EXPERIENCES OF HIV POSITIVE PATIENTS ON ANTIRETROVIRAL TREATMENT AT THULAMELA MUNICIPALITY IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE, SOUTH AFRICA

By

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DECLARATION

I, **Tshifhiwa Violet Ndou,** hereby declare that "**Experiences of HIV Positive Patients on Antiretroviral Treatment at Thulamela Municipality in the Vhembe District, of Limpopo Province, South Africa"** is my own work and all the sources quoted and used have been reflected and acknowledged by complete references and this work has not been previously submitted for a degree at this university or any other institution.

SIGNATURE

TVNdou ---------- 15/08/2014 ----------

T.V. NDOU **DATE**

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Abstract

Antiretroviral treatment (ART) has improved the quality of people who are (human immune virus) HIV positive. They have been document to decrease the morbidity and mortality of people its introduction in the late 1990`s. The study addressed the experiences of HIV positive patients in the Vhembe District of Limpopo South Africa.

The aim and purpose of the study is to identify, explore, and describe the experiences of HIV positive patients on antiretroviral treatment (ART).

A qualitative research method was used where experiences of HIV positive patients was explored and described in detail. A non-probability purposive sampling was used and the target population was those HIV positive patients on ART treatment who are eighteen and above. The researcher used an in depth interview as a means for data collection.

The open coding method was used for data analysis. Six themes emanated from the study as presented underneath; each theme consists of sub-themes: Dominant tales of perceived family support for HIV positive relative on ART resulting in feelings of despair and those of being accepted; Stigma and discrimination related to taking ART; Participants' experiences while on ART; Knowledge related to ART process; Disclosure of HIV positive status; and Experiences on healthcare providers' practices in the ART clinic.

The study revealed that the role of family support is of utmost important to HIV positive patients and the government should carry out intensive support, education making awareness campaigns to affected families and patients in order to reduce stigma and discrimination and improve care and support.

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CHAPTER 1

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OVERVIEW OF THE STUDY

1.1 Introduction

Since 1990's the introduction of highly active antiretroviral therapy has modified the clinical course of HIV infection, reducing the rate of disease progression, the incidence of opportunistic infection and mortality (Colombo, Colangeli, Biagio, Viscoli &Viale, 2011: 1) Furthermore, antiretroviral treatment (ART) has dramatically reduced human immune virus (HIV) associated morbidity and mortality and has transformed HIV into a chronic manageable condition. Despite the remarkable improvements in the HIV treatment and prevention, economic and social barriers that result in continued morbidity, mortality, and HIV infection persists. According to Yoder, Mkhize, and Nzimande (2009:6), it is important to understand the experiences of HIV positive patients taking medications in order to understand their experiences on taking ART.

According to Heyer, Mabuza, Couper, and Ogunbanjo (2011: 233), people living with HIV and AIDS (PLWHA) face challenges and they usually experience symptoms like anxiety, shame with shattered sense of hope and life purpose and control of self-worth. Aggleton, Wood Malcom and Coram (2005:4) state that from the start of AIDS epidemic, stigma and discrimination have fuelled the transmission of HIV and have greatly increased the negative impact associated with the epidemic creating major barriers to preventing further infection, alleviating impact and providing treatment, adequate care and support. HIV positive patients who are receiving ART need much support from friends, family, and community for effective prevention and treatment of HIV and opportunistic infections. Mlobeli-Dlakhulu (2007:1) states that their families are mostly involved in their care and support in and out from the hospital. However, after being diagnosed with HIV they go to their families who did not get any form of counseling on information about HIV/AIDS or ART to prepare them on how to care for them. This impacted negatively on the family relationships with the HIV positive client on ART as well as on their care and support.

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A study in China, Yunnan by Li, Wu, Wu, Sun, Cui and Jia (2006:5) showed that the whole family experiences shame both within and outside the family and consequently family relations change causing family members to feel isolated and or restricted when they interact. Some families resort to avoiding being seen with an HIV positive patient when he/she becomes sick for fear of being stigmatized and discriminated. In accessing comprehensive care and treatment especially, ART HIV positive patients often encounter health systems which are ill equipped to meet their needs effectively whereby there is a delay in issuing ART to a person coming from another facility accessing ART in another facility due to administrative or procedural issues. This may result in the HIV positive patient missing doses or dropping out. This study is about exploring and describing the experiences of HIV positive patients on ART, in order to develop recommendations about the care for these patients. The study was conducted in a regional hospital in the Thulamela Municipality of the Vhembe District of South Africa.

1.2 Problem Statement

The researcher is a community health nurse, working at one of the clinics within Vhembe District. Her day-to-day activities with patients made the researcher realize that most HIV patients on ART are not accompanied by their relatives for support when they are very ill and weak when coming for consultation at the clinic. Mostly, patients were weak due to the side effects of ART. The situation hampered patients care because whatever explanation given to the patient couldn't be understood well as they were too ill. This led to serious complications such as poor adherence; hence, the study seeks to document the experiences of HIV positive patients on ART.

According to Foundation for Professional Development (FPD) (2010:118) there are some practical issues to be followed by both the health providers and the patient before starting with treatment. Some of the patients who are HIV positive became unavailable or are unwilling to undergo these practical issues. Once identified an HIV positive patient undergoes adherence counseling especially when about to start ART and information about what to expect and do about the side effects of the treatment is given. The researcher observed that patients usually are anxious and become frightened by the issue of taking a lifelong treatment. When a person is eligible for ART, one has to disclose to a support

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1.4 Purpose of the Study

The purpose of this study was to explore and describe the lived experiences of HIV positive patients on ART treatment in the Thulamela municipality in the Vhembe district of Limpopo province of South Africa.

1.5 Research Question

The following question guided the study:

- What are the experiences of HIV positive patients who are on ART at Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa?

1.6 Research Objectives

The objectives of this study were to;

- Explore and describe the experiences of HIV positive patients who are ART
- Propose recommendations on the establishment of care and support of services of HIV positive patients on ART

1.7 Definitions of Terms

Experience: According to the Oxford Advanced Learner's Dictionary (2005: 513) experience is the knowledge and skill that has been gained through doing something for a period of time. In this study, experience refers to gaining knowledge from seeing, hearing, doing and feeling things. The knowledge gained may mean challenges and difficulties faced by HIV positive patients when they were taking ART treatment as well as pleasant experiences encountered during the process of taking ART treatment.

HIV: Human Immune Deficiency Virus that causes AIDS in human beings (Van Dyk, 2008:492).In this study, HIV refers to Human Immune Deficiency Virus that causes AIDS in human beings.

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HIV positive patient: The person who has been tested blood and found to be having antibodies to HIV are present in their bloodstream – an indication that they have been exposed to, and therefore is infected with HIV (Van Dyk, 2008:493). HIV positive patient in this study refers to a person who is 18 years and above and has undergone HIV counseling and testing and the results came out being positive.

Antiretroviral treatment: Drugs used to decrease the viral load by suppressing the HIV virus thereby delaying the opportunistic infections and development of AIDS (Van Dyk 2008:95). In this study antiretroviral treatment, referred to as ART will be used throughout the study. ART refers to drugs used for the treatment of HIV/AIDS.

1.8 Research approaches

A qualitative approach was used for this study and a brief outline of the research design and methods that were utilised are briefly described below.

1.8.1 Research Design

According to Burns and Grove (1997:225), the design of a study is the end result of a series of decisions made by the researcher concerning how the study was conducted. According to Cormack (1996:111), research design represents the measure of methodological thrust of the study, being a distinctive and specific research approach, which is best, suited to answering the research question or problem. The research design of the study was described in full in Chapter 3.

1.8.2 Setting and population

Babbie (2007:190) defines population as the theoretical specified aggregation of the elements in a study. The setting of the study was at Thulamela Municipality in the Vhembe District, Limpopo Province, South Africa. The researcher planned to conduct a study on experiences of HIV patients who are on antiretroviral treatment.

1.8.3 Sampling

Sampling refers to the process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest

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(Burns & Grove, 1997:36). In this study, non–probability, purposive sampling was used. Non –probability sampling means that not every element of the population has an opportunity for selection in the sample (Burns & Grove 1997:40).

According to (Welman, Kruger, and Mitchell, 2005: 55), it is not necessary to involve the whole population in a research project. The size of the sample was influenced by the kind of data analysis, the accuracy of the results for the research purpose and the characteristics of the population Maree (2007:178). At least ten interviews were conducted the same data was comingupagainand again and thus data saturation occurred.

1.9 Data Collection Methods

Burns and Grove (1997:393) define data collection as "the process of selecting subjects and gathering data from subjects". The data gathering method of choice was in-depth individual interview. Data collection was conducted in a comfortable, non-threatening environment, to explore and obtain experiences about the given problem or topic of interest. The interview allowed the researcher to interact with participants and provides the opportunity for clarification of responses, follow-up questions and the probing of questions Welman et al. (2005:167).

1.10 Data analysis

According to De Vos, Strydom, Fouche, and Delport to (2005:333) data analysis involves reducing the volume of information, sifting significance from trivia, identifying significant patterns and constructing a framework for communicating what the data reveal. Furthermore De Vos et al (2005:333) state that data analysis bring order, structure and meaning to the mass of collected data. The researcher in this study recorded the interviews using a tape recorder then listened to the tape transcribing them. The transcriptions were then put in a computer where they were read carefully to identify what was significant and related. The related data were grouped and categorized and themes and subthemes were identified and described. The final data analysis occurred when the researcher found out that the same information were repeating itself repeatedly and that data saturation had occurred.

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1.11 Measures to Ensure Trustworthiness

Lincon and Guba's model (1985) in de Vos (2005:346) for assessing and ensuring trustworthiness was used for the study. The goal for the model was to accurately represent the participant s'experiences. Trustworthiness is a method of establishing rigor in qualitative research without sacrificing relevance. The four criteria that were used to ensure trustworthiness were truth value, credibility, consistency, dependability, neutrality, conformability, applicability and transferability. These four criteria have been described with relevant strategies to meet those criteria in chapter three of this study.

1.12 Ethical Considerations

Ethics is doing what is right and good during the research process. Ethics is typically associated with morality and concerns matters of right or wrong. Ethical considerations are those issues in social scientific research in which there is a general agreement by researchers on what is proper or improper (Babbie, 2007:62). It is the application of all ethical principles to the research process. The researcher observed several ethical issues to be considered when conducting research which included permission to conduct research and the rights of the participants. The counsellors in the hospital were arranged to attend to those participants who may need the service due to being emotional during the interviews because of unpleasant memories.

1.13 Limitation of the Study

Owing to the decentralization of ART services to the primary health facilities, only patients who had been coming for collection of their treatment at the hospital, because they had problems which needed consultation by the doctor, were interviewed. The researcher anticipated that owing to the sensitivity of the stigma attached to HIV and AIDS, it might be possible that participants found it difficult to participate openly in the study and thus some of the information might have been missed.

1.14 Dissemination of Findings

The findings will be disseminated at the following areas:

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- Department of Health Limpopo, Provincial Presentation at annual Research day held once a year;
- Report will be submitted to the HIV/AIDS Directorate;
- Workshops on the recommendations will be conducted for health care workers;
- In workshops for all stake-holders within the community to disseminate results; and
- Media will be used in broadcasting information by means of radio talks and using pamphlets in the language of the local people.

1.15 Conclusions

In the first chapter the introduction and background of the study, problem statement, significance of the study, purpose of the study, objectives of the study, definitions of terms, research approaches and design, data collection, measures to ensure trustworthiness, ethical considerations, limitation of the study and dissemination of information were described and concluded with outlines of all the chapters. In chapter 2 literature review was described in detail.

1.16 Chapters Outline

The first chapter comprised of the overview of the study as follows: The introduction and background of the study; Problem statement; Significance of the study; Purpose of the study; Objectives of the study; Definition of terms; Brief discussion of research approaches and design; Data collection; data analysis; Measure to ensure trustworthiness; Ethical considerations, Limitation of the study and dissemination of information and conclusions.

Chapter 2 outlined literature review as related to experiences of HIV positive patients on ART.

Chapter 3 covers the discussion on research methodology: The subheadings discussed include the following: research methodology, research design, research setting, study population, sampling, data collection, data collection instrument, data analysis, measures to ensure trustworthiness, ethical issues, limitations of the study and conclusions.

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Chapter 4 comprises of presentation of findings and data analysis of collected data with participants who had attended ART clinic in a regional hospital at the Thulamela Municipality in Vhembe District of Limpopo Province. Data analysis reflected the biographical information, thematic presentation of the lived experiences of HIVpositive patients on ART. The findings of the study were discussed and the results were interpreted.

Chapter 5 provides the conclusion and recommendations of the study. A summary of conclusion and findings is given including recommendations regarding the community, research, nursing health education, patient care and health service management.

In the next chapter the researcher explored the literature dealing in the following manner; Introduction; Art rollout coverage worldwide, The rationale for introduction of ART, Identified Antiretroviral Drugs in South Africa, Experiences related to ART adherence, Outcomes of lack of adherence to ART, The role of community and family support on ART, Experienced Side effects of ART, Physical Experiences, Psychosocial Experiences, Socio-Economic Experiences and Political Experiences

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CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The previous chapter dealt with the introduction and background; the research problem has been identified and the purpose of the study and the objectives were discussed. The researcher wished to explore and describe the experiences of HIV positive patients on ART.

Chapter 2 aimed at providing the literature that is relevant to the experiences of HIV patients on ART (Ndala-Magoro 2010:12).Under this chapter, the following will be described:
The experiences of HIV positive patients on ART with the focus on physical, social, psychological, economical and political aspects, identification of different ART drugs South Africa, side effects of antiretroviral drugs, adherence of ART, need of family support by those taking treatment.

2.2 ART rollout coverage worldwide

The Joint United Nations Program on HIV/AIDS (UNAIDS)states that though ART is currently in use, HIV epidemic remains a major global public challenge with a total number of 33.4 million people living with HIV worldwide (UNAIDS 2010:7). By 2009, the World Health Organization (WHO) (2010:53) indicated that the total number of people in need of retroviral treatment worldwide were 13 500 000 -15 800 000. Meanwhile those who were accessing treatment were only 6 million. The Joint United Nations Program on HIV/AIDS estimated at the end of 2009 that 25 million people from middle and low income countries were receiving antiretroviral therapy, with sub-Saharan countries mostly affected as 3 911 000 people were receiving antiretroviral treatment (UNAIDS, 2010:51). In the sub-Saharan Africa, 22 million people are living with HIV/AIDS and only a few of these are on ART.

Most HIV positive patients in African countries like Zambia, Botswana, Malawi, Lesotho and Swaziland are living in poverty and find the cost for transport and collecting ART too high (Roura, Wringe, Busza, Nhandi, Mbata, Zaba and Urassa 2009:37). UNAIDS (2010:52) further illustrates the following figures on people receiving antiretroviral

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treatment in different countries: Eastern and Europe and Central Asia had 114 000 people on ART, Latin America had 425 000 people, Asian countries had 739 000 while North Africa combined with Middle East had 12000. South Africa has the highest number of people living with HIV in the world: between 5 and 6 million (FPD 2010:9).By 2009, only 971556 with 56% coverage of people were receiving ART. By the middle of 2011 the number of patients receiving ART in South Africa was 1.79 million (Johnson, Mossong, Dorrington, Schomaker, Hoffmann 2013:23).

2.3 The rationale for introduction of ART

Makoae, Portillo, Uys, Dlamini, Greeff, Chirwa, Kohi, Naidoo, Mullan,Wantland, Durrheim and Holzemer (2009:1) state that the development of ART medications in the late 1990's altered the face of HIV/AIDS, transforming it from a fatal disease into a chronic illness. The success of ART was seen by that time of introduction to be depending on the experiences of the HIV positive patient and the ability to make informed choices about the treatment they would be taking (Do 2011:1). In the United States of America (USA) and other parts of the developed world HIV treatment has advanced rapidly through improved understanding of patients' experiences (Limkulong, Sanchit, Kristopher &Williams 2006:12).

Outcomes for ARTs utilization

The Department of Health (DoH) (2010:2) states that the use of antiretroviral treatment have been well documented to decrease morbidity, mortality and improve the quality of life for many patients all over the world. Furthermore, Gilbert and Walker (2009:2) state that it is now widely accepted that effective medical technologies such as antiretroviral drugs have transformed HIV/AIDS from an acute life threatening condition to an established chronic disorder which can be managed. Additionally the treatment of HIV infection requires a lifetime commitment with a sequence of treatment regimens, with the goal of maximizing life expectancy as is possible (Mauskopf, Kitahata, Kauf, Richter, and Tolson, 2005:562).

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2.4 Identified Antiretroviral Drugs in South Africa

South Africa's National HIV Programme has been the topic of much debate. The South African government was initially hesitant about providing antiretroviral treatment to HIV-positive people, and only started to supply the drugs in 2004 many years after other nations had begun to do so following pressure from activists (Van Dyk 2011: 94) Antiretroviral treatment is a pharmacological treatment for HIV that works by inhibiting the ability of HIV to destroy the white blood cells. ART consists of a combination of at least three antiviral drugs that suppress the virus to stop or slow the progression of the disease. The drugs reduce the viral load; thus, increase the CD4 cell count (CDC 2007 in Kamau 2010:8). According to the South African Guidelines 2010 (DOH 2010) there are three main types of drugs available which are nucleosides analogue reverse transcriptase inhibitor, non nucleosides reverse transcriptase inhibitors and protease inhibitors which are listed with their examples, action, and side effects in the following table:

Table 2.1: Antiretroviral treatment in South Africa and side effects patients' experience.

Antiretroviral Drug	Action	Examples	Side effects patients experience
Nucleoside Analogue Reverse Transcriptase Inhibitor (NRTI)	Prevents healthy T-cells from becoming infected with HIV by preventing the conversion of viral RNA into viral DNA.	• Emtricitabine • Lamivudine • Tenofovir • Abacavir • Stavudine • Zidovudine • Didanosine • Zalcitabine	• anemia • bone marrow suppression which is most severe with zidovudine • peripheral neuropathy which is most severe with Stavudine, Didanosine and Zalcitabine • myopathy • cardiomyopathy • pancreatitis • hyperpigmentation which is common with Emtricitabine and Zidovudine • rash • fever • nausea • vomiting • diarrhea • flatulence • headache

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			• dyspnea • fatigue • optic neuritis • abnormal cholesterol levels • insulin resistance
Non-nucleoside Reverse Transcriptase Inhibitors (NNRTI)	Prevents healthy T-cells from becoming infected with HIV by interfering with the reverse transcriptase enzyme which the HIV uses to convert viral RNA to viral DNA.	• Efavirenz • Nevirapine • Nilpivirine • Etravirine • Delavirdine	• headache • fatigue • nausea • vomiting • diarrhea • raised liver enzyme levels • High cholesterol levels.
Protease Inhibitor	Prevents infected T-cells from producing new copies of the virus by blocking the protease enzyme which helps produce new copies of the virus.	• Atazanavir • Darunavir • Indinavir • Amprenavir • Fosamprenavir • Lopinavir • Nelfinavir • Tipranavir • Ritonavir • Saquinavir	Long term use of protease inhibitors (except Atazanavir) is associated with central obesity, buffalo hump (fat deposition in the back of neck), increased cholesterol and blood sugar levels. Other adverse effects are diarrhea, nausea, vomiting, abdominal pain, headache, peripheral neuropathy, abnormal sensations (parenthesis), reduced white blood counts, increased liver enzymes, and skin rash. Increased bilirubin is seen with Atazanavir and Indinavir. Kidney stones and crystaluria are common with Indinavir.

(DoH2010: 3)

2.5 Experiences related to ART adherence

WHO (2013:1) definition of adherence focuses on both medication and health-related experiences of patients on ART which include seeking medical attention, adherence to prescriptions, obtaining immunizations, following up appointments, executing behavior modification that addresses personal hygiene, risky sexual behaviors, unhealthy diet and insufficient levels of physical activity.

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Jones (2005) in Mabuse (2008:1) says that ART adherence refers to taking the correct medication as scheduled observing right doses and route. Chabikuli, Datonye, Nachenga, and Asong (2009: 349) state that as an increasing number of people are being put on ART adherence becomes a major concern. According to Mabuse (2008:1) HIV positive patients are experiencing challenges concerning taking ART because they demand lifelong commitment and responsibility. Patients further experience severe side effects, internal conflicts, and social stress which lead them to poor adherence to treatment due to feelings of guilt over previous lifestyles, relationships, and lack of support from family and friends.

Nyambura (2009:9) states that ART adherence is an essential part of success to treatment program. If a patient does not take their treatment correctly, there will be several effects they will experience which will include amongst other things major risk of drug resistance as mutations will be allowed to develop between their intermittent treatments. Nemes et al.(2004) in Nyambura (2009:17) explained that a study on ART therapy adherence done in Brazil revealed that adherence prevalence was 75%, and the factors that influenced non-adherence included missed appointments, more complex regimens and a large number of pills.

