to the health care sector for both government and healthcare providers. Adhering to ART is one of the biggest concerns in the public health sector and also for people living with HIV (Eyassu, 2015; Nakiyemba et al., 2005).

The Self-Determination Theory maintains that for one to attain personal wellbeing, inherent growth tendencies must prevail where in self motivation depend upon intrincic, extrincic and introjected motivation. How well a person adhere to ART is determined by self motivation. This theory also alludes to the fact that people have unique psychological needs, therefore, if one's need to relatedness, autonomy and integration is skewed due to HIV diagnosis, then motivation to adhere will be disturbed. The health belief model looks at the behavioural and psychological components of compliance; the rationale for action is based on perceived benefits. In this research, if patients can perceive the benefits (recovery while using ART) they are more likely to adhere to medication.

c) ART treatment and defaulting

The self-report about defaulting was 19.6%, and 14.3% of patients agreed to have missed a medical appointment. Eyassu (2015) found that 23% reported to have defaulted treatment; Hansana, (2013) on the contrary, found a higher rate where 62.2% of patients forgot taking their ART. Gesesew, Ward, Woldemichael & Mwanri, (2017) found 5.8% of patients defaulted ART treatment. Similalrly, 20% of women reported missing pills twice (Claude et al., 2003). Deribe, Hailekiros, Biadgilign, Amberbir & Beyene, (2008) found that 8% had missed two or more clinical medical appointments with healthcare providers.

d) Reasons for missed medical appointment

The current findings show that 4.8% who missed their medical appointment forgot about the appointment, 3.8% indicated that the appointment was not at a convenient time, 3.8% had other commitments, 3.8% were feeling better and decided not to go for the appointment, 2.9% overslept, 1.9% of patients were too sick to attend, 1.9% were in the hospital at the time, 1% indicated that the appointment was not with the health care provider of their choice and 1% could not get transportation. Similalrly, Tweya et al., 2018; Chesney, 2000; Chesney, Morin & Sherr, 2000; Chesney, 2003; and Maskew et al., 2007 all found that some patients missed their appointment due to being too sick, appointment was not scheduled with the healthcare provider of their choice, some struggled with transportation while others were feeling better. Katz, 2013; Lourdes et al., 2005 reported that patients also missed appointments because they were feeling better and some decided to stop taking ART for some time. The HBM postulates that perceived severity or threat determines if a patient will adhere to ART strictly, therefore if the patient does not perceive the seriousness of the diagnosis, s/he is more likely to skip taking ART or stop taking ART when feeling better (Pender, Murdaugh & Parsons, 2011).

Yehia *et al* (2015) classified feeling sick as one of the barriers and reason for patients to skip their medical appointments or rescheduling their appointments. The side effects of the medication compromise immune system and commonly cause colds and flu, and sometimes feeing emotionally low. The results are consistent with findings by Kgatlwane, Ogenyi, Ekezie, Madaki, Moyo, & Moroka (2006) who reported that most of the reasons for patients to miss their medication were forgetfulness, logistics/cost and work/home duties. Michael and Matlakala (2012) maintain that in Kwazulu-Natal treatment for HIV is free but transport money is a huge problem for people on ART, leading patients to miss medical appointment with healthcare practitioner and ultimately leading to challenges to adhere. Also, Yehia *et al* (2015) indicated that transportation to the healthcare facilities is a big challenge. Some patients are unable to afford the public transportation. Similarly, Zeleke (2012) found that forgetting/unable to attend an appointment for refill were some of the reasons leading to poor adherence. The health belief model maintains that in the behavioural component, action is perceived sometime with barriers. In relation to this study, reasons given above serve as barriers preventing adherence to ART. Furthermore, the health belief model states that on an individual level, the belief that an individual holds about perceived severity, threat, benefits, barriers result in outcome behaviour. In this study if patients do not perceive non-adherence as a threat, if the patient’s beliefs about missing appointment is not perceived as detrimental, consequently the patient will display non-adherence behaviour, then it becomes easy for the patient to skip medical appointments. In contrast, when a patient perceives a threat (skipping an appointment = non-adherence = sickness) that might lead to death, and then the patient is more likely to overcome the barriers to ensure that medication is refilled. Forgeting appointment dates, losing appointment slips, not entering information in a calendar or a phone, or not writing a reminder note was identified as challenges leading to missed appointments (Yehia *et al*, 2015).

Therefore hypothesis 1 – H_1 - there is high level of adherence to medication among HIV-diagnosed patients was rejected.

6.4 PHASE 2: QUALITATIVE

6.4.1 Objective 1: To explore patients’ perceptions of HIV diagnosis

Patients’ perceptions of HIV diagnosis – negative and positive view

The results from the qualitative data explored the knowledge about HIV diagnosis, focusing on the perceptions and transmission of HIV diagnosis. Respondents perceptions about HIV varied, some expressed a negaitive view about HIV and others expressed a positive view about HIV. Most participants knew how HIV is transmitted. In a study by Mulelu (2016), participants were asked questions to check whether they have knowledge about the treatment of HIV. In the currenty study it was found that most of the participants have knowledge about the ART they are taking, even though all of them could not be able to call ART using correct names.

In the current study it was found that some participants had adequate knowledge about HIV, the benefits of ART, the appropriate time of taking ART and the importance of adherence. Christopoulos, Massey, Lopez, Hare, Johnson, Pilcher, Fielding, Dawson-Rose (2013) add that patients’ perceptions of HIV differs with the risk; those who have no information regarding their infection, those who expected the diagnosis, and those who feel betrayed by their partners, each handle the disease differently. Several patients refer to a state of shock that left them unable to process the diagnosis; others refer to not being able to have any emotional response at all. The way patients perceive their HIV diagnosis has an impact on adherence to HIV medication.

