

MINI-DISSERTATION

**EXPERIENCES OF STUDENTS WITH IMMUNOLOGICAL AND VIROLOGICAL
FAILURE ON ANTIRETROVIRAL DRUGS AT THE UNIVERSITY OF LIMPOPO,
LIMPOPO PROVINCE, SOUTH AFRICA**

by

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DECLARATION

I, **Mahlodi Phildah Maphakela**, solemnly declare that the mini-dissertation hereby submitted to the University of Limpopo for the degree of Masters of Public Health has never been submitted by me or any other person at this or any other University, that this is my own work in design and execution, that I am aware of the implications of plagiarism as academic dishonesty, and that all sources of reference used have been duly acknowledged.

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Signature

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Date

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ABSTRACT

Virological failure occurs when the viral load fails to suppress to undetectable limit and immunological failure is when the immune system fails to improve with the CD4 count remaining low on clients on antiretroviral drugs. These being markers of poor adherence to antiretroviral drugs or treatment failure. Upon routine blood-monitoring of students on antiretroviral drugs, the researcher noticed that some students' viral-load levels were not suppressing and their immune system was not improving. The purpose of the study was to identify the experiences of those students whose viral load is not suppressing and their immune system not improving. The objective was to identify and describe the experiences of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo. A qualitative, explorative and descriptive study design was used. Convenience purposive sampling method was adopted. Using a semi-structured interview guide, face-to-face interviews were conducted on 10 students on antiretroviral drugs at the Student Health and Wellness Centre, University of Limpopo. Techs' method was used to analyse data. Guba's model for establishing trustworthiness was used. The study yielded the following themes: Disclosure, stigma, antiretroviral drugs packaging, side effects of antiretroviral drugs and service delivery. The study concluded that students are afraid to take their treatment for fear of stigmatisation and disclosure is still a problem. Students tend to forfeit taking drugs when studying for examinations due to side effects of the drugs. It is recommended that service delivery and antiretroviral drugs packaging be user friendly.

Key words: Disclosure, stigma, side effects, antiretroviral drugs packaging and antiretroviral drugs.

DEFINITION OF CONCEPTS

Adherence: The extent to which a person's behaviour in relation to taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health-care provider (WHO, 2010). In this study, adherence means a person's behaviour in relation to taking medication, specifically ARVS.

CD4: Cluster of differentiation 4, a glycoprotein that is found primarily on the surface of helper T-cells. Human T-helper cells expressing CD4 antigen (WHO, 2010).

Clinical failure: It is defined as the occurrence or recurrence of HIV-related events after at least 3 months of treatment, with the exception of immune reconstitution syndromes. This definition therefore excludes residual immune deficiency that persists in the early period of Anti-Retroviral Therapy. Clinical failure usually follows virologic and immunologic failure in that order (UNAIDS, 2012). In this study, clinical failure means as the occurrence or recurrence of HIV-related events after at least 12 months of treatment, with the exception of immune reconstitution syndromes.

Compliance: Patient's passive following of provider's orders (WHO, 2013). In this study, compliance means patient's following of orders on how to take ARVs.

Determinants: An element that identifies or determines the nature of something or that fixes or conditions an outcome, and are referred to as those inter-connected patient-related variables, treatment-related factors, disease characteristics, aspects of patient-provider relationship and clinical setting that may affect the adherence of patients to anti-retro viral drugs (MERCK Manual, 1997). In this study, determinants mean an element that identifies or determines the nature of an outcome and are referred to as those interconnected patient-related variables, treatment related, disease characteristics, aspects of patient provider relationship and clinical setting that may affect adherence to anti-retro viral drugs.

Immunological failure: A CD4 count that is not improving on routine monitoring of patient on antiretroviral drugs (WHO, 2010). Immunological failure in this study means a CD4 count that is not improving on routine monitoring of blood results of a patient on ARVs.

Medication Adherence: Patient's conformance with the provider's recommendation with respect to timing, dosage and frequency of medication-taking during the prescribed length of time (American Medical Association, 2012).

In this study, medication adherence means a patient's conformance with the provider's recommendation with respect to timing, dosage and frequency of medication-taking during the prescribed length of time.

Non-adherence: The extent to which the patient continues the agreed-upon mode of treatment under limited supervision when faced with conflicting demands, as distinguished from compliance or maintenance (American Medical Association, 2012). Non-adherence in this study means the extent to which patients are able to follow the recommendations for prescribed treatments.

Viral load: A measurement of the amount of a virus in an organism, typically in the bloodstream, usually stated in virus particles per millilitre (UNAIDS, 2012).

Virological failure: The inability to achieve or maintain suppression of viral replication to an HIV RNA level <200 copies/mL or Lower than detectable limits (WHO, 2010).

LIST OF ABBREVIATIONS/ACRONYMS

AIDS:	Acquired Immune Deficiency Syndrome
ARVs:	Anti-retro Viral drugs
DOTS:	Directly Observed Therapy, Short Course
FDC:	Fixed-Dose Combination
HAART:	Highly Active Anti-Retroviral Therapy
HIV:	Human Immuno-Deficiency Virus
OI:	Opportunistic Infection
PHC:	Primary Health Care
PLHIV:	People Living with HIV
STI:	Sexually Transmitted Infection
TB:	Tuberculosis
VCT:	Voluntary Counselling and Testing
WHO:	World Health Organization

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 Introduction and Background

Highly Active Anti-Retroviral Therapy (HAART) also termed Antiretroviral drugs (ARVs) as commonly known, is the recommended form for Human Immune Deficiency Virus (HIV) treatment. HAART consists of a combination of at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease. The purpose of this drug cocktail is to reduce the HIV viral load in the blood by stopping the progression of HIV to undetectable limits and increase the CD4 cell count of the infected person to a baseline count of between 500-2010 cells/mm³ (Trotta, Cozzi-Lepri, Ammassari, Vecciet, Cassola, Caramello *et al.*, 2010). If ART is taken reliably and correctly, the drugs can reduce the virus to a level in the blood when it can no longer be measured (undetectable limit), restore the immune system, prevent HIV transmission, reduce HIV-related morbidity and mortality and improve the quality of life. CD4 cell count usually rises when treatment suppresses viral load.

A study done by Bravo, Edwards, Rollnick and Elwin (2010) in Wales, UK on tough decisions faced by people living with HIV/AIDS revealed that HIV positive patients verbalised that they experienced tough psychological needs and complex decisions concerning their lives, ranging from disclosure, stigma, social support, adherence, decisions on sexual activity and desires about parenthood. This affecting their practices in seeking and taking treatment, thus having a great influence on treatment outcome.

A cohort study in Tshwane District Hospital, done over a period of 5 years (2004-2009) among 870 adults patients on ARVs showed that 38.28% experienced treatment failure, 6.9% failed virological and 35.28% failed immunologically. The study revealed a significant correlation between treatment failure to non-adherence, interrupted treatment, defaulted treatment, older patients, gender, place of residence, employment status and level of education (Sokoya, 2012).

ARV drugs do not cure the virus, but dramatically reduces the amount of virus in the body so as it cannot destroy the immune system (WHO, 2010).

HIV positive clients will have to use these drugs every day, same time for the rest of their lives, until a cure is found. If not taken at the same time every day, the drugs may cause resistance and increased risk to treatment failure (WHO, 2010).

A serious challenge facing the sub-Saharan is the growing infection rate among adolescents, which is the age group between 15-24. This age group accounts for 60 percent of all new infections in many countries. This group is particularly vulnerable to HIV because of the physical, social, psychological and economic attributes of adolescence, they are still at the stages of exploring and engaging in high risky sexual behaviors. Peer pressure also plays a part to obtain luxury items and may lead to transactional sex amongst young women (Asante & Oti-Baddi).

According to the Clinicians tool in Managing HIV, follow-up laboratory investigations are done as follows: CD4 – Every 12 months unless clinically indicated. Viral load – initially at 6 months since drug resistance emerges very early during treatment failure, then in 12 months and annually thereof (Department of Health, 2015). CD4 count as well as observing kidney functioning are done annually as well.

This study therefore intends to explore and describe students on ARV drugs' experiences in order to identify the causes of immunological and virological failure. Recognising the causes will assist in identifying those gaps that have an impact in obtaining immunological and virological success, avoiding treatment failure early and also inhibiting the development of resistance among students.

1.2 Problem Statement

Students at the University of Limpopo who have tested HIV positive are initiated on ARVs at the Student Health Centre and all follow-up treatment, blood routine and care is done at the Health Centre. The researcher noticed on follow-up visits of routine blood-monitoring and through students' ARV files that there is an improvement in viral-load suppression and CD4 count increase in some students whereas there is none or limited improvement in others, wherein the viral load increases or remains high and the CD4 count drops. Students are initially monitored

at 6 months after initiation of ARVs for viral load according to the Department of Health's guidelines for follow up and treatment. Based on observations, the researcher sought to identify what are the experiences of those students with immunological and virological failure whilst on ARVs at the Student Health and Wellness Centre, University of Limpopo.

1.3 Literature Review

This section presents a review of literature pertaining to global, international, national and local perspectives on what are the experiences of clients on ARVs. Aspects contributing to immunological and virological failure such as adherence and non-adherence, educational status, disclosure, health provider's role, family support, stigma, knowledge and beliefs about ARVs and side effects which are discussed in Chapter two.

1.4 Aim of the Study

The aim of the study was to explore the experiences of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo.

1.5 Objectives

The set objectives for this study were, namely, to:

- Describe the experiences of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo; and
- Identify the causes of immunological and virological failure among students on antiretroviral drugs at the University of Limpopo.

1.6 Research question

The following research question was posed as a guide for this study:

- What are the experiences of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo?

1.7 Research methodology

In this chapter, a brief discussion on the research methodology applied was provided. A more detailed approach is further described in Chapter three, after Literature Review (Chapter two), as follows:

- 1.7.1 Research design: A descriptive, exploratory study with a qualitative approach was used.
- 1.7.2 Study site: The study was conducted Health and Wellness Centre, University of Limpopo, Mankweng, Limpopo.
- 1.7.3 Population and sampling: The target population was from University students on HAART with purposive sampling used to interview those with immunological and virological failure only.
- 1.7.4 Data collection: One on one interview with the participants using a semi-structured interview guide was used. The guide used included as list of open-ended questions based on the objectives, literature review and professional experience.
- 1.7.5 Data analysis: Data analysis process was done in alignment with Tesch's 8 steps model (1985) for open coding as described in Creswell (2004).
- 1.7.6 Measures to ensure trustworthiness: To ensure trustworthiness in the quality of data findings in this study, Lincoln and Guba's model for establishing trustworthiness was used. The Model looks into 4 aspects, which are, namely: credibility, dependability, confirmability and transferability of the data obtained.
- 1.7.7 Bias: To avoid bias measures to ensure trustworthiness were adhered to throughout.

1.8 Ethical Consideration

The research proposal was submitted to the Turfloop Research Ethics Committee (TREC) for ethical clearance and was approved, and the certificate is included in document as Annexure A.

1.9 Significance of the Study

The findings of the study might assist in understanding and identifying those barriers leading to immunological and virological failure among students on ARVs. This in turn will assist in the prevention of treatment failure and drug resistance. It might

also help to inform programmes aimed at strengthening prevention of immunological and virological failure among students on antiretroviral drugs.