The South African national antiretroviral treatment (2010) guidelines recommend "ideal adherence" being when a patient takes more than 95% of his or her doses. According to the guidelines if a patient takes less than 95% of his/her doses, they are at risk of developing viral resistance to the treatment. Additionally if a patient takes less than 80% of his/her doses, their treatment is unlikely to be successful and will give passage to opportunistic infections. Moratioa (2007:3) explained that non- adherence to ART emanate from individual reactions to HIV positive status, social support system experienced and health system resources arrangement and treatment regimen given. According to Machtinger and Bangsberg (2005:1) interventions to promote adherence and minimizing challenges experienced include among others; direct observed therapy, using medication organizers such as pill boxes, reminder devices like cell phones and alarms. In a study done in Zambia by Sanjobo (2007:21) it was found that lack of communication and information about ART medication were some of reasons in barriers to adherence. In a study conducted in Swaziland (Ntshakala 2012:146) participants revealed that they faced many challenges which caused them not to adhere to treatment such as; failure to adhere due to non disclosure of HIV status, lack of reminders from family, friends and significant others, lack of food for PLWA and their family

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associated with poverty, tiring lifelong routine use of ART and busy schedules for PLWA. In another study, Do (2011: 85) participants indicated that it was not easy to follow prescription at times but they used reminders like phone and clock alarms, using appropriate time like when going to work, using family members like spouse, sisters, sons or daughters to set alarms and remind them to take pills as they rang. In a study done in Khayelitsha by Barnett, Patten, Kerschberger, Conradie, Garone (2013:13) participants verbalized that they failed to adhere well to treatment because of side effects of medication, medication timing, large pill size, pill fatigue forgetfulness, non disclosure to family members and friends.

2.6 Outcomes of lack of adherence to ART

According to Sanjobo (2007: 21) antiretroviral drug resistance is a major challenge to treatment programs in both developing and non developing countries. Additionally Davies (2013:42) states that it is imperative that all patients enrolled in South African ART programme are able to access a continuous supply of ART. Treatment interruptions, whether of single or multiple dose of ART, will lead to patient experiencing poorer clinical outcomes, increased rates of virological failure and the emergence of drug resistant HIV.

According to Conradie (2012: 162) a full viral suppression is essential because HIV reproduces itself rapidly, slight mistakes in treatment adherence may lead to virus mutations, and the virus will further duplicate itself more rapidly. Additionally if ART is suboptimal, drug resistance becomes high thus high replication. This is why combinations of antiretroviral drugs are prescribed in most AIDS treatment plans. When a patient begins ART, their viral load normally falls to undetectable levels. Furthermore Conradie (2012: 162) can affect the individual and community in spreading the resistant viral strain.

The available support to PLWA on antiretroviral treatment has a strong effect on ART access and adherence. In a study done in Zimbabwe by Scott, Campbell, Madanhire, Scovdal, Nyamukapa and Gregson (2013:13) participants reported that family members offered to support by encouraging them to take treatment and remind them of the upcoming appointment and thus in turn encouraged them to take treatment well. In a study done Ndala-Magoro (2010: 92) women with HIV and on treatment were empowered, learned new information, were able to share their experiences with other women, and received the support from other women with the same situation as them and they felt their wellbeing is enhanced

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and they improved responsibility to healthy lifestyle. Zerfu, Yaya, Dagne, Deribe, Ruiesnor-Escudero (2012: 5) reported in their study that participants indicated lack of psychosocial support from different organization providing caring services for them due to lack of referral and linkage forms for intra-organizational communication resulting in them not being followed up. According to Nakiyemba, Kwasa, Akurut (2012:13) living alone, social isolation and lack of support from family and friends have been associated with non adherence of treatment while having a partner, social and a family support and peer interactions and better relationships are characteristics of adherent patients.

2.7 The role of community and family support on ART

The available support to PLWA on antiretroviral treatment has a strong effect on ART access and adherence. In a study done in Zimbabwe by Scott, Campbell, Madanhire, Scovdal, Nyamukapa and Gregson (2013:13) participants reported that family members offered te support by encouraging them to take treatment and remind them of the upcoming appointment and thus in turn encouraged them to take treatment well. In a study done Ndala-Magoro (2010: 92) women with HIV and on treatment were empowered, learned new information, were able to share their experiences with other women, and received the spport from other women with the same situation as them and they felt their wellbeing is enhanced and they improved responsibility to healthy lifestyle. Zerfu, Yaya, Dagne,Deribe, Ruiesnor-Escudero (2012: 5) reported in their study that participants indicated lack of psychosocial support from different organization providing caring services for them due to lack of referral and linkage forms for intra-organizational communication resulting in them not being followed up. According to Nakiyemba, Kwasa, Akurut (2012:13) living alone, social isolation and lack of support from family and friends have been associated with non adherence of treatment while having a partner,social and a family support and peer interations and better relationships are characteristics of adherent patients.

2. 8 Experiences on Side effects of ART

People taking ART are likely to experience some side effects during their treatment. But most scientists and doctors agree that the benefits of ART outweigh the side effects of the drugs. It is important that patients are made aware of known side effects so they maintain their treatment adherence whenever possible. According to Moratioa (2007: 12) adverse effects of treatment experienced by patients influences their willingness to adhere to ART.

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According to Mathivha (2012: 5) ART regimen can be a challenge because patients experience more side effects of the treatment which result in making them sick and as a result they do not adhere to treatment as advised by the healthcare professionals.

According to Van Dyk (2008: 101), DOH (2010:132), Byron, Gillespie and Nangami (2006:1), patients experienced the following side effects: weight gain or lipohyperatrophy with maldistribution of fats on the neck, abdomen shoulders and breasts, weight loss or lipoatrophy which is evident on face, limbs and buttocks, nausea and vomiting. According to Fox, Mazimba, Seidenberg, Crook, Sikateyo, and Rosen, (2010:4), some patients experienced treatment-related hunger. HIV positive patients complained that the ART increased appetite very strongly.

One of the important factors in the success of treatment to reduce the side effects is how well the patient experiences and tolerates the ART. Decisions related to treatment-taking are difficult to make and according to Horne, Cooper, Gellaitry, Date, and Fisher (2007:334), it is important to understand a patient perceptions and likely reactions to treatment in order to improve their care and support. The researcher has reviewed the literature and found out that the experiences of HIV positive patients could be divided into, physical, psycho-social, socio-economic, and political experiences.

2.9 Physical Experiences

Living with HIV and placed on ART has physical changes experienced by the patients which result from the effects of taking ART. According to Moskowitz (2003:1), the body changes appear to be due to a combination of a number of risk factors which include, the effect of HIV, compromised immune system, advancing age, history of obesity in the family, the shape of one's body before starting with HIV therapy, diabetic or genetic predisposition diabetic or insulin resistance, lack of exercises, period duration of HIV therapy and ART. According to WHO (2006:4), most HIV positive patients were satisfied with the quality of the ART they were receiving because they were no longer emaciated as they were eating well with less vomiting but ART side effects experienced were still a problem to them.

Gilbert and Walker (2009:34) revealed that patients verbalized that the ART meant life to them and they would die if they were no longer accessible. They felt that they were given a

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new lease in life. HIV patients on ART revealed that they have experienced reduction of opportunistic infections, improved quality of life and better health (Gilbert and Walker 2009:13, Ndjeka and Manhaeve 2006:56, Yoder, Mkhize and Nzimande 2009:2, Li 2009:59). In a study done in Johannesburg, Gilbert and Walker (2009:58) state that HIV patients explained their experiences at their work places because their employers do pay for their transport which lead to decreasing tiredness which was caused by walking long distance to work. Additionally Cockcroft, Anderson, Milne, Mokoena, Masisi (2007:38) revealed that HIV positive patients experienced increased sex drive while on ART treatment.

Weiser, Tuller, Frongillo, Senkungu, Mukiibi and Bangaberg (2010:8) and Nechenga, Knowton, Deluca, Schoema, Watkinson, Efron, Hasson and Maartens (2006:8) stressed that food insecurity was an important barrier which patients experienced during taking ART. Increased appetite and absence of food lead to severe physical side effects. Other patients therefore resort to the reduction of doses to avoid excessive hunger (Weiser et al., 2010:7).Other patients complained of hepatic-related symptoms such as itchy rash on the whole body when they are on ART (FPD 2010:200).

2.10 Psychosocial Experiences

A research done in South Africa, Johannesburg shows that HIV positive patients experienced improved quality of life and they were able to return to their work after they have placed on ART (Gilbert & Walker 2009:14). This helped the clients in building their self-esteem again and their hopes for the future were revived (Li 2009:60). According to WHO (2006:16), some of the HIV positive patients on ART experienced psychosocial support from families, and friends. Employers helped with the cost of transport to and fro the wellness centers to collect treatment. However, there were those patients who experienced stigmatization and discrimination by community members, employers, and family.

According to Bravo, Edwards, Rollnick, and Elwyn (2010:85) HIV positive patients experience tough psychosocial needs, and decisions to make concerning their lives and these range from whether to disclose or not to disclose. Therefore this need or decision is charged with worries related to the judgment they might receive and the treatment they would experience in different way such as stigma and discrimination which might lead to exclusion

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from social support and make them to live in an isolated world where quality of life is affected. The other aspect of the HIV psychosocial needs, involve whether to choose to or not to follow treatment as prescribed due to reasons of patients denying their HIV positive status, not feeling sick, interpersonal motivation which improves relationship, having children who play an important role of wishing to live and have hope in life. HIV positive patients are concerned with interpersonal relationship which leads to them protecting partners and their children, having safer sex practices (Bravo et al., 2010:86). Bravo et al. (2010:86) further indicate that amongst other things HIV positive couples consider parenthood as the right which can bring them happiness and the hope to live but they are aware of the health and psychosocial risks that could mean to their families including the newborn.

The other aspect is the psychosocial need which covers how to maintain active sexual life and manage it.

UNAIDS (2009:9) states that there is usually a delay of accessing treatment because HIV positive patients are afraid to disclose to a support buddy and to be seen in long queues at the ART clinics (Fox et al 2010:58).This resulted in patients resorting to relying on using traditional healing methods and stopping ART for fear of being associated with HIV and AIDS which exposed them to abuse and violence. Abuse and violence against those who were known to be HIV positive and on ART treatment were also experienced from spouses, family, and friends. UNAIDS (2009:19) show how HIV positive women were unable to swallow their treatment fearing that their husbands would ask them until they almost stopped them. In support of UNAIDS, Gilbert and Walker (2009:8) outlines that HIV positive patients on ART were discriminated against even by families, neglecting them to sleep alone even when they were very weak and did not want to use same eating utensils they used. These psychosocial aspects further lead to socioeconomic aspects which are experienced by the patients on ART as discussed below.

2.11 Socio-Economic Experiences

ART is accessible free in South African public healthcare sectors. However, HIV positive patients experience to travel long distances which is costly in order to collect their treatment from the wellness centre or clinics. ART sites are still not enough when compared to the

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highest number of people living with HIV / AIDS. This makes patients to wait in long queues for many hours. Cockcroft et al. (2007:42) state that patients experience an increased treatment-related hunger which forces them to buy nutritious food whilst they don't have enough. Patients choose to buy themselves food instead of spending money on transport which leads to aspects such as lack of adherence emanating from socio-economic state of individuals. Additionally side effects also increase the costs of frequent visits to the clinics and this causes some to stop treatment because they feel they will not be having enough money to go to the clinic for blood evaluations (Weiser et al 2010:9).ART in the private health sector is costly and it can be afforded by those who are financially able.

HIV positive patients are also experiencing discrimination in the business world. Nghifikwa (2011:9) states that because of the use of ART, the quality of life has been increased but certain insurance companies still deny HIV positive people life covers because of their status even when they are taking ART. Some institutions still make it a prerequisite for someone to reveal their status before employment by doing HIV testing or asking if one is using ART. Stigma in the business world can cause HIV positive patients on ART to lose their jobs thus becoming poor.

The study conducted in India ILO (2003:32) revealed that HIV positive persons' monthly income would have been better if they had been free from illnesses during the first six month period. Their expenditure increased on basic needs such as medicines, food and they had to cut costs for their expenditure on education and entertainment. In addition to medicine costs, the consultation fees, blood tests, and ART were too expensive in such a way that persons infected with HIV needed to adjust themselves by selling their assets and taking loans thus making them poorer. Furthermore, ILO (20O3: 34) states that many of the HIV positive patients received support, in the form of medicines, hospitalization, referrals and counseling from NGO's and networks which releaved their socio-economic status.

2. 12 Political Experiences

HIV positive patients from neighboring countries such as Malawi, Swaziland and Zimbabwe have been experiencing ART and health staff shortages making it very difficult for them to access ART (UNAIDS 2009:9). This caused many of them to migrate to South Africa for treatment. According Lawson (2006: 43) in the study of the African and

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the Caribbean people on HIV/ AIDS in immigration caused additional stress to those with HIV as it causes them to be away from their families whom they needed psychological support. Furthermore, people who have HIV reported that racism; homophobia also played a big role in them being discriminated against.

In a report from UNAIDS (2009:22), HIV positive patients on ART were denied entry in other countries due to their status. Continuity of care is also difficult as experienced by HIV positive patients on ART who live in foreign countries. If a person is from another area it is difficult to get treatment in a new area (Gilbert & Walker 2009:2).According to UNAIDS (2009:22), some HIV positive patients on ART were denied entry, employment and making relationships because of their health status in foreign countries. According to law, Refugee Act 130 of 1998 outlined that refugees and other asylum seekers should be treated as South Africans in terms of access to free public healthcare services, however the Act recognize legally refugees and asylum seekers but it is ambiguous regarding non citizen groups in accessing free health services including ART.

2.13 Conclusions

The above reviewed literature confirms that patients' who are on ART have several experiences which include lack or poor family support while on ART, problems accessing ART , stigma and discrimination. Literature revealed the fact that healthcare providers who are providing ART services are aware of patients' experiences and need to address them in order to improve treatment adherence by addressing the patients' experiences.

In the next chapter research design and methodology was described in detail with regard to how the lived experiences of HIV positive patients on antiretroviral treatment was explored.

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CHAPTER 3:

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter focuses on Research Design and Methodology. The research approaches used in this study was a qualitative one because the researcher wanted to explore and describe the experiences of the participants. The aspects discussed included the following: Research Methodology, Research Design research setting, study population, sampling, data collection, data collection instrument, data analysis, measures to ensure trustworthiness, ethical issues, limitations of the study and conclusions.

3.2 Research Methodology

Babbie and Mouton (2008:647) define research methodology as the methods, techniques, and procedures that are employed in the process of implementing the research design or research plan as well as the underlining principles and the assumptions that underlie their use. Bless, Higson-Smith and Kagee (2006:4) also define research methodology as the systematic investigation of a question, phenomenon, or problem using certain principles. The research procedures in this study had been scientifically planned and grounded. The methods and design have been described fully in the subsequent paragraphs.

3.3 Research Design

Research design is a set of guidelines and instructions to be followed in addressing the research problem (Mouton, 2009:07). A research design is a plan or a blue print of how you intend conducting the research. According to Babbie (2007:87), a research design is a plan of what you are going to observe, how and why you are going to observe it. Bless *et al* (2006: 71) define research design as a specification of the most adequate operations to be performed in order to test a specific hypothesis under given conditions. Creswell (2009:173) defines

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design in qualitative as "the entire process of research from conceptualizing a problem, to writing the narrative", while *tradition of inquiry* is the term used to refer to "an approach to qualitative research that has distinguished history in one of the disciplines has spawned…. distinct methodologies that characterized its approach"

The research design was qualitative, phenomenological, descriptive and explorative in nature. The researcher used this approach to describe experiences related to antiretroviral treatment. Various designs used by researchers depend on the purposes of the study, the nature of the research questions and the skills available to the researcher (De Vos et al., 2005:269). Furthermore, De Vos *et a.l* (2005:268) define research design as the options available to qualitative researchers to study certain phenomenon according to certain ''formulas'' suitable for their research goal. For the purpose of the study, a qualitative approach was used because the researcher needed to explore and describe the experiences of people in their own context. Qualitative approach focuses on methods for examining social research data without converting them to numerical format.

3.3.1 Qualitative approach

Qualitative research is a systematic subjective approach used to describe life experiences and to give them meaning (Burns & Grove, 2001:61).Qualitative research is an artistic, philosophical approach that is thought to produce "self". The primary concern some researchers have with qualitative research is that it lacks objectivity and control that are essential to "hard "scientific science (Burns & Grove, 2001:62). It is a loosely defined category of research design and models all of which elicit verbal, visual, tactile, olfactory and gustatory data in the form of descriptive narratives like field notes, recording, or other transcriptions from audio and video tapes. In qualitative research the people were studied in their setting in order to discover the social world of cultures and languages by living with them and learn by observing and talking to them. Qualitative researchers have emphasized six significant characteristics in their research(1) a belief in multiple realities, (2) a commitment to identifying an approach to understanding that supports the phenomenon studied, (3) a commitment to the participant's viewpoint ,(4) the conduct of inquiry in a way that limits disruption of the natural context of the phenomenon of interest, (5) acknowledged participation of the researcher in the research, and (6) the conveyance of an understanding of the phenomenon by reporting in a literary style rich with participants commentaries

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(Streubert & Carpenter, 1999:15).Qualitative research identifies the characteristics and significance of human experiences as described by participants and interpreted by the researcher of different levels of abstraction (Burns & Groove, 2001:62)

The researcher used this method to look at the phenomenon under inquiry as a whole in order to generate the knowledge of which the researcher was not aware. The researcher interviewed participants using in-depth interviews; the participant's point of view was reflected in the research report.

According to Barker, Pistrang, and Elliot (2005:92), qualitative approaches use language as their raw material in order to examine participants' thoughts, feelings, behavior, or linguistic strategies. Patton (2002) in Maree (2007:257) states that the sample in qualitative studies is small and the researcher purposefully selects those participants who have the most experience with the phenomenon under study. Marshall and Rossman (2006:3) outline the following characteristics of qualitative approach: phenomenology, exploratory, descriptive, and contextual. The goal of qualitative research is to explore and understand a central phenomenon which is the concept or process explored in a qualitative study. Furthermore, the researcher found qualitative approach suitable for this study to use because the research took place in the natural world and used multiple methods that were interactive and humanistic, focused on the context. According to De Vos (2005:257), qualitative data is collected from people in the setting of everyday life in which the study is framed. The researcher used the broad open-ended question to allow them to share their views about and experiences with the phenomenon. The researcher, using qualitative approach, was able to engage the subjects in their natural world where interaction generated data that was needed. The rationale for using a qualitative approach was to explore and describe experiences of HIV positive patients on ART. The qualitative approach was the most appropriate way to capture their life experiences.

3.3.2 Phenomenology

Babbie (2007:295) defines phenomenology as a study that seeks to make sense out of the informants' perceptions of the world. Furthermore, De Vos *et al* (2005:270) state that a phenomenological approach is the systematic study of people's experiences and ways of viewing the world. The goal of a phenomenological approach is to describe accurately, a

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person's lived experience in relation to what was being studied (Balls, 2009:1). This was revealed in the research question *"What are the lived experiences of HIV positive patients on ART?"* The researcher planned to explore and describe the experiences of the subjects in order to generate data that is meaningful, in order to critically assess the data collected. The researcher planned to interview, record observations of the physical, social and psychological behavior of the subjects, exploring the subjects in depth in order to gather new knowledge. The data was recorded and compiled by making notes on interviews and using audiovisual means which were then transcribed for further analysis (Maree, 2007: 257).

3.3.3 Exploratory

According to a Neuman (2011: 33), exploratory research is a study in which the primary purpose is to examine a little understood issue or phenomenon to develop preliminary ideas and moves towards refined research questions by focusing on the "what" question. Exploratory studies seek to explore what is happening and to ask questions about it (Gray, 2009:35). The purpose of exploratory research was to give new knowledge about a phenomenon (Wysocki 2008: 61). Exploratory research is usually done for three purposes, namely, to satisfy the researcher's curiosity and desire for better understanding, to test feasibility of understanding a more extensive study and to develop the methods to be employed in any subsequent study. Previous researchers have used exploratory approaches with good results of gaining new knowledge about the phenomenon under study. Gilbert and Walker (2009) in their study entitled, "They (ART) are my life, without them I'm nothing,'' used an exploratory approach. Furthermore, another study titled "patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence in London" also used exploratory approaches (Horne, Cooper, Gellaitry, Date & Fisher, and 2007:334). According to Gray (2005: 35) exploratory research is a study in which the primary purpose is to examine a little understood issue or phenomenon to develop preliminary ideas and moves towards refined research questions by focusing on the ''what'' question. In this study, the researcher used an exploratory approach to achieve a better understanding on the experiences of HIV positive patients on ART. Data was collected using an in-depth interview where focus will be on physical, psychosocial, socio economic and political experiences. The researcher will use all communication skills as suitable to gain the data needed from the participants. During the study, the researcher went to the Thulamela

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Municipality in the Vhembe District of Limpopo to explore the experiences of HIV positive patients on ART in their own setting in order to attain the objectives of the study.