The current study revealed that patients seem to know that HIV is transmitted through unprotected sexual intercourse with a person who is HIV positive. Consistently Mandal (2017) found that participans described the common method of HIV transmission, which included: having unprotected sex with someone who is HIV positive, sharing needles for injections with patients who are likely to be HIV positive from an infected mother to her child before or after birth. Similarly, Haffejee, Ports and Mosavel (2016) found that most participants were knowledgeable about the transmission of HIV from unprotected sexual intercourse, sharing of needles and or razor blades with infected persons.

Objective 2: To explore perceived barriers towards HIV medication adherence.

In South Africa there is a high production/ availability of HIV medication and at least 95% adherence is important for the medicine to work. Attaining this high level of adherence remains a concern. This section discusses the barriers to HIV medication from the qualitative data. According to the Health Belief Model, perceived barriers refers to “an individual’s own evaluation of the obstacles in the way of adopting a new behaviour or continuing with the same behaviour” (Hayden, 2009). The Health Belief Model perceived barriers to ART include, side effects and stigma, individuals may lack support of family members or friends.

Stigma and discrimination

This research has revealed a number of challenges experienced by people living with HIV in adhering to ART treatment. These include fear of stigma and discrimination.

The major challenge that participants experienced on a more social level was captured by the sub-theme of fear of stigma and discrimination. The findings of the current study were supported by Gilbert, & Walker (2010) who indicated that fear of stigma and discrimination plays a significant role in patients’ experiences of the disease in the early stages after testing, disclosure, initiation and commitment of the ART. The fear of stigma and discrimination also impacts on the relationship of patients with their family members. Participants in the current study indicated that telling someone about one's status is very risky because no one knows how that person will react or the treatment that will follow after knowing about the HIV status. Many HIV patients has reported that they hesitate to disclose their status to friend and family because they are afraid of how they will react or respond, consequently patients feel anxious and it affect the ability and courage to attend medical appointments with healthcare practitioner (Yehia *et al,* 2015).

Similarly, in a studydone in Zimbabw, Kwanisai (2014), found that HIV women reported to be pointed by fingers when infected with HIV, treated like outcasts in public gatherings because people avoid giving any opportunity to HIV infected people. Similarly, Syed, Syed, Hassali, Thiruchelvum, & Lee (2014) described fear of stigma as one of the most central reasons for non-disclosure highlighted by almost all the participants. They believe that people's behaviour changes immediately when they learn about one's status and shared experiences when they were side-lined by the public and the authorities.

Where stigma and discrimination exists people are reluctant to get tested or get involved in education and preventative measures. Much of the stigma concerning HIV has been found to be associated with lack of understanding of the disease, myths about how HIV is transmitted, fear, shame and blame (Moratioa, 2007). Kylma, Vehvilainen, and Lahdevirta (2003) is consistent with the current findings because most of patients reported that fear of being discriminated against was one of the reasons or factors that contributed to their poor adherence.

Disclosure

In the current study it was found that almost all participants had disclosed their status, either to their relative, friends, or loved ones, with the purpose of needing support.

Participants mentioned that disclosure is a difficult task to do. Kwanisai (2014) concurs with the current finding because he reported that disclosure is a difficult decision to make for some women living with HIV; participants took time to disclose their status to their family and community because they knew that after disclosure there might be major life changing consequences. Maswikiti (2011) supported these findings by observing that disclosure seemed as a turning point to most of the participants. It was found that disclosing status to family helps in improving the lives of people living with HIV, as this increase support and serves as reminder when it’s time to take the medication.

The current findings indicated that participants have disclosed to at least one person about their HIV status. People living with HIV indicate that they do not disclose their HIV status to friends and family because of fear of rejection or discrimination (International Centre for Reproductive Health Coast Province General Hospital, 2004). A study by Moratioa (2007) indicated that patients keep their HIV status a secret in fear of being rejected. Similarly, Kambale (2013) indicated that caregivers of adolescents on ART find it difficult to disclose their status. Bossier (2016) is consistent with current finding as he found that disclosure is a challenge for people living with HIV and interferes with ART adherence.

In the study of Cloete, Strebel, Simbayi, Van Wyk, Henda, & Nqeketo, (2010) disclosure was linked with stigma. Patients were afraid to disclose their HIV status with the fear of rejection from partners and families or losing their jobs. One of the participants said that “For me it was fear of rejection that somebody should find out that I’m positive, so for a long time I kept it to myself.” Azia, Mukumbang, & Van Wyk (2016) indicated that disclosure of one’s status is a very difficult process to live with, those who missed appointments were afraid that their status might be known somehow if they are seen in the queues in the ART clinics. Some of the patients described difficulties prior to disclosure of their HIV status to family member, more specially their children. The SD Theory postulates that a person's personality integration is dependent upon the fulfilment of the need for relatedness in order to achieve oprimal personali wellbeing. Therefore, stigma and discrimination impact on the motivation that patients must have to continue to adhere despite being rejcted.