1.10 Conclusion

This chapter has provided the scientific foundation of the study. The background, aim and objectives were explained. An outline of the methodology has been included. The literature review and conceptual framework, which serve to support the rationale, are discussed in the next chapter, i.e., Chapter Two.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

According to Polit and Beck (2008), the purpose of a literature review is to familiarize oneself with existing knowledge. That will serve two main purposes, namely: the identification of existing knowledge gaps or problems and the identification of existing solutions to the problem. Reviewed literature was obtained from journals, peer-reviewed articles, published research studies, abstracts, book chapters and websites as cited in referencing. This chapter looks into the HIV epidemic in South Africa through global, international, national and local views on what could lead to immunological and virological failure whilst on ARVs.

2.2 HIV Epidemic in South Africa

There are 34 million people living with HIV/AIDS worldwide (UNAIDS/WHO, 2012). South Africa has the biggest and highest profile HIV epidemic in the world, with an estimated 7 million people living with HIV in 2015. In the same year, there were 380,000 new infections while 180,000 South Africans died from AIDS-related illnesses. With the largest antiretroviral treatment (ART) programme globally, these efforts have been largely financed from its own domestic resources. The country now invests more than \$1.5 billion annually to run its HIV and AIDS programmes and currently has 48% of the 7 million population on ARVs (AVERT, 2017).

Having so many funds spent on treatment, it is empirical that the treatment works as designed in order to win the war against HIV/AIDS. If ART is taken reliably and correctly, the drugs can reduce the virus to a level in the blood where it can no longer be measured (undetectable limit), restore the immune system, prevent HIV

transmission, reduce HIV-related morbidity and mortality and improve the quality of life. CD4 cell count usually rises when treatment suppresses viral load (Trotta *et al*, 2010).

2.3 Adherence and non-adherence to ARVs.

Recent data from the World Health Organization (WHO, 2015) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) indicate that access to Human Immunodeficiency Virus (HIV) treatment and care services in low- and middle-income countries has expanded dramatically. UNAIDS (2012) states that over 9.7 million people living with HIV in these countries are receiving antiretroviral drugs. Despite this increase, ensuring adherence to HIV treatment remains challenging in all countries. A meta-analysis of patients in North America ($n = 17\,573$) and Africa ($n = 12\,116$) estimates that only 55% and 77% in these areas, respectively, achieve over 80% adherence and a global meta-analysis, which includes 33 199 patients on ART, also reporting that only 62% of those patients achieve over 90% adherence. An indication that a high degree of adherence to ARV drugs is necessary for optimal virological suppression (UNAIDS, 2012). An indication that >95% of the doses should be taken for optimal suppression. Lesser degree of adherence is more often associated with virological and immunological failure (WHO, 2015). Adherence levels of > 95 % are required to maintain virological suppression. Common reasons given for poor adherence include adverse effects, excessive pill burden and/or dosing frequency, dietary restriction, or simply not having medication available or forgetting to take doses (WHO, 2010).

The World Health Organisation (2008) on Adherence to long term therapies-evidence for action found that adequate, quality service delivery, engagement of adequate health professionals, adoption of strategies that improves service delivery and availing services to the poor and underserved communities were some of the factors that improved adherence to Anti-Retroviral Therapy, ensuring optimum clinical and immunological improvement. Multiple factors related to health-care delivery systems, the medication and the person taking ARV drugs may affect

adherence to ART. The individual factors may include forgetting doses; being away from home; changes in daily routines; depression or other illness; a lack of interest or desire to take the medicines; and substance or alcohol use. Medication-related factors may include adverse events; the complexity of dosing regimens; the pill burden; and dietary restrictions.

Health system factors may include requiring people with HIV to visit health services frequently to receive care and obtain refills; travelling long distances to reach health services; and bearing the direct and indirect costs of care. Lack of clear information or instruction on medication, limited knowledge on the course of HIV infection and treatment and adverse effects can all be barriers to adherence to ART. Moreover, uninterrupted ARV drug supply and continuity of care are essential for people to adhere to their medication. Lack of continuity of care is a strong predictor of non-adherence in the longer term. Adherence to ART may also be challenging in the absence of supportive environments for people living with HIV and due to HIV-related stigma and discrimination (WHO, 2008).

A study done at University of Florida on Adherence to HIV Anti-Retroviral Therapy, concluded that drug adherence in the developed world demonstrated that higher levels of drug adherence is associated with improved virological, immunological and clinical outcomes (Machtiger & Bangsberg, 2006). An indication that if there is adherence to HAART, there is immunological and virological improvement.

Ehlers and Tshisuyi (2015) also conducted a study in Botswana on adherence to treatment by adults in rural areas. In the study, it was found that the prevalence of non-adherence to ART was 14.0%. Motivators of good adherence included disclosure of HIV-positive status to more than one person, frequent adherence counselling, self-efficacy for adherence to ART, positive interactions between patients and healthcare providers; and using adherence partners. Barriers to adherence were forgetfulness, transportation costs to and from the clinic, time away from work and side-effects. There was a strong positive correlation between adherence, CD4 counts and viral load. Participants with poor adherence were likely to have unsuppressed viral loads. Adherence to ART is closely tied to virologic,

immunologic, and clinical outcomes. Increases in adherence levels resulted in significant improvements in these outcomes (Ehlers & Tshisuyi, 2015).

2.4 Factors contributing to non-adherence towards ART.

2.4.1 Educational Status of Client on ARVs

Collazos, Asensi and Ibarra (2010), in Europe on the influence of the patients' educational levels on socio-economic, clinical, immunological and virological end points, concluded that educational level has an impact on clinical and immunological outcomes of HIV infection. They also suggested that an evaluation of some social aspects, such as a patients' educational status, should be incorporated into routine clinical practice.

A cohort study in a Tshwane District Hospital, done over a period of 5 years (2004-2009) among 870 adult patients on ARVs, showed that 38.28% experienced treatment failure, 6.9% failed virological and 35.28% failed immunologically. The study revealed a significant correlation between treatment failure, non-adherence, interrupted treatment, defaulted treatment, older patients, gender, place of residence, employment status, level of education and treatment failure (Sokoya, 2012).

2.4.2 Disclosure

A study done in Brazil on the disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS, discovered that patients who do not carry extra doses of medication while out of the house would miss a dose. This affected adherence to the drugs, resulting also in resistance to the drug. Other factors that were experienced to be associated with immunological and virological failure were seen to be, namely, lack of social support, relationship that one has with health-care providers and running out of medication (Abadia-Barreco & Larussom, 2006).

In a Qualitative study on disclosure of HIV status and adherence by Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza *et al.*, (2006) in Uganda, it was revealed that Anti-Retroviral Therapy is better adhered to where the treatment is free and in community-based programmes; thus indicating that stigma and not disclosing status to those within the radar that one lives in, have a direct impact on determining treatment success or immunological and virological failure.

Ndou (2013), in a qualitative study in Limpopo, discovered that participants in the study were still having difficulty in disclosing to their partners due to the potential risk of being blamed, loss of economic support, abandonment, physical and emotional abuse from partners, discrimination and disruption of family relationship. Participants also feared to be accused of infidelity and unfaithfulness leaving them not to disclose on their status.

2.4.3 Health-Care Provider's Role and Family Support

A study conducted in Los Angeles on Barriers to Facilitators of HIV Positive Patients' Adherence to Antiretroviral Treatment Regimens, indicated that social support and support from health-care providers affected their treatment outcome. This made participants to comply with ARVs-taking as they were reminded sometimes when they forgot (Roberts, 2000). Kurtyra (2008) shared the same sentiments in a study on effects of a structured adherence intervention on HAART in Florida that showed also that patients who were enrolled in medication programmes and received on-going medication monitoring adhered better than those who did not receive such. Those who were enrolled on the programme achieved 95% adherence, having virological and immunological success.

A study done in Ethiopia on Factors Associated with ARV Treatment, Adherence among Adult Patients concluded that living with a partner was associated with adherence to ART. Patients who were likely to be non-adherent were either unmarried or lived alone, had poor social support and were reluctant to disclose to their partners or spouses. The use of family members and peers to enhance adherence has emphasized the importance of social support in the treatment of HIV. Social support may enhance adherence through encouragement, reassurance,

motivation and masking the effect of stress, anxiety and depression through the support (Alagaw, Godana, Taha & Dejene, 2013).

Skovdal, Campell, Nhongo, Nyamukapa and Gregson (2011), in a study in Zimbabwe, revealed that men denied being associated with HIV as they wanted to protect their manhood and they viewed HIV and AIDS as a threat to their masculinity that belittles their sense of manhood. The men would further deny their wives permission to take ART and sometimes steal their drugs for their own treatment. This adversely affecting adherence among those women and thus making them take the drugs in secret or not at all (Skovdal *et al.*, 2011).

In another study done in Kwa-Zulu Natal on adherence by primary healthcare clinics, it was revealed that, for an efficient service that ensures adherence, such will require staff to be supported in terms of training and in-service education. Adequate staffing also needed to be looked into for the success of adherence. This is done in order to ensure the monitoring of patients on ART, and the detection and management of virological failure that may lead to drug resistance (Uzodike *et al.*, 2015). Other experiences were that staff-to-patient ratio led to the inability to follow up on patients' virological monitoring. The researchers recommended that alleviation of shortage of staff will improve the quality of counselling and doctor interaction, whereby clients will have more time to interact with the caregivers, thus addressing their fears and concerns (Chibikuli *et al.*, 2010).

Ndou, Risenga and Maputle (2013), in a study on Experiences of HIV positive patients on ARV in Limpopo, revealed that families are ignorant of the mode of transmission of HIV. Despite all efforts of talks and education being done in the media and healthcare facilities, they remain with an attitude when it comes to having a family member who is HIV positive. Some of the experiences in the study were reported that they were expelled from home after parents found out about their status.

Ndou *et al.*, (2013) also found that other clients had to go to Health Care Centres alone, with no family support, whilst being in their weak state, thus making it difficult to can hear all instructions well. Others who were HIV infected were treated like dogs

at home whereby they would be shoved food without even being asked how they were feeling, and if they were hungry or not. This kind of rejection by family members often led to compliance and adherence problems. Marukutira (2011) attested that good adherence in adolescents is attained when one had family support, friends' support and community support. This network of support ensured compliance to the drugs-taking.

2.4.4 Stigma

According to a study done by the ACCHO (2006) on HIV/AIDS stigma, denial, fear and discrimination in Toronto, HIV positive participants experienced a range of cultural and structural issues that increased the risk of infection, thus creating an obstacle for testing and treatment and also leading to social isolation. Gossip and fear within the community lead to isolation of HIV positive people, thus discouraging them from seeking treatment and support services.

Medisets containers were also found to reduce double dosing or missing a dose as in a normal pill container. However, it was also identified that other people were concerned with the stigma attached to the containers, alarm clocks for exact time and written notes or day planners as reminders set for taking ARVs (Roberts, 2000). Sekoni, Obidike and Balogun (2012) agreed with the above statement in Nigeria, that patients on ARVs experienced tiredness of the routine of taking their drugs and skipped their doses. Removing ARVs from the labelled containers and putting them in unlabelled pill-boxes was the adopted coping-strategy for avoiding stigma. Participants who attended the HIV clinic regularly experienced a personalised stigma and this affected their collection of the ARVs.

Also revealing that having to go to that specific unit or ward, which everybody knows that it is for HIV-infected clients only, was seen as a way of stigmatising the condition. Ndou (2013), in a qualitative study in Limpopo, revealed that HIV positive people had negative experience from immediate and distant family members due to the fear of being infected with the virus. This emanates mostly from ignorance on the mode of

transmission of the virus. Parents also were found to blame their children for being promiscuous and hence being infected with the virus.