3.3.4 Descriptive

Neuman (2011:35) defines descriptive as the research in which the primary purpose is to "paint a picture" using words or numbers and to present a profile, a classification of types, or an outline of steps to answer questions such as who, where, when and how. According to Gray (2009:35) the purpose of the study is to provide the picture of a phenomenon as it naturally occurs. In descriptive research, the researcher begins with a well-defined subject and conducts research to describe it accurately. In descriptive research a researcher describes a phenomenon without making any attempt to determine what causes it (Wysocki, 2008:227). Descriptive designs emphasize in-depth description of a specific individual situation, group interaction or social object where applicable. This approach aims at exploring the dimensions of the phenomenon, the manner in which it is manifested and other factors to which it is related (Polit & Hungler, 1997:14)

This information was gained through the use of in-depth interviews using an interview guide. An interview is a data collection encounter in which one person who is an interviewer asks questions about the other who is a participant either face-to-face or telephonically (Babbie: 2007:264). According to this type, data collection has an advantage of high response, the participant can ask questions and the researcher is there to observe non-verbal communication. Neuman (2011:301) states that the major disadvantage of a face-to-face interview is that the researcher may be biased and his presence may affect the participant.
The participants in this study were made to feel comfortable and at ease, facilitated and guided instead of dictated to. The researcher used the interview guide to describe the lived experiences of participants.

The documented information on the phenomenon was analysed and classified to provide new insight into the phenomenon. This approach was used to generate new knowledge about concepts or topics where limited or no research has been conducted. In this study, an accurate description of the experiences of HIV positive patients related to antiretroviral treatment was achieved through in depth interviews. Through interview guide a descriptive research document was used to describe the participants' actions, attitudes and feelings on

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being on antiretroviral treatment. The researcher explored and described the lived experiences of HIV positive patients on ART.

3.3.5 Contextual

Qualitative researchers hold the notion that the meaning of a social action or statement depends on the context in which it appears. According to Mouton (2009:155), the primary aim of the investigator is to produce an extensive thick description of the phenomenon in its specific context. The availability of new antiretroviral treatment and recent data on their effects warranted an update on the knowledge of the experiences of HIV positive patients on ART treatment. The researcher conducted an in-depth interview with the HIV positive patients who were receiving ART in order to generate a thick data from them.

According to Babbie and Mouton (2008:272), if one understands events against the background of the whole context and how such a context confers meaning to the events concerned, one can truly claim to understand the events. By conducting this study on HIV positive patients who were on ART treatment about their experiences, the researcher truly understood such experiences.

3.4. Research setting

Neuman (2011:224) defines setting as a geographical boundary of the study area. The study was conducted in Vhembe District of Limpopo Province South Africa. According to the DOH (2012: 2) Limpopo is the northernmost province in South Africa and has the fourth largest population. It was considered to be a poor province with approximately 87% of its people living in rural areas. Just over 97% of the population is classified as Black Africans while whites make up 2%, Coloured and Asian people make up 0.4% and 0.5% respectively. According to Limpopo Mining and Industries (2009 Edition: 9) this province has five districts namely; Capricorn, Mopani, Waterberg, Sekhukhune and Vhembe.

Vhembe District consists of the former Venda and Gazankulu homelands. Vhembe District has four municipalities: Makhado, Musina, Mutale and Thulamela. The researcher chose a regional hospital in the Thulamela Municipality based on the reason that it is a referral

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hospital for all other hospitals in the Vhembe district. This hospital also referred patients back to Vhembe District hospitals, health centres and clinics on discharge.

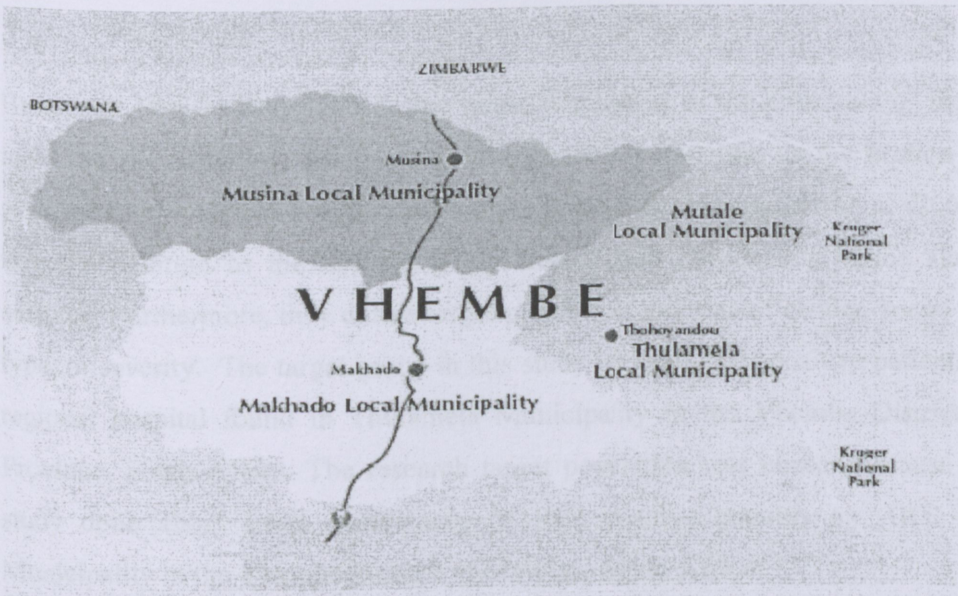

Figure 1: Vhembe District municipalities (DoH (l) 2011-12:8).

The study was conducted at the Thulamela Municipality in Vhembe District of Limpopo Province. Inclusion criteria were used to help in identifying characteristics that should deserve to be included in the sample.

3.5 Study population

According to Babbie and Mouton (2008:100), a population for a study is that group of people usually about which use of inclusions are drawn. A population can be considered to be the main focal group from whom the researcher wants to achieve specific objectives related to the study. It is the totality of the subjects that meet the requirements of a specific situation Furthermore, Babbie and Mouton (2008:174), state that a study population is that aggregation of elements from which the sample is actually selected. Whereas an accessible population can be described as all the cases that meet the criteria and are accessible for the study (Polit & Hungler 1995:33:229-230). Burns and Grove (1997:295) describe the inclusion criteria as "the characteristics that must be present for the element to be included in the study, participants resided at Thulamela Municipality in the Vhembe District of Limpopo Province

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at a regional hospital. Study population may be further divided into target population and accessible population.

Burns and Grove (2009:132) define target population as the entire set of individuals who meet the the sampling criteria and an accessible population as the portion of the target population to which the researcher has reasonable access. Barker *et al* (2005:179) define target population as the defined group from which participants in the study are to be selected. Furthermore, they define target population in terms of gender, social class problem type, or severity. The target group in this study included HIV positive patients on ART at a regional hospital found in Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa. The research target population was chosen because there was no study done about lived experiences of HIV positive patients on ART in Thulamela Municipality in the Vhembe District of Limpopo South Africa.

3.6 Sampling

Maree (2007: 79) refers to sampling as the process used to select a portion of the population for study. Furthermore, Maree (2007:79) explains that sampling decisions are therefore made for the explicit purpose of obtaining the richest possible source of information to answer research questions. In a qualitative research, only a sample of a population is selected for a study population. Only those people with the characteristics that the researcher has in mind were sampled for research. The study's research objectives and the characteristics of the population determine how many people to select.

3.6.1 Sampling method

Babbie (2007:180) defines sampling as a process of selecting units for observations. The researcher has to choose, from the entire population, the small portion of units needed for the study. The selected portion of units is called a sample. In qualitative research, subjects are selected to participate in the studies based on firsthand experience of the phenomenon of interest. Babbie (2007:184) defines purposive sampling as a type of a non-probability sampling in which the units to be observed are selected on the basis of the researcher's

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judgment about which ones will be the most useful or representative. The researcher decided purposely to select the widest variety of participants who were judged to be typical of the population in question as reflected in the inclusion criteria.

Therefore, the researcher in this study used purposive sampling to select participants. Purposive sampling is a non-probability method of sampling in which units to be observed are selected on the basis of the researcher's judgment about which ones will be the most useful or representative (Babbie, 2008:644). The researcher purposefully chose a regional hospital at the Thulamela Municipality in Vhembe District of Limpopo where all other hospitals from the district referred their patients. The researcher chose purposive sampling in order to find a group of HIV positive patients who were on ART since they had experience on antiretroviral treatment and could be able to give information. In the regional hospital, the researcher identified a wellness Centre where HIV positive patients attended for collection of their treatment. These patients who came to consult for their ART treatment were identified for research purposes. The researcher visited the wellness Centre and clinics, introduced herself to the nurses, and lay counselor who then introduced her to HIV positive patients coming to collect treatment on that day and made appointments with them, if they consented to participate in the research they were given an informed consent form to sign.

3.6.2 Sample size

According to Welman *et al* (2005:55), it is impractical and uneconomical to involve the whole populations in a research project. The size of the sample was influenced by the kind of data analysis, the accuracy of the results for the research's purpose and the characteristics of the population (Maree, 2007:178). The data was collected until data saturation occurred or until there was no more new information coming forward. At least 10 interviews were conducted using an interview guide and was guided by data saturation.

Neuman (2011:240) defines sample size as how large a sample should be. Patton (2002) in De Vos *et al* (2005:328) states that there are no rules for sample size in qualitative research. He furthermore, states that the sample size depends on what you want to know, the purpose of the study, what is at stake, what will be useful, what will have credibility, and what can be done with available time and resources available.

Qualitative samples are not predetermined, but the researcher depended on data saturation. Rubin and Rubin (2006:67) refer to saturation as getting similar data or ideas over again

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during the course of the interviewing in a qualitative study that signifies completion of data collection in a particular phenomenon. In qualitative research, the researcher is not interested in the numbers in the sample but whether data saturation is reached. Data saturation is when the researcher begins to hear the same information repeatedly from the subjects (De Vos et al., 2005:294). The researcher interviewed a number of patients until information became saturated. There was no need to determine the number of participants at the beginning of the interview.

3.6.3 Inclusive and exclusive criteria

According to Neuman (2011:226), inclusive and exclusive criteria are parameters in which the study is limited to or excluding subjects according to set characteristics. Holloway and Wheeler (2010:144) explain inclusive and exclusive criteria as follows: that inclusions are particular people who can be included in the study due to their characteristics and exclusions are those who qualify for being included in the study but are excluded because they might be vulnerable to be interviewed or have certain traits that might make research problematic. In the above explanation about specificity for people with certain characteristics, it was important to consider the research question and include factors that would enable a homogeneous selection of subjects considering age, gender, diagnosis, degree of understanding and any other attribute that might be necessary to fit or answer the question under study. It might be determined that the specific variables under study were more likely to show an effect in choosing the correct sample for the study.

In this study, the researcher interviewed HIV positive patients who had been on ART treatment for the period of three months and above, irrespective of gender; who were 18 years and above because they were eligible to a legal consent. Exclusion criteria are applied to subjects who generally meet the inclusion criteria but must be excluded because they cannot complete the study or possess unique characteristics that may confound the results (Holloway *et al*, 2010:144). The mentally ill or disabled and those who were critically ill to participate were also excluded.

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3.7 Data Collection

Babbie (2007:309) states that the advantage of field research method is the presence of an observing, thinking researcher on the scene of action. The researcher in this study chose field notes and tape recording to collect and manage data. She asked participants to record them using a tape recorder and took notes during the interview. In- depth interviews were conducted with ten participants whose knowledge, perceptions beliefs were solicited simultaneously, conducted to give participants the opportunity to describe their knowledge, beliefs and perceptions from their own perspectives intensively. In order to do this, it is important that the method of data collection allows the participants to do 90% talking (De Vos et al., 2005:288).

3.7.1 Data collection technique

According to Maree (2007:87), an interview is a two-way conversation in which an interviewer asks the participant questions to collect data and to learn about the ideas, beliefs, views, opinions, and behavior of the participant. According to Babbie (2007: 306), during data collection the researcher collects various kinds of information through various methods techniques. Furthermore, Babbie (2007:306) explains that an interview is an interaction between an interviewer and a participant in which the interviewer has a general plan of inquiry. The researcher in this study chose to conduct an interview as a means of data collection instrument. Babbie and Mouton (2008:189) explain an interview as an interaction between the interviewer and the participant where the interviewer has a general plan and direction of inquiry but not a predetermined set of questions and pursues specific topics raised by the participant.

In-depth interviews were conducted, and the interviewer encouraged participants to talk freely. Participants spoke for themselves and the interviewer could make follow-up on the information given. The researcher was able to use all types of communication skills explaining on the stories of the participants. Communications skills like reflecting, encouraging, gentle probing, and paraphrasing were used to facilitate discussion. The interviews were conducted in a hospital room or at a participant`s place and they took twenty to thirty minutes.

According to Polit and Hungler (1995:31) a researcher needed to be competent in communication skills in order to make the use of reflection, clarification, requests making of

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examples and description and convey interest to participants through the use of listening. In this type of interview the researcher started by establishing context of the interview's experiences, constructing an experience then finally a reflection of what that experience hold. Phenomenological research interviews were flexible and depended on the nature of the direction or relationship that occurs. One central question was asked "what are your experiences as a person who is HIV positive an on antiretroviral treatment?

3.7.2 Interviewing techniques

The researcher should use active listening in order to conduct a good interview. Good listening can be defined as listening with a purpose to understand even deeper meaning and can achieved by use of questions or reflecting where necessary for good understanding of the message. The researcher planned to use minimal responses followed by other body language or gestures to encourage the participant to freely express themselves. Paraphrasing would be done to ensure correct message from the participant. Minimal probing where short questions would be asked to facilitate communication. The researcher also planned to make a short summary in order to acquaint oneself with the whole meaning of the lived experiences of the participants.

3.7.3 Field notes

Field notes are a written account of the things that the researcher hears, sees experiences, and thinks about in the course of interviewing (De Vos et al, 2005:298). The researcher wrote down notes on a notebook about what she heard, saw, experienced and thought about during the interview if possible or as soon as possible immediately after the interview. The researcher recorded verbal and non-verbal cues of the participants as well as what the researcher thought of the data that did not make sense at the time. The following are types of field notes according to Neuman (2011:399)

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3.7.4 Jotted notes

These are short temporary memory triggers such as words, phrases, or drawings taken in the field. To avoid loss of data the researcher had a scribbler to jot down any memorable trigger which was then written in full after leaving the field. These included participants` body language as well as their feelings during the interview.

3.7.5 Direct observation notes

The researcher wrote those notes immediately after leaving the field. Those are written chronologically and the details include what the researcher heard and saw, like they were exactly recordings of particular word phrases or action. The researcher recorded time, date, place, and detailed description of what she heard and saw.

3.7.6 Personal notes

In the personal notes the researcher wrote about her personal feelings or reactions in order to make inference about what happened during the time of collection of data. When reading data the researcher was able to do follow-up because it was easier to identify gaps using personal notes.

3.7.7 Tape recording

According to Vos et al. (2005:298) a tape recorder allows a much fuller record than notes taken during interviews. For this advantage, the researcher in this study used both field notes and a tape recorder simultaneously. The researcher explained to the participants about the role and importance of a tape recorder, once again to alleviate their anxieties. Tape-recording data was important for documentation, transcription, and analysis.

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The decision taken for each category was to arrange them alphabetically.

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Step 7: *Assemble similar categories of data*

The researcher assembled data materials belonging to one category and placed them in one place and did preliminary analysis.

Step 8: *Data recording*

Analyzed data was recoded and the researcher was able to generate themes, categories, and subcategories.

3.9 Measures to Ensure Trustworthiness

Babbie and Mouton (2008:276) describe trustworthiness as a means of how an inquirer persuades his or her audiences and himself that the findings of an inquiry are worth paying attention to or account of.

The researcher ensured trustworthiness by observing and following the notion of objectivity as manifested by Lincon and Guba (1985) in De Vos (2007:346) which are credibility, transferability, dependability and conformability.

3.9.1 Credibility

The goal of credibility is to demonstrate that the inquiry was conducted in such a manner that the subjects were appropriately identified and described. In short, credibility answers the question how truthful is the information reported from the subjects.

The researcher in this study did triangulation of data (Babbie 2007:113). Field notes and tape recording of information was done. After reading and listening to the tape, follow-up interviews were done. The supervisors were given notes to read and to listen. The researcher observed any bias and bracketed them. The findings were presented for peer examination at a school peer review.

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sought throughout the steps of research. Four criteria to ensure trustworthiness are summarized in Table 3.1 below.

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Table 3.1: Criteria to ensure trustworthiness

Principle	Description
1. Credibility (Truth value)	The researcher spent more time with participants. The researcher interacted with each individual prior to interview and established relationship. Interviewing longer not rushing for time. Field notes were taken throughout.
2. Dependability (Consistency)	The study was audited by peer researchers. The data was coded and same data recoded to ensure accuracy.
3.Conformability (Neutrality)	The researcher spent more time with participants during the individual interview. The researcher ensured that no researcher's opinion was reflected in the participants' view. Individual interviews, field notes and literature control were conducted.
4.Transferability (Applicability)	The information was recorded on the audiotape and was described in the way that everyone could determine whether the findings of the study were applicable to the setting. A purposive sampling technique was used to select participants who fitted the criteria described. Dense description of participant's characteristics, research content and setting was done.

3.10 Ethical Considerations

Gray (2009:69) describes ethical issues as a set of moral principles or norms that are used to guide moral choices of behavior and relationship with others. Ethical issues are concerned with protecting the rights, dignity, and the welfare of research participants (Barker *et al,* 2005:188). In case of a student undertaking research for qualification purposes, they are required to submit proposals to the institution's Ethics Committee for approval (Gray, 2009:72). Furthermore, Gray categorizes ethical principles into four main areas: avoid harm

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to participants, ensure informed consent of participants, respect the right to privacy of participants, and avoid the use of deception.

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All these ethical principles are interrelated, cyclical in nature. The researcher in this study observed and considered the following ethical issues:

3.10.1 Permission for study

The researcher compiled the proposal plan; submitted it to the Higher Degrees Committee of the School of Health Sciences, then to the University Ethical Committee for approval.
An application letter was sent to the Limpopo Provincial government and to Tshilidzini Regional Hospital where the study was conducted. Permission to conduct the study was obtained from;-

- University of Venda research Ethics Committee.
- Department of Health and Social Development Research Ethics Committee, Limpopo.
- Tshilidzini Regional Hospital, at the Thulamela Municipality in the Vhembe District of Limpopo Province

No data was collected before receiving a certificate for permission and ethical clearance to conduct the study.

3.10.2 Informed consent

Barker *et al* (2005:189) define informed consent as a disclosure by the researcher before the study of what will happen during the study and of any other information that might affect the person's decision to participate. According to Babbie (2007:64), informed consent means that the subjects base their voluntary participation in research projects on a full understanding of the possible risks involved. This means that the participants have rights to adequate and relevant information before the commencement of the study. Participants were informed about their decisions regarding participation in the study. The researcher explained what the study was all about, how it would affect them, the potential risks and benefits of participation and the fact that they had the right to decline to do so if they so wished (Bless et al 2006: 142). For the sample of informed consent, see Annexure A.

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The researcher complied with informed consent principles by giving the participants full information about what the study entailed, freedom of choice in participating and a consent form to sign. The information was explained in simple language which was easily understood by the participants in English or Tshivenda where possible. A consent form with detailed information about the study was provided in simple language which the participants understood in either English or Tshivenda for them to sign.

The participants were given freedom of choice in participation or withdrawal from the study at any time they felt like. The participants were allowed to ask whatever questions they had about the study before signing the informed consent form. All subjects participated voluntarily without any form of coercion.

3.10.3 Voluntary participation

Voluntary participation is a situation where researchers follow a principle of voluntary consent from the participants by ensuring that they sign an informed consent without coercion (Neuman, 2011:135). The researcher in this study did not coerce any participant into signing by giving reward or discriminating against them. The participants were allowed to sign informed consent forms after they were given information and they understood it and asked questions about the study. The participants were allowed to refuse or withdraw at any time without being judged.

3.10.4. Right to withdraw from study

According to Bless et al. (2006:143), participants must be given every assurance that they are free to discontinue their participation at all times without being required to offer an explanation. The participants' wish against withdrawal should be respected. The participants' were assured that their withdrawal from the study would not prejudice their receiving services even if the project was being done at a health facility or government department.The participants were assured the right to withdraw from the study any time; Participants were also shown a stop button on the audio-tape so that they could stop the tape if they didn't want particular information to be recorded.

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3.10.5 The right to privacy

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De Vos et al (2005:61) defines privacy as that which normally is not intended for others to observe or analyse while Singleton *et al* (1988) in de Vos (2008:61) further explains that the right to privacy is the individual's right to decide when, where, to whom, and to what extent his or her attitudes and behaviour will be revealed.