Lack of knowledge

This current study revealed that lack of knowledge plays a big role in ART adherence. Some of the patients confessed that they lack knowledge about the importance of treatment. Knowledge is the most fundamental aspect in human life. Lack of knowledge about HIV diagnosis is a problem to both infected and affected. Patients with low literacy levels may not completely understand their disease, its challenges and complications. Patients may not comprehend instructions provided (International Centre for Reproductive Health Coast Province General Hospital, 2004). Similarly, a study conducted by Kambale, (2013) in Palapye clinics, patients showed lack of knowledge regarding ART regimen and forgot to take their medication at the prescribed time. This finding correlates with the findings by Mathebula (2014) who noted that most participants reported lack of knowledge when it comes to their treatment regimen.

In the study conducted by Haffejee, Ports, & Mosavel (2016) in urban and low income community, Durban, it was reported that many of the respondents could not be able to differentiate between HIV and AIDS with 82.1% (n=55). There was a misunderstanding about the transmission of HIV through coughing, oral sex, mosquito bites, sharing of utensils, sneezing and shaking hands with someone who is HIV positive. However, some of the respondents were knowledgeable about the contraction of HIV from sharing needles or razor blades and having unprotected sexual intercourse with someone who is infected with HIV. Bauleth, (2013) identified that lack of knowledge about ART has been the factor leading to treatment defaulting. Some of the participants have reported that when they felt better they stopped taking treatment because they thought they are supposed to take treatment when they feel sick.

Forgetfulness

The current study revealed forgetfulness as a barrier to ART adherence. Forgetfulness was due to aging and tiredness and was manifested through forgetting the time to take the doses. According to Mulelu (2016), forgetfulness can manifest when a patient attends social functions on weekends or is always away from home. Consistently, Eyassu (2015) identified forgetfulness as the most common reason for not adhering to ART. Kibicho & Owczarzak (2011) mentions various reason for forgetting to take the treatment such as interruptions in the daily routine, running out of medications and patients may also forgot to take the medication when dosing time does not fit with daily schedule.

Lifestyle barriers

It has emerged from the current study that the way people live can influence adherence to ART treatment as other people when they feel better they stop taking their medication and also the influence of substance use. Similarly, Azia, Mukumbang, and Van Wyk (2016) found that feeling better was identified as one of the challenges influencing non-adherence. In the current study, participants mention that alcohol and smoking negatively affect their adherence to treatment. Bauleth, (2013), alcohol abuse was identified as a factor that delays adherence. Some of the participants mentioned that they forget to take treatment when they use alcohol. In the study of Mokwele and

Strydom (2017) it was reported that the main problem from patients was alcohol, some patients defaulted treatment because when they drink alcohol they stop taking medication. A study conducted in General Hospital in Mombasa (Baghazal, 2011) revealed that alcohol intake was associated with forgetting to take medication. It was also revealed that female participants and healthcare workers identified alcohol as a barrier to ART adherence whereas male participants did not want to engage in the discussion, this was expected because African culture accept that men should be the one drinking alcohol compared to women.

Guilt

Fabianova (2011) states that “diagnosis of HIV/AIDS infection often brings feelings of guilty from the possibility of infecting the other people or from the previous way of life which led to the infection There is also a feeling of culpability of what disease brings to people, in one´s own family, especially children.

Self-concept/personal view of self

Self-concept/personal view of self also contributed to barriers affecting adherence to ART, as respondents indicated that they feel they are not as good a person as others because they have HIV. Patients indicated that having HIV makes them feel unclean, set apart and isolated from the rest of the world, and having HIV makes them feel that they are a bad people. Similarly, Traube, Holloway & Smith, (2011) found that there is a need to on those elements of believing in oneself that promote perseverance and integration of the medication regimen into activities of daily living. Health care providers can do this by engaging patients in how they manage their daily routine, interactions with other people, and their feelings about their role in their family, place of work and community. The self-protective behaviours promoted by the health belief model self-efficacy concept are supportive of building self-confidence as a means to affect health outcomes (Traube, Holloway & Smith, 2011).

According to Kylmä et al. (2003:770) patients can experience different fears related to HIV. These include the fears of disclosure of HIV status, rejection and HIV progression.

Objective 3: To describe coping strategies used by HIV patients

Acceptance

Findings from this current study revealed that most participants use acceptance as a way of coping. This is confirmed by Kotzé (2011) who found that accepting one's HIV-positive status is an awareness to recognise the influence that HIV can have in one's life. People who are HIV-positive might not, certainly, achieve acceptance of their status immediately after being diagnosed, but then gradually develop a sense of acceptance when time progresses. Acceptance is frequently conceptualised as a secondary control or accommodative way of coping and, as a result, more likely to be used in stressful situations where the stressor is not changeable and must be accommodated. Acceptance can be in the form of passive, resigned or even fatalistic acceptance which is related with negative effect and faster disease progression in people living with HIV. Healthy acceptance must eventually empower the person living with HIV to deal with the challenges of their illness in a realistic and proactive way (Kotzé, 2011). Acceptance could be associated with the self-determination theory of Ryan & Deci. This theory explained the notion of patient autonomy and its role in predicting health behaviours, attitudes towards adherence is likely to improve if the individual feels that he or she is freely choosing to take their medication, and because it is important to him or her. This is achievable by accepting one's HIV status.

Religion

It has emerged from the study that some of the participants in the study rely more on their churches and pastors for support. Participants indicated that when they feel down they pray or go to church. Participants also indicated that even though they receive all the comfort and support from their religion, they will never stop taking medication unless it is doctor’s orders. Singo, Lebese, Maluleke, & Nemathaga (2015), found out that the church plays a big role in supporting people who are living with HIV and AIDS; church members do home visit to infected families with HIV to pray. This was supported by a study conducted by Muganyizi (2008), which indicated that seeking religious comfort appeared to be a strong coping strategy among people living with HIV and AIDS. Participants indicated that praying improved their CD4 cell count whereas participants who did not pray for healing power of Almighty God were having 2.2 times greater risk of having less CD4 cell count.