2.4.5 Knowledge and Beliefs about ARVs

Mthembu and Van Wyk (2014), on their study on patients' knowledge and beliefs about ARV treatment and factors associated with adherence in Mpumalanga, revealed that the level of knowledge about ART had an effect on adherence to treatment. Knowledge about the effects of missing a dose was important in advising the patient, knowledge of benefits of ART to ensure adherence was deemed important. Experiences were discovered to be, namely, forgetfulness; busy schedules and routines; having visitors; and night out with friends or sleeping away from home and that contributing to them missing a dose or so.

2.4.6 Side Effects

Lekhuleni, Mothiba, Maputle and Jali (2013) revealed in Limpopo that patients on ARVs are not adhering to treatment as they faced side effects to the drugs and resorting to missing a dose to cope with everyday life. Watson, (2018) also agreed that antiretroviral drugs can cause side effects that can be severe enough that some people stop taking them and that sticking to a treatment plan is not always an easy task to do. This in a way was seen as affecting adherence to ARVs.

2.4.7 Access to ART Site

Jaka, Mshana, Liwa, Peck and Kullavya. (2009) reported, in a study on prevalence of immunological failure in one clinic in Tanzania, that the prevalence of immunologic treatment failure was 17.1% among 362, 8 patients followed for a mean duration of 29 months. In short, the study showed that different settings have different levels of immunologic and virological failure.

A study in Nepal revealed that frequent transport blockades, unexpected transport strikes, long travel distance and poor road conditions made it difficult to access treatment sites; moreover, when there is a limited number of selected hospitals that disperse the drugs (Watsi, Simkhada, Randall, Freeman & Van Teijlingen. 2012). Ndou (2013), in Limpopo, revealed that participants had to wait long queues and sometimes they even get cut in the line before accessing treatment, thus making

them miss their doses if treatment is finished. Furthermore revealing that others go to different provinces without the much needed documentation; meaning the whole process is started afresh and, if they had run out of treatment, they would then miss the doses till the process is complete.

2.11 Conclusion

This chapter presented the literature review of studies done on what could contribute to immunological and virological failure among HIV infected clients on HAART.

In the next chapter, the methodology of the study is described with regard to the exploration and description of the experiences of students on ARVs as well as the method used.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this chapter the research methods used for the study is presented. Polit and Beck (2012) defined methodology as the steps, procedures and strategies for gathering and analysing data in a study. Research design, sampling procedures, data collection process and research analysis approaches applied to address the research questions are discussed below. The first sections address issues to do with the study area and setting of the study and sampling procedure, followed by data collection and analysis methods. The last section deals with issues related to ethical clearance.

The study explored the experiences of students on ARVs taking, but only those with immunological and virological failure according to their clinical records.

3.2 Research Design

A qualitative, explorative, descriptive design was used in this study in order to understand the students' description of what their experienced feelings and opinions are being HIV positive and having immunological and virological failure whilst on ARVs.

Qualitative research entails purposefully selecting participants that will best help a researcher understand the research problem and answer the research question (Creswell, 2009). Qualitative research is also used to gain an understanding of underlying reasons, opinions and motivations. It provides insight into the problem or helps to develop ideas or hypotheses for potential quantitative research. Qualitative research is also used to uncover trends in thoughts and opinions, and to plunge deeper into the problem. This type of research enabled the present researcher to collect data without formal structured instruments and analyse narrative information in an organised manner (Brink, 2006).

An explorative study is described in Brink (2006) as a study that is aimed at exploring the in-depth knowledge and understanding of values, beliefs, practices,

perceptions of a selected population group through asking questions and probing until data saturation occurs. For this study, participants were asked about their daily routine as students who are on ARVs, how they have been taking them, challenges relating to time and other challenges as experienced. Exploratory research, as the name implies, intends to merely explore the research question and does not intend to offer final and conclusive solutions to existing problems (Polit & Beck 2004).

Descriptive research is aimed at casting light on current issues or problems through a process of data collection that enables participants to describe the situation more comprehensively. Descriptive design was selected because of the ease in which a researcher could obtain the participants' opinion through the three stages of descriptive research which are, namely:

- Observational, defined as a method of viewing and recording the participants;
- Case-study, defined as an in-depth study of an individual or group of individuals; and
- Survey, defined as a brief interview or discussion with an individual about a specific topic (Polit & Beck 2004).

The researcher adopted the Observational method during the one on one interview.

3.3 Study Site

The study was conducted at the University of Limpopo which is situated 40 Kilometres (25 miles), East of Polokwane with the inhabitants referring their township as Mankweng, named in memory of one of the chiefs in that area. The University lies in the foothills of the Hwiti (Wolkberg range) midway between Polokwane and Magoebaskloof.

The clinic is 23° 53' 37.374" S, 29° 44' 6.644" E and the physical address is: Health and Wellness Centre, University Road Mankweng-E, Polokwane Rural, Limpopo, South Africa, 0727. It is situated at the footpath of the popular Gate 2, which students use as an access point when going to respective shops, east of the University. The clinic was established in 1962 on the University of Limpopo grounds, then known as University of the North which was established in 1959. The main aim of the University clinic is to assist students with health-related problems which would

warrant them to go to local clinics, queue in lines and miss their academic classes in the process. It offers services to all registered students and has an estimated population of 21 000 students and 890 staff members.



Diagram 1: Picture of the Health and Wellness Centre

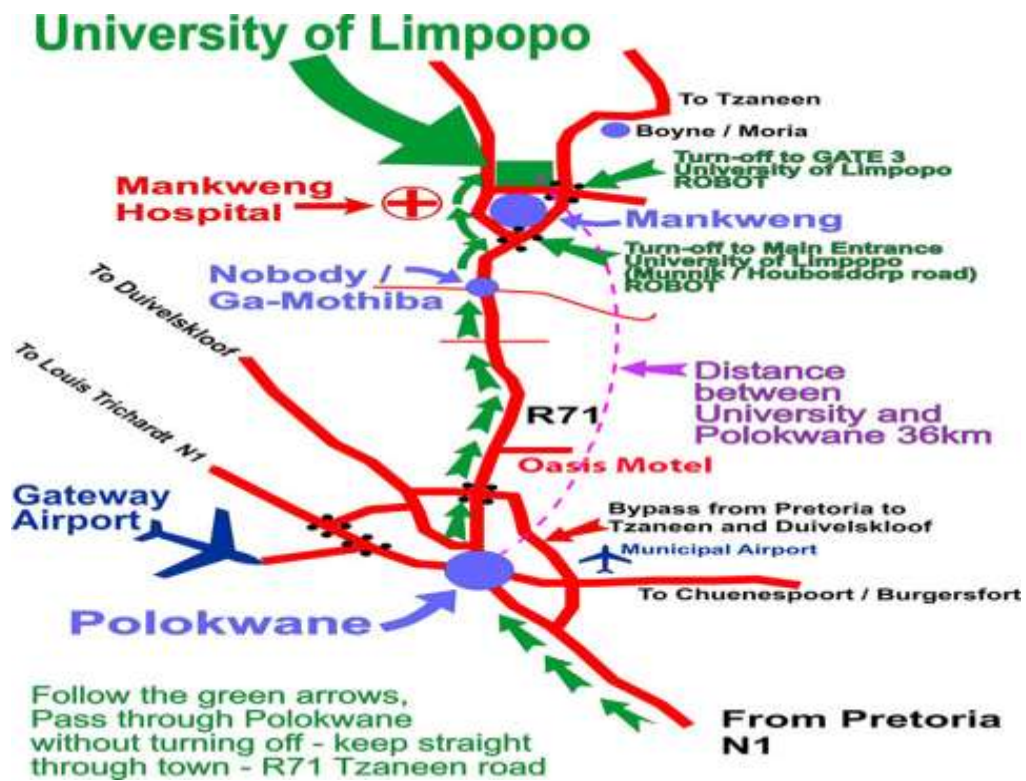


Diagram 2: Illustration of directions to the University of Limpopo

3.4 Study Population

A population is defined as an entire set of individuals or objects having the same characteristic (Polit & Beck, 2012). For this study, the target population is the University of Limpopo students who are enrolled in the HIV/AIDS programme and are on ARVs at the Student Health and Wellness Centre. Out of a total of 271 who are HIV positive, 82 are on HAART. From the ARV records, upon the routine 6 months monitoring of viral load and 12 months CD4 count, 12 were found to be having immunological and virological failure whereby their CD4 and viral load were not improving. Those are then the study population and the only people interviewed.

3.5 Sampling

Sampling is stated as selecting a portion of the population in a research area which represents the whole population (de Vos et al., 2004). A convenience, purposive sampling method was adopted to select the participants. Convenience sampling is defined as a non-probability sampling technique where subjects are selected because of their convenient accessibility and proximity to the researcher (Saunders et al., 2012). For this study, participants were identified through purposive sampling. Purposive sampling is also known as judgmental, selective or subjective sampling in which a researcher relies on his/her own judgement when choosing members of the population to participate in the study (Gerrish & Lacey, 2006).

For this study, the 12 students who were not having immunological improvement and virological suppression were sampled. The participants were given pseudo names as participant one to ten. Only ten participants were interviewed as two of the identified refused to give consent even with anonymity and confidentiality ensured. Two males and eight females were amongst those who were interviewed. Participants were identified as they came for monthly reviews and treatment collection at the clinic through their record reviews and laboratory results.

3.6 Data Collection

Data were collected between September and December 2017 at the Student Health and Wellness Centre. Students were asked to explain their experiences on being HIV positive and having to take ARVs whilst pursuing their studies. Challenges as

well as positive aspects that come with having to take ARVs as students were narrated.

In addition, through face-to-face interviews, the researcher was able to gather multiple realities based on the actual words of participants as they narrated their experiences of them being HIV positive and having to take ARVs (Creswell, 2007).

3.6.1 Data Collection Approach

The study used in-depth, one-on-one interviews from a semi-structured interview guide that was in English. Face-to-face interviews were conducted as they allow the participants to feel free to respond and not feel peer pressured by competing in answering like as in a group. Questions were posed in a neutral manner; listening attentively to participants' responses, and asking follow-up questions and probes based on those responses (Boyce & Neale, 2006).

3.6.2 Data Collection Process

Burns and Grove (2003) define data collection as a precise, systemic gathering of information relevant to the research sub-problems, using methods such as interviews, participant observation, focus group discussions, narratives and case stories. For this study, appointments were made with each participant for a time that was convenient to them. The participants were then interviewed in a convenient room secluded from gathering areas at the Student Health and Wellness Centre. Semi-structured guide, face-to-face interviews were conducted to collect data, since the researcher wanted to thoroughly understand the students' lives and experiences in order to gain full understanding of their experiences. The interviews took 15-30 minutes depending on the openness of a participant.

Semi-structured interviews were chosen as they involve asking relatively open-ended questions of research to the participants in order to discover their perception on the topic of interest. The researcher is also given an opportunity the interview to probe and find out more useful information from the participants (Given, 2008). Face-to-face interview also provides the researcher with an opportunity to probe and investigate hidden and suppressed views and experiences of the participants, also observe body language and interpret emotions, anxiety and silence gestures. Face-to face interviews also encouraged the participants to share their experiences in a

more open manner and to air their views without any pressure. This also ensured that the participants were free to express themselves in privacy (Tod, 2016).

Permission to use a tape recorder was granted by the participants wherein a participant's information sheet was given to all and consent to sign. The tape recorder was used to capture the responses of the participants and also not to miss any information that was being said. Field notes were taken for other non-verbal insinuations during the interview. An in-depth mode of interviewing is flexible and encourages the research participants to speak in length, introduce and elucidate on issues concerning the focus of research (Boyce & Neale, 2006).

3.7 Data Analysis

The purpose of data analysis is to organise, provide structure and elicit meaning from the data (Polit & Beck, 2012). The present researcher used Tesch's method to analyse the data; having to transcribe, interpret and make sense of the information contained in the data (Creswell, 2003).