The researcher in this study respected the privacy of the participants by not asking questions which intruded their privacy. The right of a participant not to disclose certain information was respected. The interview was conducted in a private room free from intrusion by other people. Private information of participants was not shared without the individual's knowledge or against his or her will. The researcher ensured that participants did not lose their dignity, friendship, employment, embarrassment or shame. Participants were made aware of the use of an audiotape and the stop button. The participants were also shown the stop button on the audiotape so that they could press the button if they felt the information they wanted to disclose should not be recorded (Burns & Grove, 2001:196)

3.10.6 The right to confidentiality

Confidentiality means that information may have names attached to it, but the researcher holds them in secret from the public. The information is not released in a way that permits linking specific individuals to responses and is publicly presented in aggregate form (Neuman 2011: 139). According to Barker *et al* (2005:193) confidentiality refers to the person's right and the researcher corresponding obligation to withhold information from third parties. The researcher in this study would maintain confidentiality to all information received from participants. Records and tapes made were stored safely under lock and key and will be accessible only to the researcher and people responsible for this research. The participants were given information on who will have access to their information other than the researcher and the reasons thereof. All personal details of participants were destroyed as soon as possible after their interview and a coding for a name was used. The researcher did not allow any other person who might have been a family member or other health professionals to have access to raw data of the study.

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3.10.7 Right to anonymity

According to Babbie (2007:64), anonymity is guaranteed in research projects when neither the researcher nor the readers of the findings can identify a given response with a given participant. This implies that in a typical interview a participant cannot be considered anonymous because an interviewer collects data from an identifiable participant. In this study anonymity was not possible to maintain because the researcher interviewed the participants. Anonymity in this study was not guaranteed by the researcher because an interview was be used to collect data.

3.10.8 Right to protection from harm

Babbie and Mouton (2008:522) maintain that social research should never injure the people being studied regardless of whether they volunteer for the study or not. The right to protection from discomfort and harm is based on the ethical principle of beneficence, which holds that one should do good, and above all, no harm (Bless *et al*., 2006:141).The clearest instance of this norm in practice concerns the revealing of information that would embarrass the subjects or endanger their home lives, friendships, jobs and their psychological wellbeing. The researcher in this study was dealing with sensitive participants where their emotions were likely to be aroused and hurt. Counsellors were arranged to counsel participants after sessions or the study when necessary. The researcher did not reveal any information which would endanger the participants` home life, friendship and jobs. Where this was not possible, reports were made in aggregate rather than individual. Clients were not subjected to physical harm; however, emotional hurting might have been aroused as the topic understudy was a sensitive one. The researcher took care not to ask questions which degraded participants as human beings. Every question was worded carefully in order to minimize or prevent anxiety and dredging unpleasant memories.

The researcher ensured that the participants were comfortable with the selected venue, time and also guarded against embarrassing the participants during interviews. As such, questioning and probing were done cautiously. The researcher ensured that participants did not incur financial loss by travelling to the area where interviews were conducted. During an interview, the researcher was vigilant in assessing the participant's discomfort in order to refer to professional intervention where necessary (Burns & Grove, 2001:196).The researcher

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avoided to ask questions that might elicit anxiety, dredge unpleasant memories or cause them to evaluate themselves critically (Babbie, 2007:68).

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3.10.9 Right to fair treatment

Neuman (2011:138) defines fair treatment as the right to be equally treated on selection procedures and other opportunities while under the study. The principle of fair treatment is based on the assumption that all people are equal and should not be discriminated against on the basis of race, gender, disability status, income level or any other characteristics in research (Bless et al 2006: 142). The right to fair treatment is based on the ethical principle of justice, which holds that each person should be treated fairly. The researcher gave every participant equal chance to participate, respected and treated every participant equally without observing one's socio-economic status, ethnicity or gender. The population and the participants were selected fairly and their role in the study was clearly discussed (Burns & Grove, 2001:196).

3.11 Limitations of the Study

Limitations are challenges which can restrict the researcher's scope of study. The researcher in this study was limited by the budget to meet different research needs. The topic understudy is very sensitive and participants were afraid to talk even though confidentiality was assured. Painful emotions were aroused and those needed the researcher to make more appointments for the interviews to alleviate anxiety.

3.12 Conclusions

The chapter discussed research methods which the researcher employed in conducting the study. Qualitative research methods were used where the experiences of HIV positive patients on ART treatment in Vhembe District of Limpopo Province of South Africa were explored and described. Data analysis was done using eight steps oftheTeschModel as explained by Creswell in Marshall and Rossman (2006:155-156). Measures to ensure trustworthiness, ethical considerations, and literature control have been taken into consideration to weigh the findings against data in the literature by previous researchers. The subsequent chapter will discuss research findings and results.

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CHAPTER 4:

PRESENTATION OF FINDINGS AND DATA ANALYSIS

4.1 Introduction

Chapter 3 elaborated on a full description of the research design and methods. The purpose of this chapter is to present the results obtained from the interview sessions conducted with 10 participants until data saturation was reached were no new information was emerging. The interview sessions lasted for approximately 20 to 30 minutes. The participants answered the central question which was guided by using all communication skills like probing, paraphrasing, nodding, and listening. The chapter will further focus on describing the themes which have emerged during data analysis of this study, followed by the actual narratives from the participants to support the findings. Literature control will be presented to embed the study findings in existing literature.

4.2 Socio-Biography of the Participants

The interviews were recorded using a tape recorder and then the data was transcribed. The participants were males and females between the ages of 29 and 58 years. Four participants were married and six were single and all had children. Patients were already on antiretroviral treatment for the period of three months and above. All patients communicated clearly and expressed themselves in Tshivenda except two one who is a migrant worker and a foreigner used English, and the other one used Xitsonga. The participants were able to express themselves clearly in their own language as the researcher was able to understand and talk Tshivenda, English, as well as Xitsonga.

4.3 Identified Themes as experiences

According to Welman et al. (2005:211), themes can be described as umbrella constructs which are usually identified by the researcher before, after, and during data collection. After the researcher had compiled data, the challenge that follows was to reduce it into manageable and understandable texts. Table 4.1shows the an overview of identified main themes and sub-

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themes reflecting the experiences of HIV positive participants on ART treatment at in Thulamela Municipality in the Vhembe District of the Limpopo Province, South Africa.

Table 4.1 Themes and subthemes reflecting HIV positive patients' experiences on ART

THEMES	SUB-THEMES
1. DOMINANT NARRATIVES OF PERCEIVED FAMILY SUPPORT FOR HIV POSITIVE RELATIVE ON ART RESULTING IN FEELINGS OF DESPAIR AND THOSE OF BEING ACCEPTED	1.1 Negative experiences 1.2 Positive experiences with relatives
2. STIGMA AND DISCRIMINATION EXPERIENCES IN RELATION TO TAKING ART	2.1 Stigma and discrimination experienced from family members. 2.2 Stigma and discrimination experienced from community members. 2.3 Self-stigma and discrimination.
3. PARTICIPANTS' EXPERIENCES WHILE ON ART	3.1 Side effects experienced while on ART. 3.2 Long waiting experienced during scheduled appointments. 3.3 Difficulties accessing ART while in another area. 3.4 Effects of shortage of medical personnel in ART clinic. 3.4 Effects of medical examination in ART clinic. 3.5 Maintenance of confidentiality and privacy. 3.6 Creation of relationship of trust. 3.7 Financial constraints experienced while on ART. 3.8 Availability of ART versus lack of ART.
4. KNOWLEDGE RELATED TO ART PROCESS	4.1 Knowledge about ART taken. 4.2 Safety precautions while on ART.
5. DISCLOSURE OF BEING ON ART	5.1 Lack of disclosure to relatives and community members. 5.2 Fear related to disclosing taking ART 5.3 Lack of disclosure to sexual partners. 5.4 Benefits of disclosure and belonging to an

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THEMES	SUB-THEMES
	ART support group.
6. EXPERIENCES ON HEALTHCARE PROVIDERS' PRACTICES IN THE ART CLINIC	6.1 Pill counting practices not acceptable. 6.2 ART clinic a clean environment conducive for speedy recovery 6.3 Observation of safety measures. 6.4 Encouragement by healthcare providers. 6.5 Negative practices by Healthcare providers.

4.3.1 THEME 1: DOMINANT NARRATIVES OF PERCEIVED FAMILY SUPPORT FOR HIV POSITIVE RELATIVE ON ART RESULTING IN FEELINGS OF DESPAIR AND THOSE OF BEING ACCEPTED

The study findings revealed that there were by family dominant narratives of perceived family support related to patients' HIV positive relative on ART resulting in feelings of despair and also feelings of being accepted members. Participants had diverse feelings concerning family support on them taking ART. Sub-themes emerged during data analysis under this main theme which is: Negative experiences and positive experiences with relatives in relation to taking ART.

4.3.1.1 Sub-theme 1.1: Negative experiences with relatives

The participants indicated that they had various negative experiences regarding support from their family members. The negative experiences related mainly to accounts of negative treatments from family members, rejection of HIV positive relative leading to feelings of despair and HIV positive test resulting in divorce and separation. Most of these negative experiences were from their distant family members usually the in-laws and also immediate family members.

These experiences were confirmed by the following direct quotes from participants who said: "*My in-laws after realizing that I am on [ART] treatment they did not want to care for my baby, they did not touch him, touch my utensils when I was ill.*"

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Another participant explained that: *"The people I am living with they always say that I am ill and they do not know the illness, then they are unable to provide me with care and they scared to be next to where I am sitting."*

Another participant added by saying: *"They put food that I must eat and water in the house and go away without even talking to me as they seem to be scared of my HIV positive status and I feel like it better to die once because I have no one to care for me."*

In this study, some clients have shown how they lacked support from family and this led to have poor compliance. This was revealed by the participant who indicated that: *"My mother did not want to do anything with me and she expelled me from home, spending some of the days without food and without taking treatment".*

On contrary to the study findings sick people are comforted by being in their own homes and communities with family and friends around them (Van Dyk, 2008:333). However, HIV positive patients who are on ART find that at times they receive poor care from their family members.

According to Li et al. (2006:16), people living with HIV/AIDS on ART show to be in great need of family support and failure thereof impacts negatively on their health. Nghifikwa (2010:10) states that those people living with HIV are being shunned by family and thus can negatively affect treatment. Evidence has shown that people living with HIV/AIDS on ART treatment experience poor care from family due to fear of the family to get infected (Ekeji, 2010:28).

Additionally the study findings found out that in married couples an HIV positive result of one partner may result in a decision to either divorce or separate. The following statement gave evidence of the fact that the participant was divorced due to being HIV positive:

"My wife has just had a baby and I was about to start treatment. My wife had tested negative several times and on learning that I am positive she decided to go back to her home and finally divorced me."

According to Schatz (2005:1), Smith and Watkins (2005:659) state that knowledge of HIV itself may lead to divorce, as there are indications that rural Malawians are coming to see divorce as a means to protect themselves against being infected by an unfaithful spouse. In a study done by Allan and Cloete (2010:5), it was stated that women who disclose to their spouses to be taking ART face divorce or ejection from their home or even subjected to

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violence. A similar study by Fedor, Kohler, and Behrman (2012:21) revealed that spouses usually divorced each other after realizing that one was infected with HIV and on ART especially in rural Malawian women. In this study, most participants, usually females did not disclose to their partners and those who disclosed did not experience any problem as their partners were also been positive before them.

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4.3.1.2 Sub-theme1.2: Positive experiences

This sub-theme highlights participants` positive experiences they had from being accepted and supported by the family and relatives. Participants expressed their appreciation from the support they received from their family members and indicated that it made them to feel valuable and good seeing how they were being accepted by their relatives.

This was pointed out in the following quotes from participants: *"Yes my relatives were able to give me support; my mother even told me that I am not the first to have this sickness."*

Another participant who was accepted by her family also indicated that *"They also accepted my status and, therefore they take me as like any other people while they always reminding me to take treatment and accompanying me to the clinic to collect my treatment."*

In a study conducted in Thailand, it was found that women who were taking treatment were mostly supported by their immediate family members Liamputtong et al. (2009:7). The study found out that the HIV positive patients on ART were supported by their immediate family more than the extended ones.

Idolor (2012:40) concludes that the family is the only primary environment identified to curtail and prevent the spread of HIV and its effects on those who are infected and affected by HIV. It has further been stated that family support to those with HIV promote strong adherence.

Furthermore the study findings pointed out that reality resulted from the fact that relatives of the HIV positive clients provided them with support. Participants commented on the caring and supportive attitude of their relatives they were taking ART as prescribed. A middle aged woman who disclosed only to her children has this to say:

"When I am sick my children take care of me very well starting with giving me food and treatment at all times that I am suppose to take it." Another participant who had the same experience said: "*My firstborn is the only one who knows that I am taking treatment, she consoled*

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me and said, mama you are not the only one." The same participant further indicated that: *"My daughter will tell me, mom you are not the first and you are not going to die, you only have to accept the disease and take your medications".*

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According to Fredriksen-Goldsen, Shiu, Starks, Chen, Simoni, Kim, Pearson, Zhao and Zhang (2011:4) members with HIV were supported by their family members who always reminded them that they were valuable as persons; supported them financially for transport, health matters and medications; reminded them on follow-up care visits and setting alarms for time to take treatment; prepare their food for them and motivated and encouraged them.

In a study done in Thailand, it was found that women who were taking treatment were mostly supported by their immediate family members (Liamputtong, P., Haritavorn, N., Kiatying-Angsulee, and 2009: 7). This study found out that HIV positive patients on ART were supported by their immediate families more than the extended ones. Idolor (2012:40) concludes that the family is the only primary environment identified to curtail and prevent the spread of HIV and its effects on those who are infected and affected by HIV. It has further been stated that family support to those with HIV promotes strong adherence. Support by family members has shown to benefit HIV positive patients on antiretroviral treatment. In a study done in Yunnan Province, China Li *et al.* (2006:1) show how the family supported their HIV positive patients by starting on disclosure processes, medical health care, financial, psychological and support for daily activities.

4.3.2 THEME 2: STIGMA AND DISCRIMINATION EXPERIENCES IN RELATION TO TAKING ART

Participants in this study experienced some form of stigma and discrimination in relation to them being on ART. There are narratives by participants of being shunned by family or community; given none or poor care; their relatives uttering statements that lead to psychological damage which affect their compliance on treatment, and care. The following sub-themes emerged under this theme and are discussed subsequently below: Stigma and discrimination experiences in relation to taking ART by HIV positive patients from their family members, Stigma and discrimination experiences by patients from community members and self-stigma and discrimination.

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4.3.2.1 Subtheme 2.1: Stigma and discrimination experienced from family members

The findings of this study showed that HIV positive patients on ART were being stigmatized and discriminated against by their family members. Some participants revealed rejection, isolation due to of stigma and discrimination. In Venda culture, the birth of a baby is considered a gift to be celebrated for especially by the elders in the family. In this study, one participant showed how her mother-in-law did not want to care for her and her baby:

> *"I was put on ART when I had just delivered my baby. At home they could see that I am not well and everyday I am swallowing the pills. They did not want to care for my baby, they did not touch him, touch my utensils when I was ill and on ART. They said she is ill and we do not know the illness, we are unable to take care of her."*

According to Mlobeli-Dlakhulu (2007:69), families usually evict their loved ones with HIV and mostly it is young women who are rejected by parents blaming them of promiscuity.

The family may attach stigma and discriminate an HIV positive patient who is on because of ignorance of the disease and fear of infection. A female client stated how her mother evicted her from her home with her baby twins and she had no place to stay until she was helped by neighbors: *"My mother removed all my belongings from the house and ordered me to go away with my illness as I brought this on myself because I did not listen".*

Another participant had this to say about how his food eating utensils were treated: *"My plates and food were placed away separately from where others put theirs".*

Stigma and discrimination have fuelled the transmission of HIV and has greatly increased the negative impact of the epidemic due to increased poor adherence. Once rejected, the HIV positive patient has problems complying to treatment well or accepting themselves Aggleton,Wood, Malcom & Parker (2005: 4).

In this study, some clients showed how they lacked support from family and this led them to have poor compliance. One participant showed how her mother expelled her from home after she discovered that she was HIV positive and on antiretroviral treatment.

"My mother did not want to do anything with me and she expelled me from home, spending some of the days without food and without taking treatment."

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According to UNAIDS (2008:10), stigma and discrimination associated with HIV infection are based on lack of understanding of the illness; lack of awareness and knowledge of stigma; and fear of acquiring HIV through contact due to misconception about the spread of the disease and linking people with HIV with immoral behavior. The participant had this to say, *"My mother did not want me to stay in the house because I disclosed that I was HIV positive and taking ART"*

4.3.2.2Subtheme 2.2: Stigma and discrimination experienced from community members

HIV positive patients who are on ART suffer alienation and isolation due to the acts of stigma and discrimination. The Oxford Dictionary (2005:35) defines alienation as the state or experience of being isolated from a group or an activity to which one should belong or in which one should be involved. The findings of this study revealed that participants felt that they were at times alienated by people living with them in the community.

This is confirmed by the statements below: *"In my area people told their children to take care when playing with my children because I am HIV positive because they might be infected too. They told them that they always see me going to the clinic to take HIV medication"*

Another participant with the same experience indicated that: "*When there is a funeral and the women are gathered helping to cook for burial ceremony, people will not want me to cut vegetables for fear you will infect them when you accidentally cut yourself."*

Additionally another participant said: *"They refrain to buy at my spaza because they say I am HIV positive."*

Aggleton *et al.* (2005:9) explain that stigma and discrimination occur at various levels; the one occurring in community settings involves discrimination in which individuals act deliberately or by omission so as to harm or deny others of their rights or entitlements. Examples are shunning or avoiding everyday contact, accusations, physical violence, verbal discrediting, and blaming, gossiping, verbal harassment and denial of traditional funeral rites. Manala (2005:903) describes how HIV positive patients are still alienated by the health staff, church and community members were their clinic cards have stickers to indicate they are on ART.

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Additionally the study participants pointed out that they were alienated at work and in social gatherings by community member. When a person is alienated by friends, family and community, they become isolated from them.

These were confirmed by the participant who said that: *"People usually ask if am taking my treatment in a public place, why am taking this treatment because i look healthy and not ill. What I usually tell them is to mind their business."*

Aggleton *et al.* (2005:9) found that it was also identified that the community still alienated and isolated HIV positive patients at times even if they are taking treatment and looked well .

4.3.2.3 Sub-theme 2.3: Self-stigma and discrimination

Self-stigma is likely to make an individual more sensitive to both actual and anticipated rejection by others which negatively affect the way the individual feels even if the ART improved the physical health status. Disclosure of a person's HIV status and that one is taking on ART may bring positive or negative consequence on the self including self stigmatization.

In this study, some participants showed how they also experience negative perception of self and self-discrimination after realizing that there were people who knew about their HIV status. The following quotation illustrates the feelings of one participant:

"I felt very bad, people will look at me when I walk and I knew they know that I am HIV positive because my body had become disfigured due to ART." Another participant who has self-stigma aspects indicated that: *"I will take care not to wash myself using my mother's and child's washing basin for fear of infecting them."*

Another participant added by saying: *"I have to sleep alone in my room even when I was very ill because I felt free taking treatment without anyone asking but then I needed their support sometimes they declined. I had to go to the clinic alone without help even if was very ill for my family felt embarrassed to be seen with me as they will be associated with HIV/AIDS".*

Aggleton *et al.* (2005: 9) explained that self-stigma and discrimination or internalized stigmatization is when people living with HIV and on ART may internalize the negative responses and reactions of others and as a result attach stigma and discriminate themselves. This type of stigma and discrimination is described as 'felt' as it primarily affects an individual's or affected community's sense of pride and worth. For HIV positive on ART,

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this may be manifested in feelings of shame, self-blame, and worthlessness, which, combined with feelings of being isolated from society can lead to depression, self-imposed withdrawal, and even suicidal feelings.

4.3.3 THEME 3: PARTICIPANTS' EXPERIENCES WHILE ON ART

The study findings revealed that participants had diverse experiences while on antiretroviral treatment at the ART clinic which included both negative and positive experiences. Nine subthemes emerged during data analysis under this main theme. Participants' experiences while on ART emerged under this theme and the sub-themes are Side effects of ART, Long waiting experienced during scheduled appointments, Difficulties experienced to access ART, Effects of shortage of medical personnel in ART clinic, Effects of medical examination in ART clinic, Maintenance of confidentiality and privacy, Creation of relationship of trust, Financial constraints experienced while on ART; and Availability of ART versus lack of ART.