Social support

Participants in the study spoke about support which they receive from their spouses, loved ones and friends as a way of coping with the HIV. Kumar, Mohanraj, Rao, Murray, and Manhart (2015) reported that in their study, some participants mentioned that disclosing their HIV status to families helped to get all the support needed. Other participants indicated that they used to get help from friends and spouses in overcoming many barriers which were affecting their adherence level. Support from the spouse has been proven to be important to many people living with HIV and AIDS.

6.5 Chapter summary

The chapter presented discussion of the findings guided by objectives, comparing and contrasting previous studies with the current results, theorectical framework was also integrated in the discussion.

CHAPTER SEVEN: RECOMENDATIONS, CONCLUSION, AND LIMITATION OF THE STUDY

7.1 INTRODUCTION

The aim of the study was to investigate adherence through an exploration of perceptions and behaviour of patient's on Antiretroviral Therapy attending the Thohoyandou Health Centre in Vhembe district, South Africa. This chapter presents the summary, strength, the recommendations, conclusions and limitations based on the findings.

7.2 SUMMARY OF THE STUDY

Chapter one provided an introduction and background of the study. A research case was built on 'why' the need for a study that investigates adherence, perceptiona and behaviour of patients on ART. HIV/AIDS is a global burden therefore adherence is central to the management of HIV. Aims, objectives, research question and hypothesis were outlined together with problem statement and the significance of the study.

Chapter two of the dissertation provided details regarding the two theoretical frameworks utilised in this study, namely, Self Determination Theory, and the Health Belief Model.

Chapter three captured the review of the past and present literature that was available and relevant to ART adherence by patients. The researcher explained adherence, barriers to ART treatment, coping strategies in conjunction with various studies done internationally, nationally and regionally.

Chapter four, a description of the two methods (mixed method) that were used in the collection of the data, was given. The study employed both the quantitative and qualitative research methods, divided into two phases. Phase 1 utilised a questionnaire, patients' files and SPSS to analyse the data. In Phase 2, voice-recorded face-to-face interviews and field notes were used to obtain the qualitative data and ATLAS ti was used for analysis. The description of setting, population, sampling, instruments, pre-testing, data collection and anaylysis was done.

Chapter five presented the findings of both quantitative and qualitative results according to objectives.

Chapter six presented a discussion of the finding on the basis of study objectives in conjunction with previous studies, integrating the theoretical framework.

Chapter seven presents the study summary, limitations, recommendations, strengths of the study and concluding remarks.

7.3 Strength of the Study

The first strength of this study is in its approach of mixed methods wherein both quantitative and qualitative approach were utilised. The current study has brought forward valuable contribution regarding knowledge especially the aspect of patients who are on ART. It is also thought-provoking that self-report of adherence seems to misrepresent the actual levels of adherence, therefore, future studies must consider other ways to assess and report on adherence from an evidence based objective way.

The second strength is that this is the first study that looked at adherence, perceptions and behaviour Thohoyandou Health Centre to the researcher's knowledge.

The third strength is that the current study taps information from people who are living with HIV, hence, the source of information is relevant and holds power.

The fourth strength is that the results of this study can be generalised to all patients whose origin is Venda, living in rural area with similar characteristics as the current study.

7.4 Limitations of the Study

The results could have been representative of all the ethnic groups in South Africa if it was collected in different parts of Vhembe District, the dominant language is Tshivenda and Xitsonga, but almost all participants were Venda speaking except for the least English speakers who were hardly represented. The study only explored the association between demographic factors and non-adherence. Therefore, it is important to note that there are other factors that could be involved which this study never explored such as patient's mental health. Some data was not analysed because it forms part of the bigger study. The results may not be generalized to the province since Thohoyandou Health Centre is not the only health centre in the Vhembe District. People who consult at Thohoyandou Health centre are dominantly Tshivenda speaking, and Limpopo Province has various ethnic groups which were not represented in this study, therefore, the results cannot be generalised to other ethnic groups.

7.5 Recommendations

Based on the findings of the study, the researcher makes the following recommendations for practice and further research.

Given the expected 95% rate of adherence, various studies indicated that patients default treatment, therefore, enhancing practical guidelines for implementing adherence management strategies is recommended and these include: continued adherence to counselling, and more campaigns educating the community about HIV. High levels of adherence do not guarantee adherence for a long period of time, thus, it is important that adherence should be monitored regularly and closely. It is recommended continuous research that evaluate ART adherence must be done from time to time.

Thohoyandou Health Centre is in the Centre of Vhembe district and most people travel from far to come and collect medication because patients do not want their HIV status to be known. Even though patients have disclosed their status to someone in the families, they are still afraid of their status being known by the community. It is therefore, important to do community mobilization with the aim of creating an environment where people are free to take medication and disclose their status.

The findings of the study have shown that there are more females than males attending the clinic, and the few men who form part of the study did not understand HIV very well when it comes to transmission of HIV. It is recommended that there should be programs targeting men in issues of HIV/AIDS.

The majority of participants in this study were older people, and some of the reasons of missing medical appointment were forgetfulness. It is recommended that there should be an old age programme which can assist older patients to manage ART better. This could also help in improving the level of adherence. The other reasons for missing a medical appointment was when patients felt that the appointment was allocated at a time that was not convenience to go back to the hospital. Some participant work during the week and it is difficult for them to maintain their appointments so there should be a way that can accommodate everyone who is on ART to get their medication at their convenient time. Health care providers must assess convenience before imposing a date for follow-up.