Tesch's eight steps of data analysis were used as described in Creswell (2003), namely:

- The researcher listened to the audio-tape recordings, making transcripts out of the voice recordings.
- The researcher then read and re-read the verbatim transcripts thoroughly in order to make sense of what was said by the participants, while considering the underlying meaning from the responses obtained.
- The researcher continued to read and analyse the transcripts, each and every one of them, until all were analysed. A list of all topics was compiled. Similar ideas or themes were then clustered together and organised into columns that were arranged into major topics, unique topics and exceptions.
- The topics were then abbreviated into codes and the codes were written next to the proper fragments of the text. The researcher then checked whether new categories and codes were emerging.
- The researcher then identified the most descriptive or meaningful wording for the topics and turned them into categories. Topics that related to one another

were then grouped together, thus reducing the total list of categories. Connecting lines were drawn between the categories to show interrelationships.

- The researcher made a final decision on the abbreviation for each category and wrote them in alphabetical order.
- The researcher assembled data belonging to each category in one place to make a preliminary analysis known as coding.
- The researcher recoded the existing data.

3.8 Eligibility Criteria

3.8.1 Inclusion Criteria

The study included those students whose viral load was not being suppressed and whose CD4 count had been found not to be improving after 6-12 months of being on treatment according to their follow-up record in their ARV files.

3.8.2 Exclusion Criteria

Excluded were those who did not give consent to participate in the study and also those who were less than 12 months on treatment.

3.9 Measures to Ensure Trustworthiness

To ensure the quality of data findings in this study, Lincoln and Guba's model for establishing trustworthiness was used. The model was used to look into 4 aspects which are, namely:

3.9.1 Credibility

This refers to the confidence in the truth of data and interpretation of that data (Polit & Beck, 2012). This was achieved by applying the procedures of prolonged engagement and creating rapport with participants, persistent observation by taking field notes and use of tape recorder, all of which is using multiple sources to collect data to ensure triangulation. Member checking was also ensured by having an on-going conversation with the participants and reflecting back what was said and the interpretation thereof. There was no language barrier as both the researcher and

participants were conversant in English, which was the language used. Probing questions were asked during the interviews in order to obtain relevant rich data.

3.9.2 Dependability

Polit and Beck (2012) refer to dependability as the stability of data over time and conditions. The researcher comprehensively documented the research methodology to provide future researchers with evidence with which they can verify the results.

3.9.3 Confirmability

Confirmability refers to the objectivity or neutrality of data, or the potential for congruence between two or more independent people about the accuracy, relevancy, or meaning of the data (Polit & Beck, 2008). Field notes and audiotape recording were kept in a safe place where they cannot be accessed and manipulated. The researcher ensured that transcripts are in line with the audiotape recordings and a detailed report on how data were collected, how long an interview took and how data were analysed. The researcher also invited other researchers to do some independent transcribing, co-coding and official examination of the collected data. Agreement about the findings between the researcher and co-coder were met. Information on the use of an independent coder who is an expert in the field with all credentials in place, is provided (see Annexure G).

3.9.4 Transferability

This refers to the extent to which the findings can be transferred to other settings or groups. This is ensured by providing sufficiently thick, rich and detailed description of the research method used for data collection, analysis, as well as the settings where the study took place (Polit & Beck, 2008). To ensure transferability of the study, all data collected and results were based entirely on the participants' opinions and experiences. Since the data were collected entirely from university students, it may only be transferrable to university settings.

3.10 Ethical Consideration

The study involves human beings and the researcher must exercise care and ensure that the participants' rights are protected (Polit & Beck, 2008). Permission from

different platforms in order to conduct the study is discussed where it was sought, the three basic ethical principles and how they relate to this study is discussed.

3.10.1 Permission

Permission to conduct the study was sought from TREC (Annexure A) as well as from the Director at the Health and Wellness Centre of the University of Limpopo (Annexure C).

3.10.2 Ethical Principles

3.10.2.1 *Beneficence*

According to LoBiondo-Wood and Haber (2010), research and the research process must maximise benefit (beneficence) and minimise harm (non-maleficence) at all times. The present study benefited the students in a way that the reasons for them having virological and immunological failure were addressed and this will prevent treatment failure and possible regimen change which is more expensive.

Research participants were not subjected to any harm or discomfort and no invasive procedures were carried out, only their clinical records were used to obtain the blood results. Protection of the privacy of research participants was ensured where they were given pseudonyms and only known as participants in order to ensure anonymity. An adequate level of confidentiality of the research data was ensured whereby they were assured that their consent was not to be kept at the same place as with the recordings. Any deception or exaggeration about the aims and objectives of the research was avoided and only true information was communicated to the participants. Any type of communication in relation to the research was done honestly and transparently.

3.10.2.2 *Justice*

LoBiondo-Wood and Haber (2010) state that this principle deals with the right to fair treatment and the right to privacy. In this study, privacy was ensured in that the patients' audio-tape recordings were kept under lock and key at the researcher's office and the key to the locker was kept only by the researcher, and it was maintained as such throughout the study. One-on-one interviews were held in a secluded room to ensure privacy.

3.10.2.3 Respect for Dignity

LoBiondo-Wood and Haber (2010) state that this principle entails ensuring that the researcher respects the confidence of the research subjects and recognises that they have the right to decide. For this study, anonymity was ensured in that no names would appear on the data collected and only codes would be used. Confidentiality was ensured as well that no one would have access to the data collected, except supervisors. Full consent was obtained from participant after being made to understand all this. Consent was obtained to protect the participants and ensure that they are willingly partaking in the study and they may at any point; withdraw if feeling uncomfortable, without fear of prejudice. Respect for dignity of participants was ensured where participants were prioritised and their time was respected where appointments were set. There was also full disclosure of the nature of the study and likely risks and benefits of the study to the participants. Permission to use a tape recorder to capture all information articulated was as well sought from the participants.

3.11 Bias

To avoid bias in this study, Lincoln and Guba's model for establishing trustworthiness was used. The researcher avoided bias questions that would have influenced participants' answers. Biased questions were recognised and avoided by not asking leading questions. The researcher formed rapport with the participants in order not to intimidate them during the interview and avoid giving opinions to them. Participants were asked to be as much truthful as possible in order to avoid biased answers. A biased sample was avoided by only choosing participants who are having only immunological and virological failure.

3.12 Conclusion

The research design, sampling procedure, data collection process and data analysis approaches were clearly described in this chapter, including also a description of ethical issues that were followed. Chapter 4 that follows further discusses the research findings.

CHAPTER 4

INTERPRETATION AND PRESENTATION OF FINDINGS

4.1 Introduction

In this chapter, a summary of the findings from the semi-structured interview guide's responses during data collection is discussed. The participants have been on ARVs for more than a year and their blood results were reviewed to see progress of their viral load and CD4 count. Based on the participants' responses, the researcher identified five themes that could be seen as factors that affected the students' virological and immunological status as established in their blood results. These themes were broken down into sub-themes that overlapped.

4.2 Characteristics of Participants Illustrated in a Table

Pseudo names	Age	Gender	Study level	Marital status
Participant 1	22 years	Female	2 nd level	Single
Participant 2	32 years	Male	Honour's degree	Single
Participant 3	28 years	Female	3 rd level	Married
Participant 4	26 years	Female	3 rd level	Married
Participant 5	30 years	Male	Master's degree	Married
Participant 6	28 years	Female	4 th level	Engaged
Participant 7	27 years	Female	3 rd level	Single
Participant 8	21 years	Female	4 th level	Single
Participant 9	21 years	Female	3 rd level	Single
Participant 10	23 years	Female	Honour's degree	Engaged

4.3 Summary of Themes and Sub-Themes Reflecting the Findings from the Interviews

THEMES	SUB-THEMES
1. Disclosure versus stigma, thus making it difficult to take treatment when amongst people.	1.1 Lack of disclosure among roommates, which makes it difficult for one to adhere to treatment. 1.2 Lack of disclosure among family members affecting treatment-taking when at home. 1.3 Fear of rejection from partner following disclosure of HIV status.
2. ARV packaging too noisy and indirectly disclosing one's status.	2.1 ARV container perceived as disclosing one's status. 2.2 More improved ways of containing ARVs suggested and discreet ways of handling ARVs when in public.
3. Side effects of ARVs affect studies.	3.1 Students are unable to adhere to ARVs as they put their studies first. 3.2 Side effects of drugs also make time schedule different to adhere to, thus resulting in missing doses.
4. Service delivery affects adherence to ARVs.	4.1 Isolated or secluded rooms for HIV positive clients stigmatise users of the service. 4.2 Attitude and competence of health-care providers affect follow-up visits and treatment outcome. 4.3 Supermarket approach reduces stigma in HIV clients.
5. Being part of a support group encourages compliance and adherence.	5.1 Support from people in a similar situation makes it easier to accept status. 5.2 Support group for other conditions could help reduce stigma.

Theme 1: Disclosure versus stigma, thus making it difficult to take treatment when amongst people

After data were analysed and coded, it was found out from participants that disclosure of one's HIV status was a challenge. That made it difficult for them to take treatment when they are in the company of peers. The theme yielded three sub-themes that are discussed below.

Sub-theme 1.1: Lack of disclosure among roommates makes it difficult to adhere to treatment

Participants who share rooms with other students found it difficult to disclose their status to their roommates and having to skip taking their medication on time because of that. A student related her fear of being stigmatised by her peers that she is close to and feared that they will isolate her if they knew about her status.

Participant 1: *“Yea, my perceptions is yes, because some of the things we discuss in maybe in maybe we discuss in class like in class there is the discussions concerning information sharing, you find that people they speak much bad about HIV information statistics and so on. So it’s clear to my mind it does say, if people can able to understand or know about my status maybe they’ll stigmatise me or they’ll run away from or be disassociated with me. So it’s one of the other challenges that most of the students they come across, so they unable to disclose because of the peer pressure within their schoolmates.”*

This was confirmed by another student who had to disguise her medication taking in front of her peers as she did not disclose to them.

Participant 6: *“No, my roommate and even friends don’t know about my status. Yes I remember this other day I visited my friend and it was halve past eight, so I had to take my medication, I just pretended as if I was taking a tissue and I put that pill there, I pretended as if I wanted to spit out something and I took my medication and drink water, they did not know that I took the pill.”*

Another student indicated that he did not trust and he feared disclosing as he fears rejection from his peers if they were to know about his status.

Participant 7: *“No I haven’t told them. And I don’t know how they will take it and sometimes they have conversations and you can hear from the conversations that they can support but then not really they wouldn’t be comfortable with the person that know is closer to them having infected. So, for me to disclose, it still a bit challenging cause I don’t know what I’m going to expect.”*

One student reported that she skips taking her medication when her roommate is around; this posing a big risk when it comes to adherence as the drugs have to be taken same time every day.

Participant 9: *“When she’s in the room I don’t take my medication.”*

Disclosing of HIV status can have an effect on people as they might react differently to the news and it might go negatively or positively. Others might embrace and support whilst others might reject and be scared for the affected person or themselves. Disclosing your HIV status to others may seem challenging and complex as having to cope with the disease itself. It can leave one vulnerable to a number of possible responses any of which can cause anxiety, fear or being overwhelmed with fear of rejection, loneliness or social isolation. Disclosure, on the other hand, can bring about relief and improved interpersonal relations amongst peers, family members and the society at large.