4.3.3.1 Subtheme 3.1: Side effects experienced while on ART

The study findings revealed that patients on ART are experiencing side effects as evidenced by the following quotes by the participants: *"I will take it at 7 o'clock in the evening and I will not see Generations (SABC 1 soapie at 20h00) and I will sleep until ..."*

Another participant added by saying: *"I now I have a big belly, I am big here (participant pointing) on top of my sides, yes I find myself too fat."*

Additionally another participants confirmed having side effects by saying: "*When I sleep I have terrible dreams such as, I see myself hanging committing suicide.*" One other patient commented: *"I am tired of swallowing these pills every day without resting; I wish the government to introduce them in an injection form where we will only get them on three month basis like contraceptives."*

According to FPD (2010: 201), most HIV positive patients may experience side effects in the first months of life. Patients need to be warned about those side effects and appropriate symptomatic treatment be given if necessary. Efavirenz is known to cause terrible nightmares and causing sleepiness. Tenofovir causes renal problems when patients take them. Furthermore, FPD (2010: 202) showed the life threatening side effects as follows: lactic acidosis, severe drug induced hepatitis, kidney toxicity, pancreatitis, severe drug rash from

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Nevirapine hypersensitivity, and Abacavir hypersensitivity. (Chizanga, 2010:115) reveal how the participants in their study complained about cosmetic changes which includes enlarged breasts, fats on the abdomen and wasting of muscles on the face which occurs when one is taking stavudine.

Further the study findings revealed that participants mentioned the effects of ART side effects on their daily life activities and relationships. The participant outlined that she do all the evening chores and then take the medication and sleep for fear of family members who can her up because Efavirenz has effects of one to fall in deep sleep. This was confirmed by the participant who indicated that: *"In the evening I quickly prepare everything needed for the family, eat and then sleep avoiding somebody will awaken me wanting something".*

Another participant with the same experience said: *"After using treatment you feel sleep and you do not want to be disturbed doing sex because the drug will be working, you see."*

There are several side effects experienced and this was revealed by the participant who indicated that: *"What is boring me is that I am losing weight even if I am taking treatment well and feeling well."*

Additionally another participant said: *"I have a lot of appetite, I like eating a lot, and at night I sometimes wake up and eat.*

ART was further seen as having side effects related to the desire to have sexual intercourse as one participant confirmed that by saying: *"I never care about any affection or romance due to ART because when you take them you fall asleep and do not have time for sex you know."*

In a research done in Uganda, Nakiyemba, Aurugai, Kwasa and Oyabba (2012: 40) revealed that participants were also affected by life style adjustments like eating all the time.

Previous findings by the same researchers Nakiyemba, Aurugai, Kwasa, and Oyabba (2012: 7) reported that most ART users mentioned experiencing ART side effects. According to a study done by Miller, Kethlapile, Rybasack-Smith and Rosen (2010:1), participants overwhelmingly reported that ART improved their health status and quality of life; side effects associated with ART were mentioned among others as barriers to treatment though less influential. According to WHO (2006: 6)in a study conducted among participants in Botswana the results showed that ART side effects were a serious problem to them, participants complained of rash, nausea and pains in the feet. Early symptoms include

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gastrointestinal and flu like symptoms, headache, dizziness, vivid dreams, rash and hepatitis, these can be expected in the first four months of treatment initiation and they phase away as time goes on (DOH, 2010: 19) Fox *et al.* (2009: 1) states that the majority of people on barriers accepting ART has identified fear of side effects and lack of belief for the need or benefits of ART treatment. This study has identified similar findings with other previous studies. The researcher noted that the participants were calm about their side effects even they complained about them, they had a belief that the side effects would go away as time went by. According to Gilbert and Walker (2009: 16), despite difficulties attached to ART, participants signaled their willingness to adhere to medication.

4.3.3.2 Subtheme: 3.2: Long waiting experienced during scheduled appointments

In this study the problem of long waiting times was cited as a challenge, especially because most participants stayed very far from the ART clinic. Participants cited the following reasons for waiting too long at the ART clinic: *"There was no difference from people who went to take treatment early in the morning and those who went late because they would go back home late in the afternoon. Sometimes you will be told the results are not ready repeatedly".*

Another participants with the same experience had this to comment: *"You come at the wellness clinic at 7o'clock in the morning and arrive home at 4'oclock in the evening what makes you wait longer is when you are being taken blood and waiting for results"* Additionally a worried looking man commented: "*My problem is that I have to take a day off because I will not be able to return to work on immediately on time. People at work will realize that I am not on duty if I decided to just go without telling anybody because I will return late in the afternoon."*

Only one participant said the waiting time was short:
"*It is not like when you go for the general consultation in OPD, here the nurses are fast to issue you with ART then within a short time you will be gone."* Participants reported challenges to the ART clinic working patterns, administrative and medical procedures, as well as difficulties in securing appointments because the ART clinic had fixed working hours and long queues.

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Participants felt their daily life activities were affected by these working patterns whereby they have to have a day off from work every month for collection of treatment. In the study done in Tanzania, the problem of long waiting time was cited as a major challenge to adherence of ART amongst ART users (Nsimba, Irunde & Comoro 2010: 5). Previous research by UNAIDS (2010:3) revealed that HIV positive patients in countries like Peru, Kenya and Tanzania experienced long periods of waiting for their refill of antiretroviral treatment. Botswana and Uganda had to wait for 4-5 hours in the public health sector but in the private sector they had to wait for only one hour.

4.3.3.3 Sub-theme 3.3: Difficulties experienced to access ART in another area

Confusion resulted from the fact that HIV positive client experienced difficulties to access the ART in the ART clinics because sometimes healthcare providers indicated that they were not available. This was confirmed by the following statements:

"*I went to Gauteng to colleting antiretroviral treatment, but the queue was too long and was cut just before me. Even on the next day I found out that there are many people already in waiting. These made me to leave trying to seek treatment, until one day I say to myself, let me go back home to Limpopo. At home I went to the hospital where they start from the beginning testing me and collecting blood again even if I have told them that I know my status, what I wanted was just to be given pills only. I thought they will just believe me and give me what I wanted, I started from the scratch.*" Additionally another participant who had almost similar experience had to say: "*I am a foreigner working in this country I came here with some ART. I was asked the referral note of which I did not have for I did not know I will come here in Venda so suddenly. They ask me to bring my referral letter and I could not go back to the farms where I was working and I had to miss some doses because they said they first process opening of a file, do blood tests and wait for the results.*"

This study revealed similar experiences found out by Yoder *et al. (*2009:40) where they state that a number of participants in their study confirmed they stopped taking their pills when they moved away far from home in search of a job or to live with other family members. HIV positive on ART present themselves to a new facility late when their treatment are about to be finished.

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4.3.3.4 Subtheme 3.4: Effects of shortage of medical personnel in ART clinic

Participants verbalized shortage of health personnel, especially doctors in the ART clinic. The participants had to be seen by several health personnel before going home depending on what was at stake concerning their health. They revealed how they would wait will in long queues awaiting for their turns to be seen by a doctor.

This was confirmed by the following statements: *"the number of nurses is better and when they finish assisting you, you have to wait to be seen by the doctor. The problem is that even if you come early in the morning you will be attended by the nurses but the doctor will come late at about eleven and the queue is by then long. There is only one doctor to attend all, and the patients are many so you will go home late."*

In their study Nsimba *et al.* (2010:5) revealed how the participants in the study were not even given quality counseling when collecting treatment to work overload. In Tanzania, one health personnel usually had to attend twenty-five patients at a time and as a results heavy workload affected the provision of quality counseling session. Furthermore, the health personnel became overworked and had difficulties in coping with the work (Nsimba *et al.* 2010:6). HIV positive patients on ART can be given treatment by nurses but there are those who need to be seen by doctors because of their problems.

4.3.3.5 Subtheme 3.5: Effects of medical examinations in ART clinic

Participants usually complained of going home late because of the procedures that were to be done to them. They explained like this,

"You have to go to the nurse for filling of forms and consultation, blood taken from you or you wait for the doctor."

"It depends on days, and if they want to take your blood, or go to the x-rays it make you wait until you go home late in the afternoon." Another participant with similar experience commented: *"Too short, it depends on days and procedures".*

Additionally participant had this to say: *"Every time when you go to collect treatment you think about; pain when they collect blood you become scared but when they tell you about improved CD4 you feel happy .Sometimes you feel it is better to miss appointment and go to*

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work because always reporting going to hospital at work is not good especially if they see you are well.''

Patients on ART face administrative and procedural problems in ART service centers or hospital. Administrative and procedures policies depending on different days of the week were stated as some of the factors affecting the time spent by the participants when they collected their treatment. According to FPD (2010:19), health workers have to do routine management of HIV positive on ART to evaluate the progress of the patient.

The following are some of the approaches to be done: history taking, physical examinations, and appropriate investigations like TB, Pap smear, and blood taking for CD4 cell count, HIV viral load, and liver function tests and keratinize clearance. Furthermore, the healthcare provider should give support according to the needs of each individual patient like family planning, immunization, and referral to any other health discipline if needed. (FPD 2011: 55)

Clients complained for longer waiting times because they were not aware of what the expectations were concerning assessment of their problems.

4.3.3.6 Subtheme 3.6: Maintenance of confidentiality and privacy

In this study clients showed that there was privacy of information as nurses did not disclose information unnecessarily. The following are narratives by patients which confirm their privacy while in the consulting rooms:

"the consulting are small but there is privacy inside, the only thing that bothers me is that sometimes a person comes in unannounced and obviously he will know that I have come for ART counseling.

One participant with similar opinion had this to say: "*It is obvious that he/she know that you are HIV positive because you are receiving treatment at a Wellness Centre, but there is privacy here. Here inside nurses speak in a low voice and no one can hear them outside. The door is always closed."*

The other participant looked satisfied as he said: "*The rooms are away from waiting area no one can hear that you are discussing about ART."*

Similarly another participant said: *"The nurses assured me that I can be free as everything we were talking about will be of my personal benefits and will not be divulged without my knowing. The counselor usually says what is discussed here remains within this wall."*

A good environment is necessary for a speedy recovery of any patient. Taking ART is a sensitive issue that a patient may easily turn off if there is not enough privacy in the consulting rooms. According to Standard Operating (SOP) in Cambodia HIV counseling

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rooms should ensure privacy; people outside the rooms should not be able to hear the voices inside; and the rooms should be closed (MoH, 2006: 6). Similar situation in South Africa provide that a nurse ensures privacy and confidentiality when dealing with a patient. The findings of this study are quite similar with what the SOP laid down to be followed.

The confidentiality of patients on ART is important because patients with HIV and taking ART face discrimination immediately when other people find out they have HIV. Confidentiality is the duty of the health care practitioner to protect the patient's information.

People with HIV/AIDS may choose not to seek treatment for fear that their personal information may be disclosed by their health care providers thus making the fight against HIV/AIDS a difficult one.

4.3.3.7 Subtheme 3.7: Creation of relationship of trust.

Participants explained about the trust they developed in the medication. This is confirmed by the following quotations:

"I trust these medications (ART) that they can work, previously I used to have diarrhea and vomiting but it is now all gone. I was very thin but now I am fat and I feel I can say whatever problem even my nurses I trust them, I feel free every time I come here with my problems."

Similarly another participant had this to say: *"Now that am taking ART I trust I can see the future, I am able to think about my future and the children future."*

According to Campbell et al. (2011: 11) many ART users have successfully built a rewarding and positive relationship with motivating and supporting nurses as regard to trusting their ART medications. Treatment availability makes ART users to have a renewed sense of social value including confidence in the hope for tomorrow.

4.3.3.8: Subtheme: 3.8 financial constraints experienced while on ART

Financial constraints as a subtheme emerged where participants showed concerns about the need for money for transport costs and food. This is confirmed by the following: *"I found out I did not get my pay gully for I did not go to work for two days because I was at hospital for blood tests and again for results. I am not working and I do not have money, before they are about to take me as a domestic worker they ask me if I am taking ant treatment and when I tell them they make excuses of hiring me."*

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Another woman said: *"I do not receive any grant but I volunteer and get only R650-00, sometimes it is difficult to get money for food and transport, but my mother always helps me. What I need is more money to buy enough food as I eat a lot even at night, what I usually have is not enough because ART makes you feel more hungrier"*

Additionally another participant had this to say about finances: *"I used to be unable to go to hospital for treatment, I did receive disability grant for asthma, and I used it for transport to collect my ART because I also had asthma."*

Another participant with similar experience said: *"I usually do not have money for transport to collect treatment but my mother always asks me if I have money for transport and she gave me, I do not have even if I do not ask".*

According to Cornet (2008:51), HIV positive people may need support such as, financial support, practical help with cooking, care, transport, and emotional backup and these include the family, friends, community, and HIV clinics.

Yoder, Mkhize, and Nzimande (2009:167) stated that participants in their study also lacked money, and they were assisted by social grant money, child care grant and helped by their families. They stressed the need for financial assistance for food as ART made them feel hungrier.

Zerfu et al.(2012:3) reported that participants in his study were assisted financially by being involved in small business/activities like agriculture given seeds and a sizable proportion of land, construction material, books and pens and clothing others were given loans to generate small businesses and food packets.

Subtheme 4.3.3.9: Availability of ART versus lack of ART

During the interview, participants revealed their satisfaction about the availability of ART at the Wellness Center. Participants showed how difficult or easy one could access the ART.

"The ART are usually available, I have never came and found it being stock out. It is easy to access if they have your file at the ART clinic. Once your soldiers (CD4 count) are down they register you for free. My problem is that the hospital is very far and I have to come here because of my problems." ART is available, my only problem is that they want see you every month even if you feel better if you ask for ART for more they refuse."

Differing to the findings of this study Mugisha, Ocero, Semafumu, Ciccio, Muwanika, Otim and Makumbi (2009: 4) in their study done in Uganda revealed there were HIV positive clients who still experienced ART drug shortages which increased the rate of loss to follow-

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up. In a report presented by Wells (2010: 4) to Myamar people, it was indicated there was still poor availability of ART in the rural areas and those who got them found them from NGOs or private clinics. Furthermore, accessibility criterion for receiving was also very difficult and most patients died while still on waiting lists for treatment. According to Hardon and Daniels (2006: 8), instances of stock out of first line antiretroviral drugs have been reported throughout the country and this did not only diminish the likelihood of positive outcomes but threatened the sustainability of the ART programme as people may develop drug resistance.

4.3.4 THEME 4: KNOWLEDGE RELATED TO ART PROCESS

All the participants had something to talk about the ART namely; what are ART drugs, how Art works and safety precautions concerning it. This study revealed that participants had some knowledge regarding how art works. These are shown by their statements as follows,

"AIDS is a disease spread by sex if you do not wear a condom and it does not heal, if one takes ART, HIV become defeated and become unconscious then it is unlikely for you to have AIDS illnesses."

Another participant said, *"Antiretroviral treatment does not cure but they make an HIV virus not to have strength to destroy life, by making it unconscious"*.

According to Mlobeli-Dlakhulu (2010: 93) generally people are aware of AIDS but they lack completely accurate knowledge about it, and this lack of medical knowledge about HIV nurtured negative behavior against people on ART.

4.3.4.1 Subtheme 4.1: Knowledge about ART taken

Knowledge about ART emerged as a subtheme during data analysis.

One woman explained like these; *"I do not know them by their names but I know a certain one which is like a drug, Efavirenz, it makes me feel sleepy. We are given three types of pills which we have you take morning and evening"*

One participant said with similar experience had to say: *"I do not know them by names, I know only Efavirenz because it makes me dizzy."*Another one said: *"There is a one night*

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drug Efavirenz, I can identify other two drugs as I see them but I do not know their names. They gave us information about ART; they say ART does not cure AIDS."

One participant said: *"They gave us information about ART, they say ART does not cure AIDS but they render the HIV to be powerless by suppressing it as long as you are taking medications every day."*

One young man had this to say about what was taught to him: *"A nurse told me when you use ART you will never be ill of AIDS because the HIV remains unconscious as long as you take treatment.* He further added: *"These things are easy to forget, some words are very difficult, I wish if there booklets to take home for our family members or friends to read what we are taught here so that we gain the same knowledge".*

Serekoane (2010:35) states that inadequate knowledge to treatment also poses as a challenge to continuity of care. Furthermore, he illustrated that the high levels of adherence are associated with high levels of general knowledge about ART. Gupta *et al.* (2010:3) stated that of 207 participants studied on knowledge of ART only 134 could name only one ART drug correctly of all the drugs they were using. Kagashe and Fazal (2011:1) also found that few patients in Tanzania knew about the names of the treatment they were receiving. HIV positive patients like any other patient respond well to treatment adherence when they are given information about the treatment. Even though they did not know much about the names of ART, findings of this study reveals that participants knew that ART did not cure but only suppressed the HIV activity thus reducing the opportunistic infections.

4.3.4.2 Subtheme 4.2: Safety precautions when on ART

The participants verbalized on how being HIV positive and taking ART demanded them to change how they used to do things.

"The nurses told me to practice using condom always when having sex to protect my partner and to prevent myself from getting new viruses. The nurse told me to keep my phone battery on all the time so that the alarm will ring to remind me of the time for treatment always."

According to WHO (2006:6) information giving about ART is a major influence of preventing the spread of HIV disease. According to an Updated Antiretroviral Guideline (2010), HIV transmission when one is on ART becomes very low if the viral load has gone

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below undetectable limit. There is 96% prevention rate, which is why it is necessary for an individual to continue to protect himself even when he/she is taking ART.

4.3.5 THEME 5: DISCLOSURE OF BEING ON ART

The following subthemes emerged under this theme: Lack of disclosure to relatives and community members; Fear related to disclosing of taking ART, Lack of disclosure of taking ART to sexual partners; and benefits of disclosure, and belonging to a support group.

The narratives of the participants will be discussed in full in the subsequent subthemes below;-

4.3.5.1 Subtheme 5.1: Lack of disclosure of taking ART to relatives and community members

During data analysis the lack of disclosure of taking ART emerged as subtheme.

One participant said, *"I did not tell anyone that I am HIV positive and taking treatment, I did not tell my child but I could see that he checks my pills and he knows something about my illness."*

One participant said *"I did not tell anybody, I told myself that as long as I know what is the problem with myself and I am taking treatment is ok.""I am afraid if I tell other people they will say things about me. People like to look down upon somebody because of her being ill and taking treatment."*

Disclosure is a very important factor in the context of prevention and adherence to ART Cloete, Strebel, Simbayi, Van Wyk, Nenda & Nqeteko (2010:42). Furthermore, Cloete *et al.* (2010:1) revealed that AIDS-related stigma is associated with difficulty of disclosure of an HIV status for fear of rejection. Patients on ART lived in fear of being rejected and were not free to disclose that they are taking treatment to the family and the community.

4.3.5.2 Subtheme 5.2: Fear related to disclosing taking ART

HIV positive status still carries a lot of stigma in such a way that participants were afraid to disclose for fear of being stigmatized and discriminated against. Some of the participants had the following reasons for not disclosing:

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"Another participant decided to disclose an unknown, this is what she said: I told another person whom I met at the hospital that , I am HIV positive and I am on ART I am afraid to tell anyone who knows me." I hid my pills so that no one should know that I am on ART."

According to Moratioa (2007:28), patients who fear rejection and isolation do not reveal their HIV status to their families, health workers for fear of rejected and this experience affect how they take their ART. According to Cloete *et al.* (2010: 3) HIV positive patients are still afraid to disclose their status; reluctance and anxiety to disclose HIV positive status and fears of being discriminated against are evidence of the persistent nature of AIDS-related stigma which also poor compliance. Furthermore, Cloete *et al.* (2010: 3) state that these AIDS-related stigmas remain the barriers to curb the spread of HIV/AIDS among those who know their statuses.

4.3.5.3 Subtheme 5.3: Lack of disclosure to sexual partners

In this study, it was found that stigma and discrimination were still prevalent as some of the participants did not disclose to their partners to avoid rejection, stigma and discrimination. One participant had this to say about disclosing:

"I did not want to tell my wife for fear she will leave or divorce me. I hide my pills from her so that she will know the type I am using. I put them inside my pillow so that she would not find out." Another male participant reported *"My wife decided to leave me as soon as she found out that I was taking ART because she had tested negative."*

Divorce is the final termination of marriage of a marital union before death of either party. HIV status aware couples with at least one HIV positive partner are however characterized by high separation or divorce rates with its implications for the spread of HIV (Reniers & Ambruster, 201:1).According to Nsimba *et al.* (2010:5), disclosure to partners by HIV positive patients has the following potential risks: loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationship. Lack of disclosure to a partner due to fear of stigma and discrimination is tied to fear of being accused of infidelity, rejection and violence (Nsimba *et al.,* 2010: 5).

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In this study, the participants revealed incidents of being rejected by the partner due positive HIV status.

4.3.5.4 Subtheme 5.4: Benefits of disclosure and belonging to a support group

Participants in this study showed how they benefited while attending these support groups. One participant had this to say, *"The nurses introduced me to other patients who were sick, at first I was depressed seeing those very thin patients, but when others shared their experiences I felt relieved."*

One participant with similar experiences looked happy as she explained: *"I learned a lot from other patients who had experiences, thus building my hopes that I will also see the future."*

The other participant said: *"In a support group we live like a family, I felt love unconditionally even though I have HIV and on ART everyday."*

According to Moskowitz (2003) in Ndala-Magoro (2010:24), support groups prepare HIV positive patients for the acceptance of their status, treatment adherence, and endow them on adjustment with positive lifestyle living. According to Liamptuttong, Tantavorn, Kiatying-Angsulee (2009:6), in the study done in Thailand, it was found that support groups for people living with HIV provided emotional support to many and the members of the group learned more from others. Learning from their peers made these people living with HIV stronger and feel they were not alone. Furthermore, Liamputtong *et al* (2009:7) identified that support groups gave the people living with HIV a sense of belonging.