Adherence to HIV medication is dynamic. Continuous operational research is still needed to determine factors that influence patients to adhere to ART therapy. Future research should focus on investigating sexual life style barriers for people on ART, and the challenges faced by healthcare practitioners when helping HIV patients. The promotion of effective implementation of ART adherence by further improving the knowledge and understanding of people living with HIV, and also to contribute towards the review of the HIV and AIDS treatment protocols and policies, related in-service education for medical personnel and evaluation of health education plans for HIV-positive patients so as to increase the clinical management of HIV and AIDS is critical. Adherence to HIV medication is the first important factor to be addressed when planning the initiation of the ART, followed by education and knowledge about HIV and AIDS.

The study recommends intensification of health education campaign against stigma, discrimination, rejection and other barriers to enhance positive attitude towards HIV patients that wil consequently stimulate adherence and alleviate the burden associated with taking treatment unswervingly. Given the high percentage of infected older respondents, government must also focus its resources to educate illiterate and older people about HIV, adherence and management in order to achieve the golden standardrate of 95% adherence. Strategies to facilitate and normalise adherence among males is indicated. To improve ART adherence, it is necessary to design or implement programs that alleviate the burdens of stigma among ART patients. Challenges that contradict ART adherence such as stigma, disclosure, psychological reaction, inadequate knowledge, side effects of the medication and lifestyle barriers (for example substances) need to be addressed in order to reach maximum adherence and prevent consequences to patients’ health.

7.6 Conclusion

The goal of this study was to investigate adherence and explore the perceptions and behaviour of patients on Antiretroviral Therapy in Limpopo province, Thohoyandou Health Caentre. This study assed adherence in detail, knowledge of HIV diagnosis, barriers regarding ART adherence and coping strategies used by HIV patients. Findings from this current study indicated 67% of respondents were females, 34% of the respondents' age range was 50-60 years, 44.8% were single, 48.6% had tertiary education and 69.5% were unemployed. The self-report of ART adherence of 87.6% among patients was indicated, with 19.6% who reported defaulting ART, 14.3% admitted to missing medical appointments. The reasons for missing medical appointments were: forgetfulness, not a convenient time, patient feeling better, transportation challenges and being too sick to attend. The objective evaluation of patients' CD4 count at baseline revealed that 40.9% of patients had a CD4 count of <200c/mm3, out of 40.9% respondents (15.2%) were those aged between 41-50 years indicating that the age group between 41-50 is at a higher risk to be infected since their immune sytem is week when <200c/mm3, 31.4% of respondents did not know their CD4 count for various reasons (defaulted on treatment, missed appointments) this also indicate that many initiate ART but following through ART treatment seem to be a challenge which consequently translate to sickly patients; burdened health care system and health care providers. CD4 count follow-up data after six months revealed that 33% of patients had a CD4 count <200c/mm3 and 39% accounted for unknown CD4 count. The current study also revealed that males seem to adhere less compared to females because baseline findings show that 36.1% of males had <200c/mm3 CD4 count while after six months 41.7% of male patients had <200c/mm3 CD 4 count, on the contrary, 43.5% of females accounted for <200c/mm3 at baseline and 29% after six months; females seem to be consistent to take ART treatment compared to male. Additionally, at baseline males who had >350c/mm3 CD4 count were 11.1% at baseline and 8.3% after 6 months; for females 20.3% accounted for CD4 count of >350c/mm3 and 15.9% after six months respectively; This means both males and females seem to struggle to improve CD4 count to reach 500c/mm3 which is ideal for better health. Therefore, hypothesis 1 – H_1 - there is high level of adherence to medication among HIV-diagnosed patients was rejected. Association was examined and findings did not reveal any significant association between gender, marital status, education, occupation; however, age was significantly associated with non-adherence to ART with X2 = 3.69, df = 1, p = < .002.

Qualitative phase 2: Three themes emerged from the data, namely: Knowledge of HIV were respondents presented a negaitive and positive perception of ths diagnosis; barriers to ART adherence where sub-themes included discrimination, strigma, rejection, inadequate knowledge about the diagnosis and treatment related side effects, psychological reaction like depression, life style barries; coping strategies where acceptance, religion and social support serve as corner stones for patients. Patients know their diagnosis although they do not have full adequate knowledge regarding ART treatment, stigma, discrimination and rejection seem to hinder pateints to disclose their HIV status in fear of being treated differently and consequently impact on ART adherence. Finding also indicated that patients are depressed by many life stressors including the burden that HIV brings.

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APPENDIX 1: Information sheet- English Version

Adherence: Perceptions and behaviour of HIV patients on Antiretroviral Therapy attending Thohoyandou Health Centre, in Vhembe District.

My name is Takalani Tanganedzani. I am doing a Masters of Arts at the University of Venda. I am conducting a research as part of my degree and I am inviting you to take part in this research project. My research topic is*: Perceptions and behaviour of HIV patients on Antiretroviral Therapy attending Thohoyandou Health Centre, Vhembe District, in Limpopo Province*. The reason for doing this research project is to help us learn more about the perceptions and behaviour of HIV patients on treatment towards adherence to their medication.

Taking part in the study would mean you would be interviewed on personal facts about what you understand, think, feel and experience with taking ART and adhering to it. The interview will be conducted in a private room. The interview will take about a 20-30 minutes, but the researcher will make sure that you take a break if you get tired. You can choose not to answer any questions that you do not want to, and there are no right or wrong answers. You can say ‘okay’ now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you do not want to be in the study or if you join the study and change your mind later. If this happens and you feel like you need to speak to someone after the interview, the researcher can organize counselling for you at the shelter.