Participants found it difficult to disclose their status with their roommates due to fear of being judged and isolated with the perceived stigma of their HIV status. These quotations indicate that there is still a problem in students disclosing their status to their peers and this affecting their compliance with treatment taking. These responses from students were supported by a qualitative study on disclosure of HIV status and adherence by Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuzza *et al.*,(2006) in Uganda, which revealed that Anti-Retroviral Therapy is better adhered to where the treatment is free and in community-based programmes. This indicates that both stigma and not disclosing status to those within the radar that one lives in have a direct impact on determining treatment success or immunological and virological failure. Marukutira (2011) attested that good adherence in adolescents is attained when one had family support, friends’ support and community support. This network of support ensured compliance to the drugs-taking.

Subtheme 1.2: Lack of disclosure among family members affecting treatment-taking when at home

The following extracts indicated that students find it difficult still to take treatment when at home due to misconceptions of family members when having tested HIV positive. One student indicated that it was easier to adhere to treatment after she disclosed her status to her peers but found it difficult around her family members who did not understand and needed more sensitisation about HIV.

Participant 2: *“Yes, it is..eeeh...at first when I tried to disclose I started like preparing my family and my friends and it was easy to disclose to my friends but not to my family. To my friends, ok we are in the university they know, some they know about HIV, so it was easy for me to disclose to them, ok, fine. I cannot like keep on doing this taking my medication maybe roll it in a tissue hide, maybe going outside as if I’m going to drink water, you see those things, so I told them no, it’s time for me to tell you that ok, I’m HIV positive and when its 8 o’clock, don’t be surprised, I’m taking my medication, but when it comes to family it was a bit difficult because of my cousins or my siblings they used to maybe make, like make jokes about people who are HIV positive they’ll be like, ha that person he’s dying, oh you saw that person, oh sphamola se mo tshwere (HIV has gotten her), things like that and then it was difficult to tell them that do you see that person you are talking about, I’m also like him or her. So I try to like, at first I just, when it was 8 o’clock I just took my medication and put it on the table and then drank it and then my mom was like what is that for and then I just said it’s my medication it is something that will keep me alive for a long time because of I’m having an infection, and then she was like mhh ok. She didn’t have a problem. And then next month, are you still taking this thing?” and now it’s ya I’m still taking it I’m taking it forever and then she’s like ‘hawu (expression of disbelief), are you having cancer?’... she didn’t mention HIV, she mentioned all this other, infections and diabetes and stuff, high blood, and then I was like no its because I’m HIV positive and then she laughs.”*

This statement was supported by another student who found it difficult to disclose her status to her mother as she did not understand HIV dynamics and still had misconceptions about HIV.

Participant 4: *“Yooh, at first I took time to disclose more especially to my mother, I remember I was pregnant at that time. And I couldn’t tell her gore now I’m pregnant and positive as well so I didn’t disclose to her. it took me almost 5 months and I disclosed to her after I knew that the baby as well is infected, then I disclosed to her, cause you know our parents they believe in those traditional things they’ll want the child to go do some things, what what, then I had to tell her my child doesn’t do this and that because of the status.”*

One student feared disclosing to family members as they would see her as being promiscuous and sleeping around. This leads to them having to hide behind other family members who are sick in case they are caught out.

Participant 7: *“Uhm in my family, nna my mother, eish my mother o, she's, oa re roga (insults us), thata (a lot) gore (that) "ya (yes), le... bashimane*

(boys) or le even if you find condoms in our bag, but my aunt, my sister to my mother o mo nnyane (younger), aah yen when you talk to her very nice, and because le yena (she) is HIV positive, so it's nice for me to talk to her and sometimes even if they find the pills , they know gore it's her and they don't think it's mine. and then I take the pills as if I'm reminding her, gore mmane ke nako ya di pilisi (aunt it's time for pills), le, even if they find it in my hand , kere haai (I say no) ne ke isetsa mmane (I am waiting for my aunt), and then sometimes we sit together and take them together....”

Participants also indicated that it is difficult for them to disclose their HIV status to family members. The fear led to them being unable to take medication in front of family members. Students feared being rejected or judged by their family members when having disclosed their status to them. Adherence to treatment then becomes a problem as they have to wait for awkward times to take their treatment, hence disturbing the routine schedule and thus leading to virological and immunological failure.

Ndou, Risenga and Maputle (2013), in a study on Experiences of HIV positive patients on ARV in Limpopo, revealed that families are ignorant of the mode of transmission of HIV, despite all efforts of talks and education being done in the media and healthcare facilities, they remain with an attitude when it comes to having a family member who is HIV positive. Some of the experiences in the study were that

Others reported to have been expelled from home after parents found out about their HIV positive status. Ndou et al., (2013) also found other clients having to go to the Health Care Centres alone, with no family support, whilst in their weak state, thus making it difficult to can hear all instructions well.

Others who were HIV infected were treated like dogs at home where they will be shoved food without even being asked how they are feeling, and if they are hungry or not. This kind of rejection by family members often led to compliance and adherence problems.

Marukutira (2011) attested that good adherence in adolescents is attained when one

had family support, friends' support and community support. This network of support ensured compliance to the drugs.

Subtheme 1.3: Fear of rejection from partner following disclosure of HIV status

The majority of participants reported that they fear being rejected by those close to them if they reveal their HIV status to them. This led to them not disclosing and having to hide their medication. Some even reported that they might be regarded as different human beings due to their HIV status. Participants related their experiences by explaining that:

Participant 1: *“Eish, it would be difficult still I believe that if I say, I’m HIV positive, he would actually see it as me being a risk to his life than him accepting me the way I am, so us having a baby I do see the future, it’s not gonna be easy, an easy future.”*

This other student feared being in relationships and even resorted to not having a relationship at all as he feared having to explain himself and his status.

Participant 2: *“I think maybe because of a bad experience that I got with the HIV status it makes me to be cautious and say no, what else is in the person I’m going to be who is going to understand me as a man, a person who is normal, who’s going to give a life, a love life in a full or is the person that I’m going to be involved could re infect me if ever the person is not aware of his or her status, so I had to be cautious about that. So is one of the elements to make me say let me sit back and understand the what elements that I should consider to be involved in relationships.”*

One student found it easy to have a partner that is HIV positive as it made things easier. The positive partner also served as a support structure as they would also remind each other to take treatment.

Participant 3: *“No, I met him after I’ve tested positive and then to find out that he’s also positive when I tried to disclose my status to him and then he told me that you know I was about to tell you the same thing that I’m also HIV positive.”*

One student who reported to be in an abusive relationship feared for her life if her partner was to know about her status, though she herself did not know about her

partner's status. This was brought about by that the partner is supporting her financially too and fears what would happen if he finds out about her status and decides to leave her.

Participant 7: *“I’m, no he doesn’t know, he doesn’t know as well because if he knows, I don’t know, he’s one of those abusive people so might, you know, harm me at some point, and at some point he supports me so I don’t think it will be good, like financially, yes, and all that. Now, if I tell him that I’m HIV positive, it’s something else he’s just gonna stop and he’s gonna run and I depend on him, he helps me with my stuff sometimes during the month.”*

The statement was supported by another student saying that she feared being stigmatised by her partner as he usually talks about HIV positive people negatively.

Participant 9: *“Yes...no he doesn’t, fear of being stigmatised. I once... we once had a conversation, and he stigmatised the people so I’m afraid that since it’s he had the audacity to stigmatise another person it’s easier with me too. The fact that he’s in a relationship with me won’t stop him.”*

Studies from both developed and developing country settings identified that disclosure rates to sexual partners are increasing overtime. Whilst others fear of a negative outcome like rejection, blame, abandonment, stigma, majority who disclose reported kindness, increased social-support acceptance and strengthened relationship. Students also experienced such outcomes.

Ndou (2013), in a qualitative study in Limpopo, discovered that participants in the study were still having difficulty in disclosing to their partners due to potential risk of being blamed, loss of economic support, abandonment, physical and emotional abuse from partners, discrimination and disruption of family relationship. Participants also feared to be accused of infidelity and unfaithfulness leaving them not to disclose on their status. Parsons, Van Ora, Missildine, Purcell and Gomez (2004) also mentioned negative experiences associated with disclosing of a positive HIV status to sexual partner such as rejection, loss of intimacy stigma and often threats.

Theme 2: ARV packaging too noisy and indirectly disclosing one’s status

ARV packaging has always been a concern among users. Participants on ARVs often complain that the rattling sound draws attention and they become paranoid which in way can be self-stigmatisation.

Subtheme 2.1: ARV container perceived as disclosing one's status

One student mentioned that students are aware of what an HIV container sounds like as compared to other containers and thus indirectly disclosing their status with the noise that the container is making. The student population was seen as smart to can tell the difference.

Participant 1: *"Oh the container. If you take the container of the ARVs or a container of just mere normal pills and shake them, they don't sound the same. And I believe people have noticed that, the containers they don't sound the same when you're shaking the pills, you can hear gore this is ARV container. In here it's ARVs and in here are just normal pills. So if maybe the containers made the same sounds it would be better, because either, whether I'm carrying ARVs or I'm carrying just normal pills, no one will know, no one will notice...eh."*

This was also confirmed by the next participant who also shared the same sentiments about the noise the container makes.

Participant 3: *"Ok, at first, that container they are using, eish because you'll find that maybe I'm coming from the health centre to take my medication, when I'm busy walking you hear "kgonche! Kgonche (sound gesture)!" so everyone knows that, oh, ARVs, they, for me I think if maybe if you people should change their containers, maybe use something that won't make that sound or maybe something...that English is gone. Something e tlo dirang (that will make) gore ebe (it be) manageable, something o tlo kgona go swarang ka yona e sa diri (that you will be able to carry without a) sound, yes."*

The next student also faced the same challenge with the container and it was seen as drawing attention to other students.

Participant 6: *"...but then even walking around with the containers Ahhh!. Is a challenge, the noise that the pills are making inside the container..."*

ARV packaging was seen by this student as an obstacle for adherence as immediately one takes it out, then it draws attention.

Participant 7: *“Oho, ok, uhm... maybe the packaging, I would say the packaging, ke yona ya go regherisha (it’s telling on us). I mean, honestly speaking, if people did not know the packaging of the ARVs, I wouldn’t have a problem of taking the medication public. But with people are well aware of the packaging and how they look like, so the moment I take them out I’m gonna have a problem, hence I’m hiding them from my friend and hence I can’t take them out even when I’m in class cause it would be time cause the minute I take them out it would be oh so she’s positive so she’s taking medication and I don’t want people to think that way you see...”*

This other student reported that people are aware of the packaging and indirectly disclosing status and made suggestions on what could assist in better adherence.

Participant 9: *“I’m thinking the packaging ...it’s very noisy, so maybe change of the packaging or maybe we are provided with trays that don’t have the name because since time are evolving people know the names of the product that is written on the packaging...”*

Participant 10: *“Ok, the noisy container, chokgo chokgo chokgo (sound), you see I’ve realised that pills or tablets come in different packages....”*

A researcher in Botswana Mr Fabian Schlatter posed the question on research gate if there is any literature available regarding the effects of ARV packaging on PLWHA. In his line of work on ARV adherence he had noticed that PLWHA receiving their plastic bottles are annoyed of the shaking noise the tablets make inside the bottle. This was reported to be worse when using public transport as one would be recognised as HIV+.

Mr J. Craig Phillips in inner city Miami also had similar concerns as patients would use paper towels to put in their pill bottles before leaving the clinic to prevent the pills from rattling.

Sekoni, Obidike and Balogun (2012) agreed with the above statement in Nigeria, that patients on ARVs experienced tiredness of the routine of taking their drugs and skipped their doses. Removing ARVs from the labelled containers and putting them in unlabelled pill-boxes was the adopted coping strategy for avoiding stigma. Participants who attended the HIV clinic regularly experienced a personalised stigma and this affected their collection of the ARVs.