In another study done by Heyer et al. (2010:237), they showed that the participants in their research revealed how support groups had benefited them emotionally by having freedom to share their experiences with others, having a sense of belonging and developing friendship that progressed beyond the support group. In the study by Ndala-Magoro (2010:54) it was identified that participant saw support groups as a means to impact on their behavior on lifestyle changes and a platform to share (Ndala-Magoro, 2010:54).

4.3.6 THEME 6: EXPERIENCES ON HEALTHCARE PROVIDERS' PRACTICES IN THE ART CLINIC

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Participants in this study expressed both positive and negative experiences concerning the practices of the nurses in the ART clinic. Participants reported non-professional practices as well as good practices from the nurses. The following were the subthemes that emerged during data analysis: Pill counting practices not acceptable, observation of safety measures; provision of care to the needy; and negative practices by the health care providers.The subthemes are discussed subsequently below.

4.3.6.1 Subtheme 6.1: Pill counting practices not acceptable

Participants appreciated the general cleanliness of the environment of the ART clinic; however, they verbalized their feelings for a disgusting practice made by nurses to count their medications using their unwashed hands and then expect them to start by taking those pills at home. They felt that they were contaminating their pills. One participant had this to relate:

"One day the sister put my pills down on the table, started counting using her hands unwashed, and then tells me, you should start by taking these old ones before the new ones. Some of the pill fell onto her lap and she took them and continued as if there was nothing wrong. I felt it very disgusting that I have to swallow them when I reach home"

Another participant showed how he observed a nurse just taking a piece of a paper and counts his pills without following the correct procedure.

"I felt bad when my pills were put in a piece of paper and counted using bare hands, why don't they use plastic/wooden things to count them."

Pill counts are often used to measure adherence of patience to treatment (Achieng, Musangi, Billingsley, Onguit, Ombegoh (2013: 1). According WHO (2013:30) the standard for good dispensing states; using hands is bad practice for both hygienic and product quality reasons, furthermore counting should be done using clean piece of paper and clean knife or spatula, clean tablet counting device, lid of the stock container and or any other clean dust free surface.

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4.3.6.2 Sub-theme 6.2: ART clinic, a clean environment conducive for speedy recovery

Positive remarks were stated by the participants in relation to the environment and cleanliness maintained by healthcare providers at the ART clinic. A participant confirmed that by saying, *"The rooms were clean, they were not dirty." "It was always clean, chairs dusted all the time."* The participants in this study showed how the counseling rooms and pharmacy were clean: *"I always find that the wellness care clinic is clean."*

It is of crucial importance that the health facilities be kept clean for the health of the HIV positive patients on ART. According to Standard Operating Procedure (MOH, 2009: 8) HIV counseling rooms should ensure privacy; people outside the room should not be able to hear the voices inside the room and the rooms should be closed.

The rooms should be free from dirt, smoke or any other thing like water spilling now and then from the basins.

4.3.6.3 Subtheme 6.3: Observation of safety measures in relation to ART

Participants related stories that showed they did not experience any problems concerning observation of safety measures in the ART clinic. The following quote illustrates this: *"The nurses check your name when issuing your medicines and ask if what they giving are the correct medication which you usually receive."* Additionally another one said *"I was never given expired medication."*

"I have never heard anyone fell due to slippery floors. Sometimes when you want to pass the cleaners will ask you to use another way or put a warning showing it is wet."

There were other participants who mentioned observation of safety about the storage of sharps: *"They put all needles and waste away free of reach from the patients."*

Sheahan (2012:1) argued that in order for medical facilities to effectively secure patients' safety, they should identify and eliminate known hazards by using adequate cleaning and disinfectant procedures and standardized measure for needle and waste disposal. In this study, participants felt safe and they showed how needle and waste disposal were used. Jackson (2010:854) revealed how the participants in her study showed that they lacked physical resources as the clinic was too small and there was no shelter during rainy and windy days.

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4.3.6.4. Subtheme 6.4: Encouragement by healthcare providers

Overall participants in this study indicated that they did not experience any negative attitude towards the staff in the ART clinic. Participants reported themselves being accepted by the staff irrespective of their HIV positive status. They felt that nurses' encouraged them to take HIV as any other chronic illness that could be managed and controlled by ART.

Although negative attitudes by staff towards clients have been documented, this study has found that most participants reported good attitudes towards them. Some of the participants reported staff attitudes towards the HIV positive patients on ART as that of acceptance and friendly.

The following quotes illustrate this: *"They accepted me as who I am. They told me to compare ART as any other treatment for other chronic illness like hypertension and diabetes which are also taken daily for a lifetime period."*

Another client with similar experience said *"The nurses were friendly and informative about taking ART. They just tell me that ART is like any other medications for chronic illness and were friendly towards me."*

Another participant was grateful for the acts of the staff: *"The staff was friendly towards me as a patient. They accepted me and encouraged me to continue taking treatment, they even show me others who are sick like me and are now well I felt encouraged and grateful."*

Attitude has been one of the central areas of study on HIV/AIDS due to the impact it has on the health service. The study findings of Aghamolaei, Tavafian, Hasani, and Zare (2009:299) revealed that the health care providers had positive attitudes towards patients with HIV. According to Stein (2003:6) there is some survey evidence suggesting that HIV/AIDS stigma has already diminished substantially over time both in South Africa and worldwide due ART. Two surveys conducted in South Africa identified decreasing HIV/AIDS stigma in the general population. Furthermore, Stein (2003:2) stated that South Africans are adopting accepting attitudes towards people living with HIV/AIDS. The researcher in this study found out that the participants experienced health care providers and family as encouraging.

4.3.6.5 Subtheme 6.5: Negative practices by healthcare providers

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One participant related how he experienced negative attitude from the nursing staff while he was admitted in the hospital ward. The following is the quotation: *"When I was admitted in hospital I felt very much isolated as the nurse has to put on more gloves when coming to examine me whereas on handling other patients he only put on one pair. I did not like to associate with other patients in the ward because of different treatment."*

Manala (2005:903), described how a patient in hospital was put aside in his own ward, staff afraid to touch him because he had HIV/AIDS.

A study conducted by Aghamolaei et al. (2008: 4) revealed that most health care providers showed positive attitude towards patients with HIV and taking ART; however those who showed negative attitudes reported fear of infection as the major problem. Health care providers need to be notified if the patient is having HIV and or taking ART so that they can apply better protective measures not to be infected. According to Mlobeli–Dlakhulu (2007: 77) the participants in her study revealed that they were often shouted at by healthcare providers and sent home without help especially when the counselors were not around. Their health records were marked with colored stickers in order to identify their positive HIV status, Mlobeli-Dlakhulu (2007: 87).

4.4 Summary

In this chapter experiences of clients on ART were explored and described. The study provides a rich description of experiences of HIV positive patients which emanated from the process of data collection and analysis from the main six themes which emerged as follows:

Theme1 focused on perceived family support while taking ART by participants for which they had diverse feelings about it. Participants had either negative or positive feelings on family support on taking ART.

Theme 2 Participants verbalized incidents of being stigmatized and discriminated by family, friends, partners and community due to them being HIV positive and taking ART. Reasons for being stigmatized and being discriminated emanated mostly from their HIV status.

Theme 3 Issues such as side effects of ART, difficulties accessing ART due to long waiting hours for collection of treatment, shortage of medical personnel and financial problems for buying food and transport to ART clinic were discussed.

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Theme 4 focused on the knowledge the participants had on the processes of ART. Topics like how names of different ART drugs, how they work, and what lifestyle to adjust when taking them were discussed.

Theme 5 discussed the issues of disclosing when one is on ART and the advantages of belonging to a support groups.

Theme 6 focused on the experiences on health care provider's practices at the ART clinic. Participants discussed the clinical procedures performed by nurses and their attitude towards those patients taking ART.

4. 5 Conclusions

This chapter focused on the discussions of the data that originated from interview sessions conducted and the themes that emerged from data analysis of the study. The experiences of HIV positive patients on ART were described in the following themes: Dominant narratives of perceived family support for HIV positive relative on ART resulting in feelings of despair and those of being accepted, stigma and discrimination experienced to ART, participants' experiences while on ART, knowledge related to ART, disclosure on being on ART, experiences on health care providers' practices in the ART clinic. Their experiences as discussed were both positive and negative experiences as described by HIV positive patients on ART under six identified themes. The chapter that follows will outline the summary, guidelines and recommendations.

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CHAPTER 5:

SUMMARY, GUIDELINES, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

During this study, HIV positive patients were interviewed with regard to their experiences on ART. Data generated was analysed and reported in Chapter 4. Six themes and their sub-themes were discussed in Chapter 4 and included (see Table 4.1) Dominant narratives of perceived family support for HIV positive relative on ART resulting in feelings of despair and of acceptance, Stigma and discrimination in relation to taking ART, participant's experiences while on ART, knowledge related to ART process, disclosure of taking ART and experiences on health care providers' practices in the ART clinic. Chapter 5 therefore evaluates the study against its purpose, objectives and summarizes the main findings, gives conclusions and recommendations that might be considered to solve problems experienced by patients who are on ART.

5.2 Research Summary

The title of research was the experiences of HIV positive patients on antiretroviral treatment in the Thulamela Municipality of the Vhembe District of Limpopo Province, South Africa.

Problem Statement

HIV positive patients on ART have issues in relation to taking treatment, in their families, community and when attending ART clinic. They come to the clinic very weak alone without support of family members. They have problems accessing ART and adherence is sometimes difficult.

Purpose of the study

The purpose of the study was to explore and describe the experiences of HIV positive patients on ART and to develop guidelines which might be used to support and care for HIV positive patients on ART at the Thulamela Municipality in the Vhembe District of Limpopo Province in South Africa. The experiences of HIV positive patients on ART were explored and described in this study against the literature of the relevant field.

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The following question guided the study:

- What are the lived experiences of HIV positive patients who are on ART at Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa.

The objectives of this study

- Explore and describe the experiences of HIV positive patients who are ART
- Propose recommendations on the establishment of care and support of services of HIV positive patients on ART. The objectives were addressed by using qualitative research design which was explorative and descriptive of the experiences of participants. Recommendations were also proposed which might help in the care and support of HIV positive patients who are on ART.

Research design and methodology

The researcher used a qualitative research approach to achieve the purpose of the study. Purposive sampling was used to obtain relevant participants who met inclusion criteria. Data collection was done through conducting interviews. The information was recorded on audiotapes and transcribed. One central question guided the study and was followed by probing, paraphrasing, nodding asking for clarity as a means for facilitating communication. The data analysis was done following Tesch's open coding technique and measure to ensure trustworthiness was observed (Lincon and Guba 1985: 216). The researcher observed and followed ethical issues.

5.3 Findings and Conclusions

The summary of findings and conclusions of the themes that have emerged during the data analysis using Tesch's open coding method were discussed in chapter 4. Six themes emerged and are dominant narratives of perceived family support related to patients' HIV positive on relative on ART resulting in feelings of despair and also feelings of being accepted stigma and discrimination in relation to taking ART, Participants' experiences while on ART, Knowledge related to ART. Disclosure of being on ART and experiences of HIV positive patients on health care providers' in the ART clinic were described subsequently;

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Theme 1: Narratives of perceived family support for HIV positive relatives resulting in feelings of despair and those of being accepted.

The feelings of the participants concerning family support were diverse because some felt that they obtained no support or poor support was experienced and they were being stigmatized, discriminated against leading up to divorce and rejection by their family members.

Participants showed that some of the family members reacted negatively because they feared they might get infected with HIV also. These negative reactions by family members made some of the participants not to disclose their status at home. However, there were participants who revealed that they were accepted by their family members. The participants stated that in certain cases they were spoiled with the supplies as a way to encourage them not to stop treatment. Their relationship bonds increased and these led them to see how valuable their lives were to their family. Mhlongo (2010:67) recommends that the role of the significant others is very important in motivating patients for treatment. Zerfu *et al.* (2012:6) suggest that it is important for families to accept people living with HIV and not ostracize and judge them.

In summary, this study found out that participants experienced negative treatment such as lack of support, rejection and divorce because their families had fear of HIV infection and being stigmatized because of lack of knowledge on the spread of the disease.

Theme 2: Stigma and discrimination in relation to taking ART

HIV related stigma and discrimination have accompanied AIDS epidemic from the start and experience with it has reduced individuals' willingness to practice prevention, disclose HIV status to others and to adhere to ART treatment (Charles, 2009:14). Banda (2010:9) recommended that in order to alleviate issues of stigma and discrimination which is also common in some congregations in Zambia, sermons and songs are used were people living with HIV and AIDS feel they are unloved and have resulted in isolation at home. The sermons and songs assist in alleviating suffering experienced due to stigma and discrimination.

According to Liamputtong (2009:4), women are more stigmatized and discriminated against than men and people believe they got the disease from sleeping around with men other than their husbands and that effect he suggest that education related to the subject be given.

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This study found out that participants were experiencing discrimination from their families and communities. Both men and women were all stigmatized and discriminated against. Charles (2009:15) states that self-stigma and discrimination relating to personal, social, and emotional aspects of a person which must be dealt with during treatment initiation. The community members must be educated related self-stigma and discrimination. Even though people did not say anything, they felt people were 'looking at them' and tended to isolate themselves from other people. The communities and families with people living with HIV and AIDS need special or intensive attention and education to reduce fear resulting from lack of knowledge.

Theme 3: Participants experiences while on ART

According to Nakiyemba *et* al. (2009: 46), side effects often appear with the initiation of ART and disappear over time. In this study some participants experienced side effects which affected their physical and psychosocial wellbeing. Those who experienced side effects were able to tolerate them because they were warned about them before starting with ART. However, the benefits of ART in their bodies were said to be encouraging them to take treatment despite the side effects as they experienced better health after some months of taking treatment. The participants did not stop taking treatment because they realized that the benefits of treatment outweighed their side effects. Emphasis must be on enhancing education given to patients at all times.

The problem of long waiting was also mentioned as a major challenge. The health care managers must come with the improvement plan to shorten long waiting hours.

Shortage of personnel, logistic and administrative procedures was also mentioned to be the causes. It is suggested that more posts for doctors be created for community care on specific days for patients on ART to be followed up at their respective local clinics if possible

Participants did not relate/discuss a lot of other staff members other than nurses and doctors. The healthcare managers must motivate all health professionals to become actively involved in ART activities in order to motivate the patient on ART as collective.

Few participants related on how difficult to access ART because of administrative procedures if you were from another area, requesting them from a new facility. Miller et al. (2010: 12) argue for interventions in policy changes with regard to simplifying referral and transfer

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systems that the health care managers must be sensitive for the clients who are visitors and were taking ART from other areas.

The study revealed that participants were satisfied about the confidentiality, privacy, and trust received from the healthcare providers. Participants related how the nurses maintained a low tone while consulting with them inside closed rooms. What disturbed them was interruption by people coming inside during a session abruptly disturbing a session by wanting to discuss something with the staff. It is appreciated that there are must maintenance of confidentiality, privacy, and trust. The interruptions must be limited or eradicated during consultations with patients on ART. It is suggested that posters be provided at wellness centers be placed on doors when there are counseling sessions like "**do not disturb counseling sessions on**" the staff and visitors will need to be educated on the importance of complying with such posters. Another major concern that participants had was financial constraints that made it difficult at times when they went to collect treatment. It is recommended that doctors follow up patients with problems at their local clinics on specific days.

Theme 4: Knowledge related to ART process

The level of awareness and knowledge an individual has on a particular aspect how determines he/ she will react to that aspect (UNAIDS 2007: 7). Furthermore, in this case knowledge concerning what constitutes ART, names of ART, symptoms and safety precautions and lifestyle adjustment when taking ART will influence how the patients use ART. The study findings revealed that participants were poorly knowledgeable concerning the names of ART they were receiving but they did know some of the names of the drugs they are taking, safety precautions, and lifestyle adjustment when on ART. The staff should always conduct ongoing information giving to HIV positive about the ART they are taking. The study findings further revealed that participants confirmed they were told about what to expect from medication and the information given was valuable as it enriched their knowledge about what ART, their purpose and how they worked in the body. It is suggested that the health professionals should always update the information or knowledge that the participants are having on continuous basis in relation with the new developments about ART. However, participants found lifestyle adjustment when on ART rather difficult but possible to follow if one was committed. Continuous motivation on life adjustment will help patients to adjust.

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Theme 5: Disclosure of taking ART

Most participants had problems with disclosure that they are ob ART, their families were shocked on hearing the news, and they somehow underwent stages of denial until ultimately they reached acceptance. However, not all the participants were willing to disclose. There were those who decided not to disclose to anyone and only disclosed to an unknown member of a support group in order to get medication.

Those who disclosed opted to talk only to immediate family members, usually their children, their mothers and only a few disclosed to their partners and other family members. This study's findings are similar with other studies, Li *et al.* (2009:7) reported that when participants had decided to disclose, they chose those relatives they trusted the most and those that they had strong relationships with and they usually ranged from parents and aunts, spouses and siblings. It is suggested that the healthcare professionals should help establish support groups for HIV positive patients on ART wherein disclosure should be addressed.

Furthermore, disclosure of an HIV status and that one is taking ART has both positive and negative impacts on how it affects families. Negative impacts include feelings of fear, shame, and stress by HIV positive patients, and their families. Additionally these feelings cause family members to isolate and/or avoid HIV positive patients on ART, and patients to withdraw themselves from the family and society and cause a psychological burden for the entire family. In this study, participants' reasons for non-disclosure or disclosure only to immediate members were fear of rejection, stigma, and discrimination. It is recommended that intensive education programs be established from the local clinics or villages and be targeted on affected families whose member is on ART in order to alleviate feelings of fear and shame.

Participants showed the evidence of being rejected by their other family members. Some of them showed evidence of being rejected by their partners and even by close/immediate members of their families. Few participants confirmed disclosing to their partners. It is suggested that couple counseling must be done continuously during ART until other members understand.

Participants also showed that they were sometimes withdrawn from the community due to stigmatization and discrimination. They, as a result were alienated and isolated at times from social gatherings for fear of being looked down upon by the community. It is recommended

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that talks on HIV/AIDS and ART be addressed in places like schools, church, village meetings in the chief's kraal, civic meetings, burial society, and family coming together and at stokvels. (2010:6) suggest that stigma and discrimination as an undesirable or discrediting attribute that an individual possesses must be dealt with which may result in reducing the act by the society.

Some families label their member who is on ART as deviant and thus think they should be left alone to suffer as they have brought the illness to themselves. It has already that intensive educational programs be established for affected families, it is suggested that the topic of these programs be named *"do unto others as you would have them do unto you."* This name might help affected community, families, and friends to put themselves in the HIV positive patients on ART and always realize the impact of having compassion to one another.

According to Li *et al.* (2007:8) recommends disclosure because it may have positive impacts upon the family. It strengthens family relationships and generates support for PLWHA. Furthermore, Li *et al.* (2007:8) suggest that participants must disclose to family in order to receive support and most families help HIV positive patients with medical care and provide counseling. Participants will benefit from disclosing their HIV status and being on ART to the family because they are likely to get support.

Participants are encouraged to belong to support groups because they will feel like they are united in a family of other people who are on ART.

Theme 6: Healthcare providers' practices in the ART clinic

It is advisable that healthcare professionals accept and treat the patients who are on ART well because it reduces emotional problems.

According to Sadoh *et al.* (2006:45) negative attitude, beliefs and values or misinformation limit a caregiver's ability to provide effective, respectful and dignified services for the PLWHA and their families.

Some participants pointed out that it was disgusting how nurses counted their pills with unwashed bare hands. One particular participant felt very hurt when a nurse wore more than one pair of gloves when coming to help him. He felt isolated and as a result he was withdrawn from others because he felt he was being treated differently from others. Both participants reported satisfaction that the ART clinic was a clean and safe place to attend for their health needs and cleaners communicated with them if the floor was wet or slippery. The health care managers should provide with pill counting devices like boards or trays, suitable

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papers and spatulas in all consulting/counselling rooms where pill counting is likely to occur. Hand washing drills should be done always to remind the staff about its importance. Furthermore, the participants reported that they were invited to support groups to learn about the experiences of other PLWHA and the details of the HIV disease. It was also mentioned that the support groups were welcoming, informative, and supportive to the HIV positive patients

The researcher has gained a clear picture on the experiences of HIV positive patients on ART during the interviews with participants. This study has recommendations based on the experiences of the HIV positive patients from the data collected during interviews; the researcher's experience in the workplace; the previous protocols and care of persons living with HIV and the final findings of the study. The study found out the participants needed support from their friends, family members and the community as a whole. Participants also felt that some practices in the ART clinic were unacceptable, where their pills were handled using bare hands and the shortage of personnel in the ART clinic.