If you choose to take part in this research, the interview will be audio recorded and the researcher and the research supervisor from the University of Venda will know who you are, but both of us promise to keep your identity and information private.

The researcher will write up your interview (transcript) but all your identifying information will be removed from it. Then the researcher will handle it together with the research supervisor. The audio recordings and the transcripts will be kept on her computer which has a password so only she can see the information. Quotations using your exact words will be used in the report, however, no identifying information will be included.

After the report is finished the interview recordings and transcripts will be kept in safe place for 2 years, if the research is published in a journal or for 6 years if it is not published, before they are destroyed.

If you do choose to participate, please fill out the two consent forms attached and give them back to me; one is consent from you to participate and the other is consent for the audio recording.

If you join the study please feel free to contact either me or my supervisor if you would like any further information, I will answer any questions you have, and you can ask questions at any time. Just tell the researcher that you have a question.

Kind regards

Takalani Tanganedzani

(Researcher)

Email: tdzinalawe@gmail.com

If you would like to report any problems or complaints that you had with regard to any part of the research process you can also contact my supervisor: Dr A. Maphula on 015 962 8341

APPENDIX 2: Information sheet-Tshivenda Version

Adherence: Perceptions and behaviour of HIV patients on Antiretroviral Therapy attending Thohoyandou Health Centre, in Vhembe District.

Dzina langa ndi pfi Takalani Tanganedzani. Ndikho ita Masters of Arts kha University of Venda. Ndi kho ita thoduluso sa tshipida tsha pfunzo dznga, zwino ndikho vha ramba uvha tshipida kha thoduluso yanga. Nga fhasi ha thoho I nori: "*adherence: Perceptions and behaviour of HIV patients on Antiretroviral Therapy attending Thohoyandou Health Centre, Vhembe District, in Limpopo Province"*. Tshi pikwa tsha thoduluso hei ndiu thusa uri ri pfeseses kuhumbulele na kutshilele kwa vhathu vhano tshila na HIV vhano shumisa mishonga khau dzhia mishonga yavho tshifhinga tshothe.

U vha tshipida kha thoduluso hei zwi amba uri vhado vhudzisiwa ngaha ku pfesesele kwavho, ku humbulele, ku pfele na ku tshilele kwavho kwe vha tangana nako khau shumisa mishonga ya ART nau sa pfuka unwa mishonga yavho. Thoduluso hei ido fareliwa kha lufhera lwo tsireledzea ho. Dzi mbudziso dzido dzhia tshifhinga tshire vhukati ha 20-30, fhedzi muvhudzisi udo ita vhutanzi hauri huvhe na u awela nga vhukati arali vho neta. Vhanga nanga usa fhindula dzinwe mbudziso arali vhakho baleliwa, ahuna phindula yone na isi yone. Vhanga di tenda zwino fhedzi vho tendlwa u shandukisa muhumbulo nga murahu. Zwine vhatea uita ndi u amba uri rime. Ahuna muthu anodo kwata arali vhasi tsha toda uvha tshipida tsha thoduluso hei kana vha tenda vha fhedza vha shandukisa muhumbulo nga murahu. Arali zwanga itea vha vha vhakho toda muthu wau amba navho nga murahu ha u vhudzisiwa, mutodulusi udo vha thusa ngau vha todela muthu wau vha thusa.

Arali vha nanga uvha tshipida tsha hei thoduluso, dzi phindulo dzavho dzido rekhodiwa , mu todulusi na muhulwane wawe vha University of Venda vhado divha zwidodombedzwa zwavho, fhedzi vha fulufhedziwa uri zwidodombedzwa zwavho zwido vha tshiphiri.

Mutodulusi udo nwala phindulo dzavho na fhedzi zwidodombedzwa zwavhune zwavho zwido bvisiwa. Mutodulusi udo thusiwa nga muhulwane wawe. Zwo rekhodiwa hon a dzi phindulo dzavho zwido vhulungiwa kha khomphutha ire na nomboro dza tshiphiri dzino divhiwa nga mutodulusi fhedzi. Zwe vha zwi amba zwido shumisiwa zwoto ralo, fhedzi zwiddombedzwa zwavho zwa vhune azwinga shumisiwi.

Nga murahu ha musi thoduluso iyi yono fhela dzi rkhoding dzavho na phindulo dzavho dzido vhulungiwa lwa minwaha mivhili, kana lwa minwaha ya rathi arali mutodulusi a publish mushumo wawe.

Arali vhanga nanga uvha tshipida vha humbeliwa u usumbedza thendelo yavho ngau dadza mababmbiri mavhili ane vhado ahumisela kha mutoduluso, inwe iya u sumbedza uri vhakho tenda u rekhodiwa na u tenda uvha tshipida.

Arali vha tenda uvha tshipida vhapfe vho vhofholowa ukwama mutodulusi kana muhulwane wawe arali vhana dzinwe mbudziso, ndido fhindula mbudziso dzavho, vhanga vhudzisa tshifhinga tshinwe na tshinwe. Vhato vhudza fhedzi mutodulusi uri vhana mbudziso.

Kind regards

Takalani Tanganedzani

(Researcher)

Email: tdzinalawe@gmail.com

Arali vhatshi tama u pota thaidzo ine ya tumana na mushumo hoyu vhanga founela muhulwane: Dr A. Maphula on 015 962 8341

APPENDIX 3: Consent form-English version

Adherence: Perceptions and behaviour of HIV patients on Antiretroviral Therapy attending Thohoyandou Health Centre, in Vhembe District.