Subtheme 2.2: More improved ways of packaging ARVs and discreet ways of handling ARVs when in public

Participants felt that the best way for them to adhere to medication is if ARVs packaging could be improved. This will ensure that, when they carry their medication in public, it will not inconvenience them and it would improve their medication intake. Participants explained their feelings regarding packaging of ARVs by saying that:

Participant 1: *“Oh the container. If you take the container of the ARVs or a container of just mere normal pills and shake them, they don't sound the same. And I believe people have noticed that, the containers they don't sound the same when you're shaking the pills, you can hear gore this is ARV container. In here it's ARVs and in here are just normal pills. So if maybe the containers made the same sounds it would be better, because either, whether I'm carrying ARVs or I'm carrying just normal pills, no one will know, no one will notice...eh.”*

This was supported by another student who felt it would be easier if the ARVs were packaged in a container that did not make a sound and one is able to carry it around.

Participant 3: *“...for me I think if maybe if you people should change their containers, maybe use something that won't make that sound or maybe something mmhhhh...that English is gone. Something e tlo dirang gore ebe (that will make it) manageable, something o tlo kgona go swarang ka yona e sa diri (that you can carry without a) sound, yes....”*

This one student came up with an innovative way of packaging the pills from the support group. This meant that the pills were removed from the original container and this posed a problem as there is no evidence of drug efficacy after it was removed from the original container.

Participant 4: *“Ok, since we have the support group here at the health centre, what we suggested is that since here at the clinic they have these plastic, what do they call I don't know, whatever you call, yes, then you open that meds then you put it in those packs, instead of taking them with that one that will draw people's attention.”*

One student reported being tired of the daily routine-taking of treatment and said it would have been easy to have an injection like in contraceptives.

Participant 6: *“... Aahhh nna (me) I thought gore that they can just inject us and we know that we can just go once, like family planning. So I think that once will be better. People won't be missing their doses, because it will be a once off, rather than taking every day, someday you eeehhh....”*

One student reported that the packaging could be disguised instead of the original packaging as people now know the names. This, in a way, made them to stigmatise themselves as even if people do not say anything already they have judged themselves.

Participant 8: *“...maybe we are provided with trays that don't have the name because since time are evolving people know the names of the product that is written on the packaging...yes like di...those with Sunday, Monday, Tuesday, Wednesday, then you put them in there Yes”.*

One student even suggested the use of blister packs like with oral contraceptives and TB drugs as they did not make a sound.

Participant 10: *“...the ones that they use for contraceptives the one that they pack them individually in a simple pack, plastic pack, I mean that one when you open it it's like you are opening a sweet, even if you open it in front of people it's rare that someone that someone will ask what is that, you can even cut it out and take piece out and then you go wherever that you have to be with it and then at the right time you take your tablet, but the container its very much disturbing for me , so I think that's one thing that needs to be looked into...”.*

Participant 7: *“...maybe if sometime I try taking, putting them in a different container so they don't look like ARVs, right, but then sometimes they get mistaken, my medication with other medications which the dosage, well the container looks like and I end up lying maybe but it has been working for, it's been working for me.”*

Participants verbalised frustration due to ARV packaging and has been seen as attracting people's attention, indirectly disclosing their status. As mentioned by Mr J.

Craig Phillips, in inner city Miami, those patients would use paper towels to put in their pill bottles before leaving the clinic to prevent the pills from rattling. This showed the level of discomfort of having to take medication when in public.

Theme 3: Side effects of ARVs affect studies

Participants explained that the reason they do not take their medication is that ARVs have side effects that affected their studies. They reported that their priority was studying and passing and sometimes they had to skip medication in order to focus on their studies.

Subtheme 3.1: Participants are unable to adhere to ARVs as they put their studies first

Participants found it difficult to continue taking medication because the side effects were affecting their studies. Some of them reported signs of dizziness and that affected their focus on their studies.

Participants reported their experiences by saying:

Participant 2: *“...it can affect a student life and career wise remember if ever you are taking the medication you have to read, and at the same time you cannot your highest learning or you get dizzy and so on. You end up like not studying and you just sleep and then at the end of the day it can harm your career and performance.”*

This other student also agreed that the ARVs made her dizzy but said in time the medication gets used to the body and the side effects are less.

Participant 3: *“...I started accepting my status and then it was easy for me to take them in front of anyone and another thing it also affected my academic because of they have side effects. at first I used to feel dizzy and then you find out maybe I’m preparing for my test, maybe I’m writing for my exams and then sometimes I feel nauseous things like that so it those side effects they were the ones that were giving me the problem because of I have to adjust because of my body it has to like adjust to the treatment so it was difficult at first but for now things changed because I’m used to them and I no longer hide them.”*

One student, however, reported to be skipping a dose when she had to write an exam as it meant her studying the whole night.

Participant 9: *“Also the time because sometimes I have to study, and then it’s hard for me to study when I have taken my pills so sometime I skip it to cross night and not adhere to time”*

Subtheme 3.2: Side effects of drugs also make time schedule different to adhere to, hence resulting in missing doses

By continuing with medication, participants found it difficult to adhere to medication due to its side effects. They also reported that the schedule to take medication interfered with their programme and they had to skip medication in order to focus on their studies. Some of them explained by saying that:

Participant 5: *“...you are always feeling tired, you don’t concentrate and everything like that, yes those are the challenges I had.”*

This was confirmed by this other student that the strict time schedule of ARVs-taking made it difficult for students to adhere to as she had to study.

Participant 6: *“The only problem that I have recognised from myself and also other that are taking ARVs is the problem of the side effects because like since for us as we are students like most of us well prefer like I will wake up at night and try to study, but if you are like on medication it’s kind of maybe impossible cause in the middle of the night, that’s the period where you are feeling dizzy and everything. The only option you have is to do everything in the morning. So during the night you don’t have any option.”*

These side effects were a great concern for students as also reported by this participant thus:

Participant 4: *“Sometimes those ARVs as you know they have side effects, at some point you find yourself dizzy while you have to study maybe for your test or something so the experience is that, you get dizzy at some point and maybe you lose time of your studies, and then at some point you forget, rather not forget but sometime you are at academic and some people are here and sometime you don’t have time like you are afraid to take your meds at that time, because they are people around you.”*

Students resorted to skipping a dose in order to study as they put their academics first.

Participant 9: *“Also the time because sometimes I have to study, and then it’s hard for me to study when I have taken my pills so sometime I skip it to cross night and not adhere to time”.*

Lekhuleni, Mothiba, Maputle and Jali (2013) revealed in Limpopo that patients on ARVs are not adhering to treatment as they faced side effects of the drugs and resorted to missing a dose so as to cope with everyday life. Watson (2018) also agreed that antiretroviral drugs can cause side effects that can be severe enough that some people stop taking them, and that sticking to a treatment plan is not always an easy task to do. This, in a way, was seen as affecting adherence to ARVs.

Theme 4: Service delivery affects adherence to ARVs

Participants reported that the way services are rendered exposes them to other students. They indicated that there is no privacy, which makes it difficult for them to consult in public. The theme yielded three sub-themes that are discussed below.

Sub-theme 4.1: Isolated or secluded rooms for HIV positive clients stigmatise users of the service

Participants appreciated the service they receive at the Student Health Centre as they are not secluded from other students and this is seen, in a way, as reducing stigma.

Participant 1: *“In the community, stigma, HIV positive people are being stigmatized, we are being stigmatized because they see us a threat. so on campus very better because there’s privacy, and when you consult nobody asks you are you going to take ARVs, so you just go straight and you consult, that’s it, but then...yes. But then at the communities, they always say, HIV positive people this side, mothers of new born babies this side, they actually seem to classify us and it’s not good.”*

Participant 6: *“The treatment at the health centre is good cos everyone welcomes us, they don’t criticize us to say, ‘hey wena (you) with HIV go that side’, they just keep it confidential unlike our clinics at home.”*

Participant 9: *“Very good, very good I’d like to say...the clinic yes, cause the consulting rooms don’t really isolate, they don’t isolate the consulting rooms, so people don’t know what I’m doing there.”*

Another student confirmed that, at their local clinics or hospitals, they discriminate against those who are positive and there is a specific room just for HIV patients.

Participant 3: *“...yes they discriminate people who are HIV positive then you find that there’s a place just for people who are HIV positive, maybe there’s a building that all people who are HIV positive, they just go there, then maybe there’s a, if maybe it’s a clinic, there’s a room, you know that room is only people who are HIV positive who get in that room, or maybe there’s a house out and there’s maybe 2 rooms outside, that ok, each and every person who gets to that room is HIV positive. So the treatment that could get or had from the health centre is different from the one that you get from other....”*

One student even loathed the thought of going to her local clinic and wished she could get treatment to last her the whole year if possible in order not to visit her clinic.

Participant 10: *“... when you had closed or winter recesses I just went to the clinic back at my village, I was just walking around just to see what is it I should expect that when I come back in December. So I realised that people who collect ARVs they have a certain place they have one office at the corner, right next to the one that they test for HIV, and everyone knows that that particular consulting room is for ARVs treatment collection. So it’s something that disturbed me and somehow I even wished that if it was possible I can get treatment for the whole year so that I don’t have to go there lie every month or after 3 months like whatever the case would be so, ya (yes) it’s quite different from, there is, the, like, the experience here at campus.”*

A study in India identified that service factors and the quality of care provided can serve as barriers to treatment adherence. Discrimination among clients at the point of service delivery was seen as a major barrier when treating HIV/AIDS (Beattie & Bhattacharjee, 2009).

Subtheme 4.2 Attitude and competence of health-care providers affect follow-up visits and treatment outcome

Participants appreciated the Student Health Centre staff for their attitude and understanding that they receive when doing consultation. This is what participants said regarding their experiences when doing follow-up consultations.

Participant 3: *“Sometime when I’m home ne, I feel like eish why can I maybe study forever or until I die, cause of the treatment that I get here, eish I don’t know how to compare it with other health facilities because of others you’ll find that they discriminate people who are HIV positive. Even if they are staff members, they are health professionals, you find that they discriminate and then you find that they don’t, I forgot this word, how to sort of...they don’t respect people who are HIV positive. They think if you are HIV positive, it means you were sleeping around. They are, eish...I don’t know...”*

This was confirmed by another student that a healthcare provider’s attitude does affect the way one will continue with their treatment taking. Students reported to be having attachment to the service at the health centre and even wished that they could take treatment there for the rest of their lives.

Participant 5: *“No its ,it’s not difficult because firstly I know the importance of taking my medication and also the health practitioners around here, they makes it easier for us to collect our medication, because like, during our collection of medication you can feel like the person you are consulting to like you can relate to the person, it makes it easy or it makes it easy for you to come with your status and everything so like I don’t have a problem every time I have to come and collect my medication or having to consult for any other for most sickness, so it’s very easy.”*

Participant 7: *“...Cos the staff also don’t judge you and they don’t give you that look that you are HIV positive, how did you get it, do you sleep around unlike in other public clinics kore now you’d have to, u know, try and become defensive over why you are positive, right they would be giving you looks and those looks are not nice hence sometimes I don’t go when I’m home you know.... I’d wait for me to come back to school to come.”*

Another student reported that health-care providers have an impact indeed on treatment outcome as they are the ones responsible for guiding clients on how to take treatment.

Participant 6: *“Yes health-care providers are assisting in treatment outcome as they teach everything and even when challenges, I find it easy to come and talk to them.”*

One student reported that, at the community clinic when at home, they are subjected to long queues as the clinics are always full. And she was concerned that only HIV patients are given files but not the rest; this was seen as something that created discrimination.