5.4 Recommendations

The recommendations are discussed based on the rich data identified and described during interviews with HIV positive patients on ART and the researchers's experiences. These recommendations were drawn to ensure that the care of HIV positive patients on ART might be improved. Health care services should be shaped by what matter most to patients rather than what the health care providers feel it is best for them. The following are the recommendation this study is proposing;

5.4.1 Recommendation on establishing and maintaining a therapeutic relationship between the family and HIV positive patients on ART.

This recommendation is discussed in response from problem identified in theme 1, 2 and 5. Participants felt a need of family support when taking treatment, lack of disclosure due to fear of being stigmatized, however they lacked that support and at times they were rejected and sometimes ill treated. Therefore is recommended that:

- A peer network system to be put in place that can be used to disseminate information on ART awareness in churches, schools, workplace, police and military places, youth centers, stokvel, clubs and family gathering meetings.

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- Intensive care of affected families should be done where a planned handing over programme of HIV positive patients on art is made is to them and face to face the family will be explained what their role is in motivate their member to adhere to treatment.
- Confidence building health programs in a form of talks, coaching, sports games, where HIV positive patients should participate.
- Couple counseling should be continuous and should include, issues like prevention of re infection, reproduction needs, family bond, and discordant results.

5.4.2 Recommendation on managing side effects by health care staff.

HIV positive on ART need more assistance in monitoring and treating side effects as they arise as skipping because as symptoms develops skipping or stopping them may cause resistance (Yoder, Mkhize and Nzimande, 2009:69) Participants complained of disfiguring side effects while taking art this can affect adherence of therefore it is recommended that:

- Side effects should be discussed in support group classes for patients to can identify them earlier and know what to do. Affected family members should be taught how to identify side effects of ART in order to can assist their member who is ill.
- Nurses and lay counselor should be updated on ART side effects and their management assessing the side effects of ART every time the patient comes for treatment.
- Side effects should be treated rapidly as soon as they are observed.

5.4.3 Recommendation on establishing and maintaining a working environment that is conducive for speedy recovery of patient in order to render a good care and support.

The good environment include physical and psychological aspect other patients (Jackson 2009:100). The nurse can ensure this by:

- Discuss with other staff members on how to improve the physical environment.
- Ensuring that there is hand washing basins with source of water and soap in the counseling rooms all he times and there are hand washing drills continuously to ensure all the staff follow hand washing procedure correctly.

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- Ensure that there are minimal or no interruptions during counseling sessions by planning strategies such as use of barring cards on the doors.
- Make waiting areas stimulating by educational pamphlets to read and take home, posters and videos to reduce complaints on long waiting. The client should be taught at their own language also considering their level of education.
- The nurse should practice correct procedures in caring patient especially when wearing gloves they should not stigmatized those who are HIV positive.

5.4.4 Recommendation for nursing practice

Participants were disgusted when nurses did pill count: touching them with their bare unwashed hands. Provisions of pill count boards and spatulas should be provided in the consulting rooms instead of using books, scrap papers, and dirty hands. Barring cards or posters should be placed on doors when there is a counselling session to avoid unnecessary interruptions by an outsider. The staff should protect themselves with gloves only where necessary but should avoid being impartial to patients like wearing more than one pair to one patient while using one pair of gloves to all others. Participants felt that the outsider might associate them with HIV or accidentally hear what was being discussed in the room. The following recommendations constitute strategies on improving nursing practice:

- Training of nurses on care and support of HIV positive patients on ART especially on; providing privacy, good dispensing technique, counseling, and universal precaution matters.

5.4.5 Recommendation for health education

There seemed to be inadequate knowledge regarding the spread of HIV infection and ART by the family and some of the participants. Stigma and discrimination arises due to fear of HIV infection and death. One participant wished that those on treatment could be given booklets to give their family members in order to read on HIV infection and ART especially on the spread of HIV infection and ART side effects. Therefore:

- Healthcare providers at local clinics and villages should identify and include families with persons living with HIV and should give them an intensive health education concerning their needs with their infected members.

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- This study also recommends that the health education should include topics like do unto others, coping with HIV/AIDS and lifelong ART, avoiding internalized shame and depression and how families can support their infected loved ones at home without fear of infection or shame.

5.4.6 Recommendation for Health service management

- There seemed to be delays and difficulties in accessing treatment if a person were requesting an issue of ART in a new facility. This study recommends that:
- Art clinics should have flexible hours to include weekend and after hours to accommodate those who are from work or school.
- The management computerises data of all names of those receiving ART in such a way that even if they are away from their homes, it can be easy and quick for them to receive ART in another health facility.
- Doctors' staffing ratio in ART clinics should match the number of patients and workload, if possible community visiting doctors be employed to follow up patients at their local clinics. Government should make efforts to devise means to support affected families on how to cope if somebody in the family is living with HIV/AIDS and on ART, and these can be extended to the community as a whole.

5.4.7 Recommendation for Health research

The study recommends that future research should focus on:

- The experiences of both patients receiving ART in the community and nurses issuing ART as clients are now being down referred to the community.
- Participants in this study felt that they were tired of taking treatment daily and they wished that if possible they can be given quarterly injections only four times a year like what is currently practiced with injection contraceptives.
- Above all, they hoped for a research succeeding in developing a curative ART.

5.5 Limitations

A major limitation to the study was that at that time participants were no longer collecting their treatment at the hospital ART clinic as they had been already down referred to the

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clinics and they had only come to the hospital for consultation regarding the problems they were experiencing. The researcher had to wait for participants who were coming for consultation and some of them were not eligible for study as they were very ill.

At first, participants who were interviewed in a hospital situation seemed afraid; thinking their responses might affect their care even though they were reassured. After reassurance is then that they could open up and expressed themselves freely.

5.6 Conclusions

The study provided the experiences of HIV positive patients on ART at the Thulamela municipality in the Vhembe District of South Africa. Data obtained in this study was sufficient to answer the research questions, aim, and objectives. The participants were free to answer questions and this enabled the researcher to come up with recommendations based on the findings. Community involvement and participation in ART matters is of utmost importance to reduce negative experiences which may affect the fight against HIV/AIDS which is now a manageable condition.

Government should continually carry out workshops to educate families and relatives of those who are affected and make awareness campaigns to the community at large.

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ANNEXURE A: INFORMED CONSENT

Dear Participant

I am a student at the University of Venda studying towards a Masters Degree in nursing. As part of my Masters degrees in nursing requirements, I am supposed to conduct research. I therefore request your permission to participate in the research entitled, Experiences of HIV positive patients on antiretroviral treatment at the Thulamela municipality in the Vhembe District of Limpopo, South Africa. This will require of you to participate by sharing your experiences during an interview with the researcher. The interviews will basically ask about your experiences as an HIV positive patient on ART.

More information about this process is as follows:

The interviews will be conducted at a regional hospital, or in the patient's home at a place and time convenient for the participant.

The objectives of the study are to: Explore and describe the experiences of HIV positive patients on ART and develop recommendations on support and care of HIV positive patients on ART.

Participation in this project will be voluntary which also means that a person can withdraw from it at any stage.The interviews will be conducted within 20mins-30 min and will be audio taped for verification of the findings by my supervisors and independent coder. The participants do not have to give their names during the interview, which means that their identity will be protected and all the information will be treated with strict confidentiality, kept under lock and key. Information related to the interviews will only be accessible to my supervisors and independent coder. Field notes will be destroyed and audio tapes will be erased as soon as possible, and the summary of the research study will be made available to participants if they wish.

There will no compensation (payment) for participation. Their participation in the study may benefit other HIV positive patients on ART. The guidelines which may be developed after the study may be beneficial to other patients who are HIV positive and who are on treatment.

Your kind assistance with the study will be appreciated. If you agree to participate in the project, please complete the attached consent form for participation. Please do not hesitate to

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contact me and my research supervisors, Dr P. R Risenga and the co-supervisor Prof M.S Maputle at the University of Venda, if you have any questions.

Yours sincerely

Mrs T.V Ndou (cell 072 954 6215)

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ANNEXURE B: CONSENT FORM FOR PARTICIPATION

This serves to certify that I .....consent to participate in the study entitled "**the experiences of hiv positive patients on antiretroviral treatment at Thulamela municipality in the Vhembe District of Limpopo Province, South Africa.**"

The aim of the study was explained to me. The right to participation or termination the study was also explained to me. I was assured that confidentiality and other ethical issues will be maintained. The purpose of the study is to meet the requirements of a Master's degree in Nursing in the University of Venda for science and Technology.

Signature of the participant.....

Date.....

Signature of the researcher.....

Date.....

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ANNEXURE C : INFORMED CONSENT (Tshivenda version)

Ndivhadzo

Aa

Nne, Tshifhiwa Violet Ndou ndi mutshudeni wa yunivesithi ya Venda ane a khou gudela digirii ya mastasi ya vhuongi.Kha thodea ya pfunzo dzanga ndi fanela u ita thodisiso.Sa zwenezwo ndi humbela thendelo yavho uri vha vhe tshipipida tsha iyi thodisiso kha thoho ine ya ri: **"Tshenzhemo ya mulwadze wa HIV/AIDS kha u shumisa mishonga ya u fhungudza vhuhali ha tshitshili tsha HIV(mishonga ya ART) masipala wa Thulamela,tshitirikini tsha Vhembe Limpopo, South Africa"**

Zwidodombedzwa zwa thodisiso iyi ndi zwi tevhelaho:-

Vha humbelwa uri vha shele mulenzhe nga u talutshedza nga ha tshenzhemo yavho musi vha tshi khou shumisa mishonga ya ART. Nyambedzano i do itwa tshibadela tsha dzingu kana hayani ha mulwadze fhethu hune mulwadze a do funa hone nga tshifhinga tshine a tshi takalela.

Ndivho ya thodisiso iyi ndi u sedzulusa na u talutshedza nga ha tshenzhemo yavho sa mulwadze wa HIV/AIDS kha u shumisa mishonga ya ART u itela u bveledza themendelo dzine dza nga thusa kha u londa vhalwadze vhanwe ngavho.

A vha kombetshedzwi u shela mulenzhe kha iyi thodisiso, hone arali vha dzhena u vha tshipida tshayo musi vhe vhukati vha vho humbula u litsha vha a tendelwa. Nyambedzano i nga dzhia minete ya fumbili u swika awara hafu ya awara, hu tshi khou rekhodiwa nga radio na u nwalwa kha bugu u itela uri i do sedzuluswa nga vhalavhelesi vha thodisiso. Mafhungo othe ane a do pfiwa kha nyambedzano iyi a do tsireledzwa, a do swikelelwa nga mutodisisi na vhalavhelesi vhawe fhedzi. A huna mbadelo ine vha do i wana kha u shela mulenzhe kha iyi thodisiso.

U dzhenelela havho kha iyi thodisiso zwi do vhuyedza vhone na vhanwe vhalwadze ngavho kha u nga bveledzelwa mashumele a uri vhalwadze vha HIV/AIDS vha shumisaho ART vha nga londiwa hani khwine.

Arali vha tshi tenda u vha tshipida tsha iyi thodisiso ndi humbela uri vha saine fomo ya u tenda yo nambatedzwaho afha. Vha songo lenga u kwama nne kana vhalavhelesi vhanga vho-P.R Risenga na vho-M.S Maputle Yunivesithi ya Venda, Department Of Advanced nursing sciences kha (0159628000) arali hu na mbudziso kana zwinwe.

Wavho Mutodisisi

Mrs T.V Ndou (0729546215

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ANNEXURE D: CONSENT FORM OF PARTICIPATION (Tshivenda version)

Fomo ya u tenda

Hezwi zwi khwathisedza uri, nne .....ndi tenda u shela mulenzhe na u vha tshipida kha nyambedzano ya thodisiso ine ya ri: "Tshenzhemo ya vhalwadze vha HIV/AIDS kha u shumisa mishonga ya ART masipala wa Thulamela tshitirikini tsha Vhembe, Limpopo Phurovintsi South Africa".

Ndo talutshedzwa ndivho ya iyi thodisisiso.

Ndo divhadzwa nga ha ndugelo dzanga.

Arali nda pfa ndi si tsha takalela uya phanda ndo tendelwa u litsha.

Mafhungo othe ane nda do a amba kha nyambedzano a do vha o tsireledzeaho.

Tsaino.....

Datumu.....

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ANNEXURE E: CERTIFICATE OF ETHICAL CLEARANCE

(University of Venda, Health, Safety and Research Ethics Committee)

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
NDOU TV
Student No. 11595734

PROJECT TITLE: EXPERIENCES OF HIV POSITIVE PATIENTS ON ANTI-RETROVIRAL TREATMENT AT THULAMELA MUNICIPALITY IN THE VHEMBE DISTRICT OF LIMPOPO PROVINCE

PROJECT NO: SHS/11/PDC/04/E 1011

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr PR Risenga	University of Venda,	Supervisor
Prof MS Maputle	University of Venda,	Co-supervisor
Ndou TV	University of Venda,	Investigator - Student

ISSUED BY:
UNIVERSITY OF VENDA, HEALTH, SAFETY AND RESEARCH ETHICS COMMITTEE

Date Considered: 10 October 2011
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: R Nikodem
Name of the Chairperson of the Committee: Prof. C.V. Nikodem

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8504/8484 /8313 FAX (015) 962 8439
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ANNEXURE F: LETTER OF PERMISSION TO CONDUCT STUDY

(Provincial Department of Health)

School Of Health Sciences
University of Venda
Limpopo
SOUTH AFRICA

The head of department
Provincial Department of Health
POLOKWANE

Dear sir/madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am conducting a research at University of Venda for science and technology. I am engaged in the study entitled "**The experiences of HIV positive patients on ART at the Thulamela municipality in the Vhembe District of Limpopo Province, South Africa**." The study will be conducted in the Thulamela Municipality at Vhembe District in the Limpopo Province of South Africa.

The study will conducted under the supervision of Professor M.S Maputle and Dr P.R. Risenga of the department of Advanced Nursing Science in the School of Health Sciences.

The objectives of the study are to:-

Explore and describe the experiences of HIV patients on ART. Develop recommendations on care and support of HIV positive patients on ART.

I need to conduct interviews on HIV positive on ART. The interviews will be conducted within 20 minutes to 30 minutes and will be audio taped for verification of the findings by my supervisors and the independent coder. Raw materials will be kept under lock and key to ensure confidentiality. Information related to the interviews will only be accessible to my supervisors and independent coder.

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The summary of the research study and results will be made available to participants if they wish. The guidelines which may be developed after the study may be beneficial to the policy makers and patients who are HIV positive and are on ART.

Thank you

T.V Ndou

Researcher

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ANNEXURE G: APPROVAL LETTER FROM THE PROVINCE TO CONDUCT STUDY

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Selamolela Donald

Ref: 4/2/2

Mdou TV

University of Venda

Thohoyandou

0950

Greetings,

Re: Permission to conduct the study titled: Experiences of HIV positive patients on anti-retroviral treatment at Thulamela Municipality in the Vhembe District of Limpopo Province.

1. The above matter refers.
2. Permission to conduct the above mentioned study is hereby granted
3. Kindly be informed that:-
   - Further arrangement should be made with the targeted institutions.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, a copy should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.

Your cooperation will be highly appreciated.

Head of Department

2011/12/29

Date

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

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ANNEXURE H: LETTER OF PERMISSION TO CONDUCT STUDY

(Tshilidzini Hospital Research Committee)

School Of Health Sciences
University of Venda
Limpopo
SOUTH AFRICA

The Head of Department
Tshilidzini Hospital
SHAYANDIMA
0945

Dear sir/madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am conducting a research at University of Venda for science and technology. I am engaged in the study entitled "**The experiences of HIV positive patients on ART at the Thulamela municipality in the Vhembe District of Limpopo Province, South Africa.**" The study will be conducted in the Thulamela municipality at Vhembe District in the Limpopo Province of South Africa.
The study will conducted under the supervision of Professor M.S Maputle and Dr P.R. Risenga of the department of Advanced Nursing Science in the School of Health Sciences.

The objectives of the study are to:-
Explore and describe the experiences of HIV patients on ART.
Develop recommendations on care and support of HIV positive patients on ART.

I need to conduct interviews on HIV positive on ART. The interviews will be conducted within 20 minutes to 30 minutes and will be audio taped for verification of the findings by

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my supervisors and the independent coder. Raw materials will be kept under lock and key to ensure confidentiality. Information related to the interviews will only be accessible to my supervisors and independent coder.

The summary of the research study and results will be made available to participants if they wish. The guidelines which may be developed after the study may be beneficial to the policy makers and patients who are HIV positive and are on ART.

Thank you

T.V Ndou

Researcher

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ANNEXURE I: PERMISSION TO CONDUCT STUDY (Tshilidzini hospital)

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT
TSHILIDZINI HOSPITAL

Private Bag x 924
SHAYANDIMA
0945

Tel : (015) 964 1061/8
Fax : (015) 964 1492
(015) 964 1072

An accessible, caring quality health and social development service for the people of Vhembe District.

Ref : 4/2/2
Enq : Ramukumba A.N.
Date : 22.02.2012

To : Ndou T.V.

RE: REQUEST TO CONDUCT RESEARCH

1. You are hereby granted permission to conduct your research as requested.
2. Your permission is approved provided item 3 of HOD's approval is adhered to.

Hoping that you will find this in order.

Acting Chief Executive Officer

27/02/2012
Date

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ANNEXURE J: EXAMPLE OF A TRANSCRIPT (Tshivenda Version)

Muvhudziswa 007

Mutodisisi:	Ndi masiari
Muvhudziswa:	Ndi masiari avhudi
Mutodisisi:	Vho twa hani?
Muvhudziswa:	Ndo twa zwavhudi, vhone vho twa hani?
Mutodisisi:	Zwavhudi ho luga, ndi tama u divha tshenzhemo yavho malugana na mishonga ya ART uri ndi ifhio?
Muvhudziswa:	A thina thaidzo na mishonga ya ART, fhedzi nga hunwe nga inwe ndila ndi na thaidzo nyana.
Mutodisisi:	Ndi zwifhio zwe vha tshenzhela zwone?
Muvhudziswa:	Ndo vha na dzitshanduko.
Mutodisisi:	Musi vha tshi ri vho vha na dzitshanduko vha amba mini?
Muvhudziswa:	Dzitshanduko kha muvhili wanga.
Mutodisisi:	Ee, tshanduko ya tshileme kana tshivhumbeo?
Muvhudziswa:	Tshanduko ya tshivhumbeo.
Mutodisisi:	Mhmm
Muvhudziswa:	Ndi henefho he nda thoma u vhona uri ndi na thaidzo, nga nnda ha hedzo tshanduko athi na inwe thaidzo ye nda i vhona musi ndi tshi khou nwa mishonga.
Mutodisisi:	Mishonga ya ART yo shandukisa hani tshivhumbeo tshavho?
Muvhudziswa:	Maduvha ano ndi na thumbu, ndi tshi ri ndina thumbu ndi uri ndo kukumuwa hafha (vha sumba kha thumbu na matungo ha mahada) kha thumbu na matungo.
Mutodisisi:	Hoo, vho hula hafha ntha kha muvhili.
Muvhudziswa:	Ndi pfa ndo khwathesa……
Mutodisisi:	Zwinwe vho ndi zwifhio?

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Muvhudziswa: Thaidzo inwe yenda tangana nayo musi ndi tshi thoma unwa mushonga nga matsheloni nanga masiari, ee nga matsheloni ndovha ndisina thaidzo na luthihi hovha husina tsumbo dzauri ndikho shumisa mushonga. Ndo tangana natsumbo nga masiari musi nditshi fhedza u shumisa mushonga nga msiari ndovha ndi tshi pfa u nga ndotou kambiwa ndi sa koni na u ita tshithu musimushonga hoyu u khou shuma.

Mutodisisi: Vha khou ambisa hani vha tshiri vha pfa vho kambiwa?

Muvhudziswa: Ndi pfa ndisi tshee na nungo ndi tshi khou kumedza. Ndi tea u thoma nda edela ndi sathu ita tshithu

Mutodisisi: Vho vhudza nnyi uri vha khou shumisa mushonga ya ART?

Muvhudziswa: A thongo vhudza muthu ngauri musi ndi tshi tumbula uri ndi na vhulwadze ha HIV a thongo kona u tanganedza, ndo zwi wana nga murahu ha musi ndo di hwala ndo itiwa ndingo. Arali ndi tshi khou humbula zwavhudi ndo dovha ndaya na tshibadela u khwathisedza nauri ndi thome u wana mushonga, mashudu mavhi musi ndi tshibadela hovha huna laini ndapfu zwezwa vhuya zwa ita na uri ndi vhudziwe uri ndi humele hayani ndi dotou vhuya nga matshelo, vhari dzhiela nadzi faela dzashu. Nga duvha litevhelaho thongo tsha humela ngauri ho vha huna laini na uri ari thusiwi.