Place: Thohoyandou Health Centre

If you have any questions regarding the study, you can contact Takalani Tanganedzani (researcher), on: 0823917028 kana tdzinalawe@gmail.com

I ____ (full names) hereby confirm that I have been informed by the interviewer, T. Takalani, about the nature, conduct, risks and benefits of the study. I have also read (or have had someone read to me) the above information regarding the study.

I am aware that the results of the study, including personal details regarding my age and diagnosis, will be anonymously processed into the report. I am also aware that interviews will be audio taped. I may at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions (of my own free will) and declare myself prepared to participate in the study.

________________________________	___________________________
Name of participant	**Participant's signature**
	___________________________
Date	
________________________________	_____________________________
Interviewer's name	**Interviewer's signature**
	____________________________
Date	

APPENDIX 4: Consent form- Tshivenda Version

Fhethu: Thohoyandou Health centre

Arali vhana mbudziso inwe na inwe vhanga kwama Takalani Tanganedzani (mune wa thoduluso), kha nomboro dza lutingo: 0823917028 kana tdzinalawe@gmail.com

Thoho: Adherence: Perceptions and behaviour of HIV patients on Antiretroviral Therapy attending Thohoyandou Health Centre, in Vhembe District.

Nne ____ (madzina nga vhudalo) ndi nea khwathisedzo yauri ndo vhudziwa nga T. Takalani, nga tshiimo, dzi khaedu, na mbuelo ya thoduluso heyi. Ndo vhala (kana ndo humbela munwe uri a mmbalele) ma nwaliwa are afho ntha malugana na thoduluso.

Ndia zwidivha uri mvelelo dza thoduluso iyi, zwi tshi katela zwidodombedza zwanga zwa vhune zwa minwaha na tshiimo tshanga, zwidovha tshiphiri musi hutshi neiwa mvelelo. Ndia zwipfesesa uri zwine rado amba zwi dovha zwikho rekhodiwa. Nga tshifhinga tshinwe na tshinwe ndapfa ndi sa tsha funa uvha tshipida tsha thoduluso heyi ndinga humisa thendelo yanga yausa tsha dzhenelela. Ndovha na tshikhala tshau vhudzisa dzimbudziso (ndi tshi itela nne mune) ndia tenda uri ndo lugela uvha tshipida tsha thoduluso heyi.

______________________________ ______________________________

Name of participant **Participant's signature**

____

Datumu

______________________________ ______________________________

Interviewer's name **Interviewer's signature**

____

Datumu

APPENDICES

APPENDIX 5: Questionnaire-English version

I appreciate your willingness to take part in the study. The purpose of the study is to investigate the perceptions and behaviour of HIV patients towards adhering to HIV medication. You are kindly requested to provide honest responses to the questions listed below, All your responses are valued and will be kept confidential. These questions will take you about 20-30 minutes to respond to them. Please do not hesitate to ask any question if you do not understand.

Place: Thohoyandou Health Centre

If you have any questions regarding the study, you can contact Takalani Tanganedzani (researcher), on: 0823917028 kana tdzinalawe@gmail.com

Please indicate the correct answer by putting a cross (X) in the appropriate place.

SECTION 1: DEMOGRAPHIC INFORMATION

1.1. Gender 1. Male 2. Female

1.2. Age: ______________

1.3. Marital status: 1. Single 2. Married 3. Widowed 4. Divorced

1.4. Highest education level: 1. No education 2. Primary 3. Secondary 4. Matric 5. Tertiary

1.5. Occupation: 1. Unemployed 2. Employed 3. Student

1.6. Religion: 1. Islam 2. Hinduism 3. Judaism 4. Christianity

1.7. Ethnicity: 1. Black 2. White 3. Coloured 4. Indian

SECTION 2: ART ADHERENCE

2.1. Are you currently taking any antiretroviral medicines?

1 YES

2 NO

3.2. Have you ever defaulted ART treatment since initiation?

1 YES

2 NO

3.3 Because of the barriers to care and other reasons, people often find it hard to keep all of their medical appointments and sometimes miss them. In the past six months have you missed an appointment with a doctor, nurse, or other health-care provider for HIV medical care?

1 YES

2 NO

3.4. Please indicate whether of the reasons below apply to you as a reason for missing appointments in the past six months:

3.4.1. I forgot about the appointment	1. Yes
	2. No
3.4.2. overslept	1. Yes
	2. No
3.4.3 The appointment was not at a convenient time for me	1. Yes
	2. No
3.4.4 I had other commitments	1. Yes
	2. No
3.4.5 I was too sick to attend	1. Yes
	2. No
3.4.6 The appointment was not with the health care provider of my choice	1. Yes
	2. No
3.4.7 I could not get transportation	1. Yes
	2. No

3.4.8 I was feeling better so did not go	1. Yes 2. No
3.4.9 I was in the hospital at the time	1. Yes 2. No

Baseline CD4 count_______________________________________

Follo-up after 6 months CD4 count ___________________________

Appendix 6: Questionnaire- Tshivenda version

Ndi livhuwa udi dina havho uri vha dzhenele thoduluso hei. Vhundeme ha thoduluso hei ndi u todulusa ku pfesesele na ku tshilele kwa vhathu vhare na HIV kha sia lau nwa mishonga yavho ya HIV. Vhakho humbeliwa uri vha fhindule ngoho kha dzi mbudziso dzire afho fhasi, ndi tama vhatshi pfesesa uri phindulo dzavho dzothe ndidza ndeme na uri dzido vha tshiphiri. Ndi humbela vha kondelele, vhunga zwido dzhia mithethe I linganaho 20-30 u fhindula hedzi mbudziso. Ndi humbela vha songo ofha u vhudzisa musi vhasa pfesesi.