Participant 8: *“Ohooo...you know gore the reason I’m taking them here, ya it’s because kwa (there), we used to take them, we used to stay there for a long time, because it was always full, but here when you come, there’s a room, they’ll tell you gore you tick where you’re going an then they give you your file and then you go there and then, because sometime we students, even if you tell them gore I have class, or even if you tell them gore I cannot come because I was having class, at least it’s not so much of a problem, so the only thing fela ke gore (only is that) I’m just afraid gore when I’m having my file, what about other students, maybe they already know gore the room where I’m going maybe is for people ba eleng gore (those) they are taking ARVs. So sometimes o thole gore (find that) I’m afraid of that one...”*

A study done in Kwa-Zulu Natal revealed that, for an efficient service that ensures adherence, it will require staff to be supported in terms of training and in-service education. Adequate staffing also needed to be looked into for the success of adherence. This is done in order to ensure monitoring of patients on ART, and both detection and management of virological failure that may lead to drug resistance (Uzodike *et al.*, 2015).

Other experiences were that the staff-to-patient ratio led to the inability to follow up on patients’ virological monitoring. The researchers recommended that alleviation of shortage of staff will improve the quality of counselling and doctor interaction, where clients will have more time to interact with the caregivers, thus addressing their fears and concerns (Chibikuli *et al.*, 2010). This was confirmed by Murphy *et al.*, (2000) who discovered that the relationship between clients and healthcare providers has a significant influence on adherence to ART. Patients’ satisfaction with health care and quality of communication among clients and healthcare providers was an important influence on adherence to ART. Partakers who had good communication

and positive interactions with healthcare providers said they took their medication as prescribed while those who had poor interaction reported low-level of adherence.

Subtheme 4.3 Supermarket approach reduces stigma in HIV clients

It is reported by some participants that when doing consultation, it should not be obvious to other people that there are those who are HIV positive. The Supermarket approach ensures that nobody knows who is consulting for which condition. One student reported that, if all services are conducted in one room but not in a specific rooms, then they, as clients, would not feel discriminated against. She reported that, at the health center, the service is such that in all consulting rooms one comes out having received whatever service they required and not having to go into a specific room for that.

Participant 3: *“... yes they discriminate people who are HIV positive then you find that there’s a place just for people who are HIV positive, maybe there’s a building that all people who are HIV positive, they just go there, then maybe there’s a, if maybe it’s a clinic, there’s a room, you know that room is only people who are HIV positive who get in that room, or maybe there’s a house out and there’s maybe 2 rooms outside, that ok, each and every person who gets to that room is HIV positive. So the treatment that could get or had from the health centre is different from the one that you get from other...because here the staff is friendly, they understand us, it’s sometimes I even like say maybe they do understand how we feel, maybe it seems as though they also a positive, they are on our shoes, so the treatment we are getting here, ya.”*

Participant 6: *“The treatment at the health centre is good cos everyone welcomes us, they don’t criticize us to say, ‘hey wena (you) with HIV go that side’. They just keep it confidential, unlike our clinics at home.”*

One participant also emphasized and appreciated that the health centre service is good as it is not labelling to clients. They can go to any room and get assisted without anyone knowing what they were there for. This is mentioned in the statement below.

Participant 9: *“Very good, very good I’d like to say...the clinic yes, cause the consulting rooms don’t really isolate, they don’t isolate the consulting rooms, so people don’t know what I’m doing there.”*

This participant even went to the community clinic during recess just to have a feel of how things will be when she would have completed her study. What she discovered was not appealing to her as they still separated the services.

Participant 10: *“Eish, ya I can say so since well I’ve just, I’ve been the bad news like a few months back. When you had closed or winter recesses I just went to the clinic back at my village. I was just walking around just to see what is it I should expect that when I come back in December. So I realised that people who collect ARVs they have a certain place, they have one office at the corner, right next to the one that they test for HIV, and everyone knows that that particular consulting room is for ARVs treatment collection. So it’s something that disturbed me and somehow I even wished that if it was possible I can get treatment for the whole year so that I don’t have to go there lie every month or after 3 months like whatever the case would be so, ya it’s quite different from, there is, the, like, the experience here at campus.”*

The South African handbook for Clinic/Community Health Centre (CHC) Managers also describes the Supermarket approach as the daily provision of all services to the community but does not specify how these services will be offered (Pillay & Asia, 1999). Kendall-Rayno (2009) reports that community nurses are beginning to explore ideas from supermarkets in order to improve their own productivity, including “ways of organizing their working environment as part of the productive community services programme.”

Theme 5: Being part of a support group encourages compliance and adherence

Participants reported that being part of support groups assists them in accepting their HIV status and they feel encouraged to comply with medication. The theme yielded two sub-themes that are discussed below.

Subtheme 5.1: Support from people in a similar situation makes it easier to accept status

Students reported that, because they are in a support group, they felt free with people who understand what they are going through as they are in the same boat.

Participant 2: *“...my schoolmates and my roommate doesn’t know anything about my HIV status, but the group that I’m involved in especially like the support group, they know about me and I’m too vocal on that. So I hope in the near future I’ll be able to stand up and then disclose it and able to speak whole concerning HIV.”*

“...it makes life very easier and even to understand much better about the HIV and how it’s supposed to be treated and, especially when it come to the daily medication I carry it you have to understand ok what time are you going to take your medication and what is the repercussions if ever you are not adhering to your medications.”

Participant 4: *“Ok, since we have the support group here at the health centre, what we suggested is that since here at the clinic they have these plastic, what do they call I don’t know, whatever you call, yes, then you open that meds then you put it in those packs, instead of taking them with that one that will draw people’s attention.”*

Participant 9: *“I’ve joined a support group but it’s not easy telling them, they are very welcoming, so it’s not easy telling them that I can’t take my medication because I’m afraid of disappointing them that’s why sometimes I’m not honest about it...yes”*

Support groups for people living with HIV are integrated into HIV care and treatment programs as a modality for increasing patient literacy and as an intervention to address the psychosocial needs of patients. The World Health Organization (WHO) proposes support groups as an intervention to address retention and adherence among PLHIV receiving Anti-Retroviral Therapy (ART). Both WHO and the US President’s Emergency Plan for AIDS Relief (PEPFAR) promote peer-support groups facilitated by trained PLHIV to address the special needs of fellow PLHIV and their partners. Such groups serve the purpose of sharing experiences; encouraging disclosure; reducing stigma and discrimination; improving self-esteem; enhancing patients’ coping skills and psychosocial functioning; and supporting medication adherence and improved retention in HIV care.

In a study conducted in South Africa, Visser et al., (2005) showed that support groups provide PLWHA a relaxed platform to share their experiences about HIV and AIDS and build new friendships, love and acceptance, suggesting that the formation of support groups can be a source of valuable support for people living with HIV and

AIDS. Agreeing with statements from participants they get to share their fears with group members and they learn more information about the disease and also ways of coping with the container making noise as they perceive it.

Subtheme 5.2: Support group for other conditions could help reduce stigma

Another participant reported that it would be easier to have support groups for all conditions:

Participant 2: *“I think one of the other things that will make it our concern is to formulate groups, especially in chronic diseases whereby we can talk about everything and then highlight each and every chronic diseases including HIV and aids, where people can able to understand HIV better and then to minimise the stigmatisation because the moment they understand the treatment of HIV and how it works and how they can be able to manage their own life, it will be better and substance abuse, alcohol abuse, reinfection issues and also thereby they need to be touched concerning in those supporting groups so with those supporting group they can be useful.”*

Although support and self-help groups can vary greatly, all groups share one thing in common, they are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves. In addition to providing support, some groups may also focus on community education or advocacy.

4.4 Conclusion

This chapter has presented data categories and the themes that emerged from data analysis of students' experiences on ART. Relevant literature was also presented as a control to the research findings. The following chapter focuses on the summary of findings, conclusions drawn by the researcher, implications and recommendations.

CHAPTER 5

SUMMARY, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

5.1 Introduction

The aim of the study was to explore the experiences of students with immunological and virological failure whilst on antiretroviral drugs at the University of Limpopo's Health and Wellness Centre. This chapter summarises the findings and discussions made, gives conclusions about the experiences of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo's Health and Wellness Centre.

5.2 Summary of Findings

The study revealed various factors that contributed to participants having immunological and virological failure whilst on ARVs.

5.2.1 Disclosure of HIV Status is Still a Problem

Participants found it hard to disclose their HIV status to their roommates, family members and partners due to HIV still stigmatised this leading them to forfeit taking their treatment sometimes. Those who have disclosed their status though were living freely and taking their treatment at the prescribed times. This, however, happened at a later stage when their immune system and viral-load results showed to be compromised. Disclosure thus still plays a big role in determining treatment success resulting in viral load and CD4 count improvement. Congruent to the findings of the study Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza *et al.*, (2006) in Uganda, which revealed that Anti-Retroviral Therapy is better adhered to where the treatment is free and in community-based programmes. Indicating that stigma and not disclosing status to those within the radar that one lives in, have a direct impact on determining treatment success or immunological and virological failure.

5.2.2 ARV Packaging Too Noisy and Indirectly Disclosing One's Status

The majority of participants seem to agree that they do not feel comfortable with the ARV packaging as it makes a lot of noise and indirectly disclosing their status. It could be seen as self-stigmatisation as it is subjective and could be paranoia. This

was raised by seven out of ten participants though and should not be taken lightly as it could affect one from taking their treatment well. This concern that has not yet been researched in full was also raised by Schlatter (2017) in Botswana who posed the question on research gate if there is any literature available regarding the effects of ARV packaging on PLWHA. In his line of work on ARV adherence, he had noticed that PLWHA receiving their plastic bottles are annoyed of the shaking noise the tablets make inside the bottle. This was reported to be worse when using public transport as one would be recognised as HIV positive. Phillips (2016), in inner city Miami, also had similar concerns as patients would use paper towels to put in their pill bottles before leaving the clinic to prevent the pills from rattling. Clearly, this rattling sound seems to be a concern to the consumers as identified in the study.

5.2.3 Side Effects of ARVs Make Participants to Miss Taking the Treatment

Some participants reported that when having to write for exams and tests they would forfeit taking the treatment as it makes them drowsy and tired. They opted to rather not take the treatment as they put their studies first. These findings correspond with the findings from Lekhuleni, Mothiba, Maputle and Jali (2013) who revealed that patients on ARVs are not adhering to treatment as they faced side effects to the drugs and resorting to missing a dose to cope with everyday life. Watson (2018) also agreed in that antiretroviral drugs can cause side effects that can be severe enough that some people stop taking them and that sticking to a treatment plan is not always an easy task to do. This in a way was seen as affecting adherence to ARVs.

5.2.4 Service Delivery Affects Adherence to ARVs

Participants cited that the way the ARV site is structured affects them in that, when it is isolated from all other services, it has an impact on them having to collect their medication. In the community, when they have to collect treatment when at home, the ARV sites are stigmatised such that anybody seen going there already people know what they are going there to do and for what service. This is seen as discouraging to the user of the service and thus not user friendly. The study's findings were however different from the findings by Roberts (2000) who indicated that social support and support from health-care providers affected their treatment outcome. In that case, this made participants to comply on ARVs as they were

reminded sometimes when they forgot. Participants in this study concentrated more on building structures than the social aspect and support.