Mutodisisi: Vhathu vhone vha vha tshi khou vha vhonisa hani?

Muvhudziswa: Vhovha vha sina vhuthu.

Mutodisisi: Nga ndila de?

Muvhudziswa: Sibadela ndo vhona vhathu vhanzhi vhevha vhatshi khou lwala nda vhuya nda humbula nauri na nne ndi dotou ralo. Nda fhumula, musi ndi tshi vhudziswa ndovha ndi sa tambisi tshifhinga ndi tshi tavhanya nda amba uri ndi khou lwala. Fhedzi u shumisa mishonga zwovha zwi tshi nkondela naho ndovha ndi tshi khou divha uri ndi khou lwala.Ndaya nda beba nda vhonala ndi wavhudi. Ndada nda thoma u lwala ndisi tsha kona u ita tshithu nga nne mune. Ndi si dzhie tshifhinga u thoma u nwa mushonga ngauri ndovha ndi tshi khou divha uri ndi khou lwala. Musi ndi tshi nwa mushonga ndovha ndisa vhudzi muthu na mme anga a tho ngo vha vhudza. Nda dzhia tsheo ya uya clinic ya hayani Limpopo ngauri ndovha ndo humela hayani. Musi nditshi swika avhongo vhuya vha dzhia tshifhinga vhada vha dzhia malofha, ngauri ndovha ndi tshi khou divha uri ndi khou lwala ndavha vhudza. Ndingo dzi saathu bva vha mbudza uri vhado mmbidza, vhatshi mmbidza vha nthumela tshibadela urindi tangane na dokotela ane a do shuma navha fumakadzi. Dokotela a nthumela Tshedza nda

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tsivhudzwa. Musi ndo no tsivhudziwa ndo vha ndisi tsha ofha tshithu ngauri ndovha ndi khou divha thaidzo nauri ndi tea u shumisa mushonga. Nda humbula uri mushonga wo itisa hani, nga murahu ha musi ndi tshi dzhiwa malofha vha mbudza uri ndi dovhe ndi vhuye na muthu wa hayani ane ado nthusa u shumisa mushonga. Zwo nkondela ngamaanda uri ndi vhuye na muthu wa hayani nda fhedza ndo sokou dzhiamunwe muthu henefhala sibadela uri ndi kone u wana mushonga. Nga murahu nda kona uvhudza munna wanga uri ndi khou shumisa mushonga.

Mutodisisi: Ndi ngani vha tshi shavha u vhudza muthu wa hayani?

Muvhudziswa: Ndo vha ndi khou shavha u vhudza mme anga ngauri ndo vhona uri vhanga si zwi tanganedze nauri havha vhasi vhabebi vhanga ndavha vhudza unga wana vha khou amba nga iwe badani. Nda vhona uri ndi khwine musi munna wanga a khou divha fhedzi.

Mutodisisi: Munna wavho ovha tikedza hani nga murahu ha musi vhono muvhudza uri vhakhou shumisa mushonga ya ART?

Muvhudziswa: O mbudzisa uri ndo no tanganedza na sa izwi ndi tshi khou shumismushonga? Nda mu vhudza uri ndo kona u vhona uri vhulwadze vhungasi vhe khwine arali ndisa khou shumisa mushonga.

Mutodisisi: Zwi amba uri a huna ane avha humbudza uri zwino ndi tshifhinga tsha unwa mushonga kana hai?

Muvhudziswa: Zwa tshifhinga ndo tou di vhudza nne mune sa izwi ndozwi divha ubva murahu.A thongo vhuya nda khakha u bva tshenda thoma u shumisa mushonga, na musi ndi tshi khou lwalesa ndovha ndi tshi kona uri ndi nwe mushonga.Zwavhudivhudi ndovha ndi tshi khou diniwa nga mishonga ngauri namusi ndi tshiya bungani ndovha ndi tshi pfa u vhavha nga maanda, ndo vha ndi tshi thoma ndadzula hanengei uswika ndi tshivha khwine nda kona u ita zwendayela. Nne mushonga ndodi vhetshela tshifhinga tsha iri ya 08:00 matsheloni,a thongo vhuya nda khakha, nda dovha ndavha wa mashudu ngauri a thongo tangana na masiandoitwa asi avhudi, zwezwa ita uri na hayani vhasi divheuri hu khou itea mini kha nne. Ndo vha tshi ita uri ndi le hu tshi kha divha nga matsheloni uri I tshiri 08:00 ndi kone unwa mushonga, nga masiari ndovha tshi edela nda ita uri ndi dzumbe zwothe uri vhasi vhone tshithu; nga murahu ha unwa mushonga na mushonga wono shuma ndovha ndi tshi pfandi wavhudi nga maanda. Zwo itea uri ndi thome mushonga musi ndi hayanindi tshi humela makhuwani nda tea u shumisa na wonoula mushonga wau dzidzivhadza ngauri huna muthu we ndavha ndi tshi dzula nae ndo vha ndo muvhudza uri u shumisa hani.

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Mutodisisi: Hu nga vha uri zwi zwi amba uri munna wavho ndi ene ovha tikedzaho kha zwothe zwo livhanaho na vhulwadze?

Muvhudziswa: Ee.

Mutodisisi: Zwi amba uri munna wavho ho ngo vha shavha ngauri vha khou shumisa mushonga?

Muvhudziswa: Hai, ho ngo shavha kana u ntsumbedza manwe maitele kana zwinwe, ngauri musi kha musi nda hangwa unwa mushonga nga maanda une ndanwa nga madekwana, ndi ene ane a nkhumbudza a ita uri ri tavhanye uya hayani tshifhinga tshisaathu u fhira.

Mutodisisi: Vho vhuya vhavha na thaidzo ya masheleni musi vhatshi khou uya u dzhia mushonga?

Muvhudziswa: A thongo vha na thaidzo musi ndi tshi toda uya sibadela ngauri munna wanga vhovha vhatshi nnea tshelede nauri ndovha nditshi vha vhudza uri unonwedzi ndi do tea uya tshibadela vha mpha tshelede namusi ndi makhuwani, ngauri ndovha ndi tshitou vhuya ubva makhuwani uda u dzhia mushonga hayani nda kona u dovha nda humela makhuwani, nda di ita ngauralo musi nwedzi utshi do fhela u a dovha aposa, nga murahu ha tshifhinga ndo vhudza mme anga. Hovha hu nga nyendavhusiku 2010, ndovha ndisa koni u vha vhudza. Ndi tshi vhuya Tshilidzini ndo vha ndi tshi shumisa thekisi.Linwe duvha ndo ri ndi khou vhuya makhuwani ndo tangana na khombo, nda tea u hwalelwa tshibadela nga ambulense nda tea u wana mushonga. Musi ndi tshibadela ndi tshi khou nea vhutanzi nga khombo, hayani vhatanganedza lutingo lwa uri ndo tangana na khombo ya goloi, mazwalewanga na vhanwe vhada musi ndi tshikhou fhedza u nwala fomo dza khombo yenda tangana nayo, ndazwi limuwa uri vhoda nda ita unga a thongo vha vhona. Nda gidimela hune ha dzhiwa hone mushonga ya ART nda wana husina vhathu vhanzhi ngauri hovha hu masiari. Nda humela murahu kha laini ya dzifomo dza khombo, ndori ndi tshi swika vhasi mmbone ndi tshivhuya uri ndi bva Tshedza. Ra kona uya hayani, musi nditshi khou vha vhudzangaha khombo, ndadzhia tsheo yauri ndi vha vhudze uri khou nwa mushonga ya ART. Zwo ndzhiela tshifhinga uri ndi ambe ngauri ndo thoma unwa mushonga nga 2008.

Mutodisisi: Vha zwi dzhiisa hani?

Muvhudziswa: A vhongo shanduka ku tshilele naluthihi

Mutodisisi: Mushonga uyu uya khakhisa mafhungo a vhudzekani?

Muvhudziswa: (u vhonala a tshikhou humbula)

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Mutodisisi: Minwe mishonga u pfa vhathu vha tshiri I ita uri vha pfe ndala kana uri vhasa pfe ndala, zwio cyu mushonga uya khakhisa kha zwa vhudzekani?

Muvhudziswa: Izwo ndi zwone, fhedzi ndovha ndisathu todisisa, fhedzi zwine ndanga amba nga murahu hau shumisa mushonga nga madekwana, ndipfa ndina khofhe na uri thi todi u thithisiwa kha tshithu ngauri mushonga u vha u khou shuma.

Mutodisisi: Ok.

Muvhudziswa: Kha mafhungo a lutamo na zwinwe athi athu u zwi limuwa zwavhudi.

Mutodisisi: Kha mafhungo a ndala mushonga u I kwama hani?

Muvhudziswa: Arali nda tanganyisa mushonga na wa vithamini ndi vhona uri zwi kombetshedza muthu uri a le nga maanda, fhedzi arali u songo tanganyisa na vithamini u vha na ndala yo doweleaho, zwi sa ambi uri u fhedza tshifhinga u khou ula, arali u tshi khou toda u lesa u tea u shumisa wa vithamini, arali wo fhela ndi wana uri ndila zwavhudi, nda sa sokou u pfa ndala.

Mutodisisi: Ndi tsini na u fhedza fhedzi kha vhari ndi vhudzise hezwi: Vha pfa uri mushonga uyu unga khwinisiwa hani?

Muvhudziswa: Vha amba u khwinisa mushonga?

Mutodisisi: Mushonga kana tshumelo yothe ngau angaredza yo livhanaho na mushonga?

Muvhudziswa: Athi koni u wana zwine zwanga khwiniswa

Mutodisisi: Ho luga ndo livhuwa. Vha na minwaha mingana?

Muvhudziswa: Ndina minwaha ya 34

Mutodisisi: Vhothoma lini u nwa mushonga

Muvhudziswa: Ndi minwaha miraru, ndo thoma nga Khubvumedzi 2008

Mutodisisi: Ho luga ndo livhuwa.

THE END

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ANNEXURE K: EXAMPLE OF A TRANSCRIPT *(English Version)*

(Translated from Tshivenda to English)

PARTICIPANT 007

Interviewer: Afternoon.

Participant: Good afternoon.

Interviewer: How are you?

Participant: I am find thanks and how are you?

Interviewer: I am fine. Ok, I want to know about your experiences related to the sickness and the ART, what are they?

Participant: I do not have any problem with the treatment, somewhere somehow when I started with the treatment I experienced some minor problems.

Interviewer: Hhmm! What problems did you experience?

Participant: I had some changes.

Interviewer: When you say some changes what do you mean?

Participant: Changes on my body.

Interviewer: Ok, weight or shape.

Participant: Shape.

Interviewer: Hhmm!

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Participant: That is where I have realized that I have got a problem; otherwise I did not experience any problem when I take the treatment.

Interviewer: How did the treatment change your shape?

Participant: I now have a big belly, when I have a belly I can say I am big here on top on my sides, I have changed and find myself not the same as I use to be.

Interviewer: Ok, you became big on the upper body.

Participant: Yes, I find myself too fat .....

Interviewer: What else?

Participant: Another thing is that at first when I started with the treatment I use to take it in the morning and in the afternoon, yes in the morning I had no problem even a single one, there were no signs to show that I have used the treatment. I use to experience signs in the afternoon after taking the treatment, I would feel drunk, feel like doing nothing that is when the treatment is working within me in the afternoon.

Interviewer: When you say you fell drunk what do you mean?

Participant: I mean I would feel as if is no longer I, I would feel sleepy by that time if there is something that needed attention, I would leave that and sleep first.

Interviewer: Who did you tell that you want to use the treatment?

Participant: This one I did not tell anyone that I want to take the treatment because when I found out that I was positive I did not accept, I can say I found out when I was pregnant when I was tested. If my memory still serves well I even went to the hospital for confirmation and that I could start with the treatment, unfortunately when I was at the hospital, I was in Gauteng the queue was very long to the point that they ordered me to go back home and come back the following day because it was time up and they took back our files. The

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following day I felt that I had a problem that there were many people and the health practitioners did not help me then I decided not to go.

Interviewer: How did you see the people like?

Participant: They were not pleasant you see.

Interviewer: In which way?

This should only focus on experiences (physical sideeffects and resistance, social, psychological and adherence, informational, political!!!!!!!!!!!!!!! And nothing else

Participant: I saw many people who were very sick, I started thinking that I will be like them. Then I kept quiet. I could not waste time when somebody ask me about my status I would explain to them but for me to use the ART it was very difficult and I knew about my status, then I gave birth, after giving birth I was looking fine. Then I became sick, I then realized that I am sick and I could not do anything on my own, but I did not take a long time since I knew about my status. I decided to start taking the treatment. When I do that truly speaking, I will never tell anyone because I was even afraid to tell my mother. I decided that I am going to the clinic at home in Limpopo because I am at home. When I arrive there I did pap smear and they also took my blood, since I knew about my status I explained to them and that I do not take the treatment. Before the results came out they told me that they will call me, they called me and send me to the hospital to meet with the gynecologist who specializes in helping women. Then he sends me to Tshedza and I was offered counseling. After counseling I had no fear because I knew my problem which was to use the treatment. I thought the way the treatment looked like, after that after taking my blood they told me when to come back and that when I come back I should come with someone who will also be taught on how to help me to use the treatment. Then it was difficult to come with someone from home and I just take someone at the hospital so that I may be able to receive treatment. Yes, I took the treatment without telling anyone at home. I then told my husband that I am on treatment.

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Interviewer: What is it that you mostly afraid of, to tell them at home?

Participant: The problem is it was difficult to tell my mother, I thought maybe she is not going to accept, you see, and those that I stay with them I was afraid that someone who is not your parent, you can hear him/her talking about you so I felt that it was difficult and I said as long as my husband knows.

Interviewer: How did your husband offer you support after you told him that you are using the ART?

Participant: What he told me was that now are you taking the treatment well because you were afraid, did you accept? I said I have seen that the sickness will not change, I feel sick and I cannot get help by not taking treatment.

Interviewer: This means that there is no one who can give you support when coming to the usage of the treatment as whether is the right time for treatment or not?

Participant: Ok, oh the issue of time I told myself and I knew about it sometimes back. I never made mistake because when I started using the treatment, even when I say I was very sick, yes I became sick and my sickness did not take me down for long to the point that I could not do anything for myself. In fact I was suffering from the piles, I use to wake up and work when I go to the ladies room (toilet) it was difficult because when I started experiencing pain I would not do anything and I would sit in there until the pains are better, then I would do what I went there for. When coming to the issue of taking treatment I set the time myself for 08:00 o'clock and when it comes I could not make mistake I would take the treatment and I was fortunate enough because I never experience any of the side effect to the point that at home they never realize what was happening you see. I would make sure that when the time comes I would eat porridge while there is time so that when it is 08:00 o'clock I can be able to take the treatment when is in the afternoon I would sleep and I will make sure that I hide everything that they will not see anything; after the treatment has finished working in my body I will feel fine. It happened that I start with the treatment while I was at home when I go back to Gauteng I had

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to use the drug one free, I have to use it because I used it while I was staying with somebody whom I have explained to him about the way it works.

Interviewer: Ok, this means that your husband was the one who supported you on everything you came across concerning your sickness.

Participant: Oh, yes!

Interviewer: Even using the treatment means that your husband did not run away from you because you are taking it.

Participant: No, he did not run away from me or showing me some behaviours or anything because when we are out maybe I forgot to take the treatment especially the ones that I take in the evening he is the one who makes sure that we hurry up so we may arrive home before the time for treatment arrive.

Interviewer: Did you have any difficulties financially when you wanted to collect the treatment?

Participant: I had no problem when I wanted to go to the hospital because my husband was giving me money and I use to tell him that this month I am going to the hospital and he was giving me money even when I was in Gauteng, isn't it I started here I use to travel to come and collect the treatment after that I will return to Gauteng when the next date arrive he gives me money as usual, after sometime I decided to tell my mother that I am taking treatment. It was in December 2010, I did not know how to tell her since it was difficult, and I did not know how to start. When I come back I was using a taxi which will take me to Tshilidzini so I may collect the medication before I arrive at home.

One day when I was coming back home from Gauteng I got an accident, so I was taken to the hospital by an ambulance and I had to collect the medication. When I was at the hospital busy giving information about the accident, at home they receive a call that I was involved in a car accident you see, then my mother-in-law and others came to where I was completing the accident forms,

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I realize that they have come then I dodged them (I pretend as if I did not see them). I then run to the dispensary to collect the medication and I found there were no people since it was in the afternoon. Then I went back to the line for accident forms, I had not arrived yet and they did not see me when I come back. We then went home, while I was busy telling them about the accident 1,2,3, I then decided to tell them that I am taking the treatment. I told them after a long period of time because I started with the treatment in 2008.

Interviewer: How did she react?

Participant: After telling her she did not show any sign of changing or anything.

Interviewer: Does this treatment affect things like sex?

Participant: (Seems thinking deeply).

Interviewer: Some medications you will hear others saying that some medications make them feel hungrieror make them feel without appetite, so this treatment does it affect the issue of sex?

Participant: That's true, I have not yet checked what I can tell is that after using the evening treatment you fell sleepy and you do not want to be disturbed because it will be working you see.

Interviewer: Ok!

Participant: On the issue of desire and all the staff I have never checked.

Interviewer: What about on the issue of hunger does the treatment touches that?

Participant: If you mix the treatment with the medication for vitamin I think that forces someone to eat too much but if you don't mix with the vitamin you will have a normal hunger, not meaning that you can spend your time eating, if you want

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to eat a lot you can use the vitamin, if there are finished I find that I eat normally, and fell hungry after some time.

Interviewer: I am about to finish but before that let me ask this: How do you feel the ART can be improved?

Participant: You mean the changing of the treatment?

Interviewer: On the medication or the whole service related to the treatment of ART what is it that you can say that it should be improved if any?

Participant: I cannot properly find what should be changed.

Interviewer: Ok, thank you. How old are you?

Participant: I am 34 years.

Interviewer: How long have you been taking treatment?

Participant: Actually is three years, I have started in 2008 in September.

Interviewer: It is fine, thank you.

THE END!!!

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CERTIFICATE FROM INDEPENDENT CODER

Qualitative data analysis

Master of Curationis degree (Nursing Science)

NDOU T.V

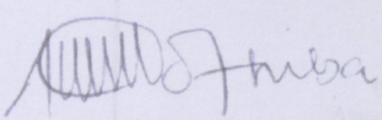
THIS IS TO CERTIFY THAT:

DR Tebogo Maria Mothiba was an independent coder for the following qualitative data: Individual in-depth interviews and field notes.

For the study: EXPERIENCES OF HIV POSITIVE PATIENTS ON ANTIRETROVIRAL TREATMENT AT THULAMELA MUNICIPALITY IN VHEMBE DISTRICT OF LIMPOPO PROVINCE

I declare that the candidate and I have reached consensus on the major themes reflected by the data during a consensus discussion. I further declare that adequate data saturation was achieved as evidenced by repeating themes.

Dr Tebogo Maria Mothiba



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ANNEXURE M: CERTIFICATE OF THE LANGUAGE EDITOR

UIGC
Univen Income Generation Centre

CERTIFICATE

LANGUAGE EDITING

The Dissertation

Entitled

EXPERIENCES OF HIV POSITIVE PATIENTS ON ANTIRETROVIRAL TREATMENT AT THULAMELA MUNICIPALITY IN THE VHEMBE DISTRICT, OF LIMPOPO PROVINCE SOUTH AFRICA

By

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3.8 Data Analysis

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Creating Future Leaders

Marshall and Rossman (2006:154) define data analysis as the process of bringing order, structure, and interpretation to a mass of collected data that is messy, ambiguous, time consuming, creative, and fascinating. Furthermore, data analysis was described as a search for general statements about the relationships and underlying themes (Marshall & Rossman, 2006:154).

The researcher in this study analyzed data using Tesch Model as explained in Marshall and Rossman, (2006:155). The researcher was interested in characteristics of language discovery of regularities, comprehension of meaning and reflection. She reviewed field notes to identify relationship in the observations made. The steps according to Tesch in Babbie and Mouton (2008:490) are as follows:

Step 1: *Getting the sense of the whole idea.*

The researcher read through the whole data all over again repeatedly to get the sense out of it. Any ideas coming to mind as data was read were written down.

Step 2: *Pick one document*

The researcher picked documents one by one reading through them, writing thoughts down. The topics were taken from data and put in a list.

Step 3: *Make a list of all topics*

After going through documents of several participants, the researcher discovered topics from which similar ones were grouped. Topics that related to each other were grouped together. The topics were classified as minor, major and unique.

Step 4: *Abbreviate the topics as codes*

The topics were then categorized, abbreviated and coded.

Step 5: *Find the most descriptive wording*

Data belonging to each category were assembled and analyzed, and their interrelationships were indicated.

Step 6: *Make a decision*

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