Fhethu: Thohoyandou Health centre

Arali vhana mbudziso malugana na ngudo heyi vhanga kwama Takalani Tanganedzani (mune wa thoduluso), kha nomboro dza lutingo: 0823917028 kana tdzinalawe@gmail.com

Vha humbeliwa vha vhee tshifhambano ho teaho kha phindulo yavho **(X).**

SECTION 1: ZWI DODOMBEDZWA ZWA VHUNE

1.1. Mbeu 1. Munna 2. Mufumakadzi

1.2. Minwaha: ______________

1.3. Tshiimo tsha mbingano: 1. U ethe 2. O vhingwa 3. Tshilikadzi 4. Talana

1.4. Ngudo dza nthesa: 1. A thongo funzea 2. Primary 3. Secondary 4. Matric 5. Tertiary

1.5. Mushumo: 1. Thongo tholiwa 2. Ndi a shuma 3. Mutshudeni

1.6. Vhurereli: 1. Islam 2. Hinduism 3. Judaism 4. Christianity

1.7. Murafho: 1. Black 2. White 3. Coloured 4. Indian

SECTION 2: ART ADHERENCE

2.1. Vhakho unwa mishonga yavho zwa zwino?

1 EE

2 HAI

2.2. Ubva tshe vha thoma unwa mishonga yavho, vhono vhuya vhadi wana vhakho litsha?

1 EE

2 HAI

2.3. Nga mulandu wa zwiitisi na dzinwe tsheo, vhathu vha dzulela u wana uri zwia konda u fara zwifhinga na uya nga maduvha au vhuelela vhuongeloni. Kha minwedzi ya rathi (6) yo fhiraho vhono vhuya vhadi wana vho hangwa mutangano wavho na vho dokotela, vho nurse, kana munwe wa muongi wa HIV?

1 EE

2 HAI

2.4. Ndi humbela uri vha ambe kha izwo zwiitisi uri zwovha zwone zwa u ita uri vha hangwe mutangano wavho kha minwedzi ya rathi yo fhiraho?

2.4.1. Ndo hangwa uri ndina mutangano	1. Ee
	2. Hai
2.4.2 Ndo rongomelwa	1. Ee
	2. Hai
2.4.3. Mutangano wovha usi nga tshifhinga tshavhudi kha nne	1. Ee
	2. Hai
2.4.4 Ndo vha ndina zwinwe zwe ndavha ndikho ita	1. Ee
	2. Hai
2.4.5. Ndo vha ndikho vhaisala ndingasi kone uya	1. Ee
	2. Hai
2.4. wovha u sina muongi ane nda mutakalela	1. Ee
	2. Hai
2.4.7. Thin go kona u wana tshiendedzi	1. Ee

	2. Hai
2.4.8. Ndovha ndi khopfa ndi khwine nda saye	1. Ee
	2. Hai
2.4.9. Ndovha ndi vhuongeloni nga hetsho tshifhinga	1. Ee
	2. Hai

CD4 count ya u thoma____

CD4 count ya vhuvhili nga murahu ha minwedzi ya rathi______________________________

APPENDIX 7: Interview guide-English Version

Age:

Gender:

Highest level of education:

Occupation:

Duration since diagnosis:

1. When did you start taking ARVs?
2. Tell me about your understanding/perceptions of a HIV diagnosis
3. What have been your experiences/ challenges since you started taking the medication?

   -What are the factors or barries to adherence of ART medication?

4. What coping strategies have you been using since you were diagnosed?

- What are the available resources that assist you in coping?

5. Is there anything else you think may be important for me to know that we haven't talked about?

APPENDIX 8: Interview guide-Tshivenda Version

Minwaha:

Mbeu:

Tshikolo:

Mushumo:

Ndi tshifhinga tshingafhani vhe na vhulwadze uvhu:

1. Vho thoma lini u shumisa mishonga ya ARVs?
2. Avha mbudze nga ku pfesesele kwavho kwa vhulwadze ha HIV
3. Ndi dzifhio khaedu dzine vhono tangana nadzo ubva tshe vha thoma u shumisa mishonga?

- Ndi dzifhio khaedu dzino khakhisa unwa mishonga?

  Ndi zwifhio zwino thivhela vhathu ushumisa mishonga ya HIV? 4. Ndi zwifhio zwe vhavha vhakho zwishumisa uvha thusa ubva tshe vha divha nga tshiimo tshavho?

5. Ndi dzifhio tshumedzo vha dzi shumisa u tshila zwavhudi?

6. Huna zwinwe zwa vhuthogwa zwine vhanga tama nditshi zwidivha zwe ra si ambe ngazwo?

University of Venda
Creating Future Leaders

14 March, 2019

This is to certify that I, **Dr P Kaburise,** of the English Department, University of Venda, have proofread the research report entitled - **ADHERENCE: PERCEPTIONS AND BEHAVIOUR OF PATIENTS ON ANTIRETROVIRAL THERAPY ATTENDING THOHOYANDOU HEALTH CENTRE, IN VHEMBE DISTRICT, SOUTH AFRICA -** by Takalani Tanganedzani (student number: 11620259). I have indicated some amendments which the student has undertaken to effect, before the final report is submitted.

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