5.2.5 Being Part of a Support Group Encourages Compliance and Adherence

Participants who belonged to a support group found it reassuring as they engaged with people with similar experiences and challenges. Those who were in support groups were also free to take their medications and were not concerned about who would think what about them, and they adhered better to treatment after disclosing their status. The findings were congruent with the results from a study conducted by Visser et al., (2005) which showed that support groups provide PLWHA a relaxed platform to share their experiences about HIV and AIDS and build new friendships, love and acceptance; thus suggesting that the formation of support groups can be a source of valuable support for people living with HIV and AIDS. Agreeing with the statements from participants as they get to share their fears with group members, they also learn more information about the disease and ways of coping with the container making noise as they perceive it.

5.3 Conclusion

This study set out to explore the experiences of students whose viral load and immune system was not improving after being on ARVs for more than a year. The findings suggest that the reasons for immunological and virological failure were that students still could not disclose their status to their roommates, partners and family members, hence making it difficult for them to take their treatment when in the midst of either of them. This causes them not to comply with the strict time schedule that the drug regimen requires. This highlights the importance of improving the social context of disclosure and programmes aimed at reducing stigma to improve a safer environment for disclosure.

The prominence of ARVs packaging also highlights the importance of more improved packaging by pharmaceutical companies as it is seen as a barrier to adherence by participants and also stigmatising their condition indirectly. The study also concludes that students still experience side effects of the drug; the worse one being drowsiness and they postpone taking the drugs in order to study. This also interfering with the strict time schedule of the drug leading to unsuppressed viral-load

copies. The Supermarket approach is the most desired approach of service delivery by students as one can go in one room and get all the necessary assistance, this in a way was seen as reducing stigma.

Those students who belonged to a support group found it easier to cope with the disease dynamics and encouraged all on treatment to do so as it would be beneficial to them and encourage adherence.

5.4 Limitations

The limitation of the study is that there is generalization. This might spark a problem in view of the fact that only students at the University of Limpopo were subjects and thus this might not be a true reflection of what other universities are experiencing.

5.5 Recommendations

The recommendations of the study are based on various issues that emerged from the study findings and suggestions made by the key informants interviewed. The proposed recommendations are as follows:

Recommendations to the government and higher education and training

- The public and communities at large need to be sensitised on issues around HIV/AIDS in order to address the issue of stigma. This can be done through awareness campaigns and giving out educational pamphlets to the entire community and not just to wait for people to come to the clinic first. Outreach programmes to be introduced and target where the communities gather, such as holding dialogues with all stakeholders on board, in universities, e.g., the use of SRC influence as they are the mouthpiece of the students.
- Introduction of Supermarket approach in all health-care services. Services not to be isolated as people tend to stigmatise and indirectly be seen as disclosing the clients' status.
- Comprehensive training to all health-care providers. Healthcare providers to be fully trained so as when a client gets into a consulting room, they can get all the assistance they need in that one room and not be sent to different rooms. This will help counteract the issue of stigma.

Recommendations to health-care providers

- Health-care providers to exercise some patience and compassion towards PLWHA. Their attitude can either make or break the users of the service.

Recommendations to PLWHA

- Those who belong to support groups and living freely with the virus can be encouraged to become ambassadors to educate the public and also serve as role models.

Recommendations to pharmaceutical companies

- Come up with more user-friendly packaging as suggested by the participants. As much as it can be said that it is not a big issue, it has been identified as a problem by the majority of the participants that the rattling noise attracts attention. Blister packs could be used instead as the pills will be individually packed.
- Make drugs with fewer side effects – Pharmaceuticals or researchers can do more research around the issue of side effects like it was in the past, as we see with improved 3:1 drugs in the market currently.

REFERENCES

- Abadia-Barreco CE and Larusso MD. (2006). The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS. Sao Paulo, Brazil. *AIDS Patient care STDs*.
- ACCHO. (2006). HIV/AIDS Stigma, Denial, Fear and Discrimination: Experiences and responses of people from African and Caribbean in Toronto. HIV social behaviour and epidemic study unit, Toronto, Ontario, Canada. https://tspace.library.utoronto.ca/bitstream/1807/10304/2/HIV_stigma_study_ACCHO_UT.pdf (accessed April, 2017).
- Alagaw A, Godana W, Taha M and Dejene T. (2013). Factors Associated with Antiretroviral Treatment Adherence among Adult Patients in Wolaita Soddo Hospital, Ethiopia. *Journal of Tropical Diseases* 1: 125. doi: 10.4172/2329-891X.1000125 (Accessed February,2017).
- American Medical Association. (2012). *Medical Dictionary for Health Professions and Nursing*.
- Avert (2017). Global Information and education on HIV and AIDS. <https://www.avert.org/> (Accessed August,2017).
- Beattie T, and Bhattacharjee P. (2009). Access to HIV testing and Treatment Services by High-Risk Groups in Karnataka, India: Barriers and Motivators. *Karnataka Health Promotion Trust*.
- Bikaako-Kajura W, Luyirika E, Purcell DW, Downing J, Kaharuza F, Mermin J, Malamba S and Bunnell R. (2006). Disclosure of HIV Status and Adherence to Daily Drug Regimens among HIV-Infected Children in Uganda. *Aids and Behaviour. Supplement 10*: 85-93.
- Boyce C and Neale P. (2006). Conducting in-depth interviews. A guide for designing and conducting in-depth interviews for evaluation input.
- Bravo P, Edwards A, Rollnick S and Elwyn G. (2010). Tough decisions faced by people living with HIV: A literature review of psychosocial problems. *AIDS Rev*.12 <http://www.ncbi.nlm.nih.gov/pubmed/20571602> (accessed April 2017).
- Brink H. (2006). *Fundamentals of Research Methodology for Health Care Professionals*. University of South Africa, 2nd ed. Juta: Cape Town.
- Bryman A and Bell E. (2007). *Business Research Methods*, 2nd edition. Oxford University Press.

- Burns N and Grove SK. (2003). *Understanding Nursing Research*. 3rd Ed. Philadelphia, *W.B. Saunders company*.
- César E, Abadía B and De LaRusso M. (2006). *AIDS Patient Care and STDs*, 20(1): 36-43. doi:10.1089/apc.2006.20.36.
- Chabikuli NO, Datonye DO, Nachega J. and Ansong D. (2010): Adherence to ARV, Virological Failure and Workload at Rustenburg Provincial Hospital. *South African Family Practice* 52(4): 350-355.
- Collazos J, Asensi V, Carton JA and Ibarra S. (2010). The Influence of the Patient's Educational Levels on Socio-Economic, Clinical, Immunological and Virological End Points in Europe. *AIDS Care-Psychology, Health & Medicine-Vulnerable children and youth studies*. <http://mc.manuscriptcentral.com/ac-phm-vcy> (Accessed February, 2017)
- Creswell JW. (2003). *Research design: Qualitative, quantitative and mixed methods approaches*, Sage publications.
- Creswell JW. (2009). *Research Design. A qualitative, quantitative and mixed method approaches*, 3rd ed. London: Sage Publishers.
- Creswell JW. (2014). *Research Design. A qualitative, quantitative and mixed method approaches*, 4rd ed. London: Sage Publishers
- Department of Health, PEPFAR and The Aurum Institute. (2015). *Managing HIV- A clinician's tool*.
- De Vos AS, Strydom H, Fouche CB and Delport CSL. (2005). *Research at Grass Root for Social Sciences and Human Service Professionals*, 3rd ed.
- Ehlers V and Tshisuyi E. (2015). Adherence to ART Treatment by Adults in Rural Areas. *Curationis* (38) 1.
- Gerrish K and Lacey A. (2006). *The Research Process in Nursing*, 1st edition. South Africa: Blackwell Publishing Ltd.
- George EOO. (2015). *Illness Experiences of people living with HIV in Kenya. A case study of Kisumu country*. Dissertation for degree in Doctor of Philosophy, University of Bidefield, Germany.
- Given LM. (2008). *Qualitative research methods Vol.1 &2*, The sage encyclopedia.
- HIV AIDS Facts sheet-AVERT. (2017). www.avert.org (accessed June 2017).
- Hoeks H. (2009). *Instant focus group questions e-book*, Focus group tips.com.<http://uir.unisa.ac.za/handle/10500/4970> (accessed November 2016).

- Jaka HM, Mshana SE, Liwa AC, Peck R and Kalluvya S. (2009). Prevalence of immunological failure and durability of first line Anti-Retroviral Therapy at Bugando Hospital Mwanza, Tanzania. *Tanzania Medical Journal* 24(2): 5-8.
- Jean B, Nachega A, Olalekan A, Uthman B, Karl-Peltzer C, Lindsey A, Richardson D, Edward J, Mills E, Kofi Amekudzi F and Ouédraogo A. (2014). Association between Anti-Retroviral Therapy adherence and employment status: systematic review and meta-analysis. doi:10.2471/BTL.14.138149 (accessed November 2016).
- Kendall-Raynor P. (2009). Supermarkets used as models for community nursing productivity. *Nursing standards: Official newspaper of the royal nursing college*.
- Kurtyka DE. (2008). *Effects of a Structured Adherence Intervention to HAART on Adherence and Treatment Response Outcome*. Graduate Theses and Dissertations, Florida. <http://schlorcommons.usf.edu/etd/350> (accessed June 2017).
- Lekhuleni ME, Mothiba TM, Maputle MS, and Jali MN. (2013). Patients' Adherence to ART at ART Sites in Limpopo Province, South Africa. *African Journal for Physical, Health education, Recreation and Dance*, March (supplement 1), 75-85.
- LoBiondo-Wood G and Haber J. (2010). *Nursing Research: Methods and critical appraisal for evidence-based practice*. 7th edition. Louisiana: Mosby.
- Marukutira T. (2012). Factors Influencing Adherence to Antiretroviral Therapy in Adolescents at Botswana-Baylor Children's Clinical Centre of Excellence: A qualitative study, University of South Africa, Pretoria, <http://hdl.handle.net/10500/6036> (accessed July 2017)
- Machtinger ER and Bangsberg DR. (2006). Adherence to HIV Antiretroviral Therapy. *HIV Insite*. From: <http://HIVinsite.ucsf.edu/InSite/>(accessed October 2016).
- Mouton J. (1996). *Understanding Social Research*. Pretoria: Van Schaick.
- Mthembu T and Van Wyk B. (2014). Patients' knowledge and beliefs about ARV treatment and factors associated with adherence in Mpumalanga, South Africa.
- Murphy DA, Roberts JK, Martin DJ, Marelich W and Hoffman D. (2000). Barriers to Antiretroviral Adherence among HIV-Infected Adults. *AIDS Patient Care and STDs*, 14(1).

- Ndou TV, Risenga PR and Maputle MS. (2013). Experiences of HIV Positive Patients on ARV Treatment at the Thulamela Municipality in the Vhembe District, Limpopo Province, South Africa. *Antivir Antiretrovir* 5:123-131. doi:10.4172/jaa.1000075
- Parsons JT, Van Ora J, Missildine W, Purcell DW and Gomez CA. (2004). Positive and Negative Consequences of HIV Disclosure among Seropositive Injection Drug Users. From: <http://www.ncbi.nlm.gov/pubmed/15491957> (accessed 25 January 2018).
- Patton MQ. (2001). *Qualitative Research and Evaluation Methods*, 3rd ed. Saint Paul, M.N: Sage publications.
- Pillay Y and Asia B. (1999). Handbook for clinic/CHC Managers. Pretoria: Department of Health.
- Polit DF and Beck CT. (2008). *Essential of Nursing Research: Methods, Appraisal and Utilization*. London: Lippincott Williams and Wilkins Company.
- Roberts K. (2000). Barriers to Facilitators of HIV Positive Patients' Adherence to Antiretroviral Treatment Regimens. *AIDS Patient Care* (14):185-192.
- Saunders A, Lewis P and Thornhill A. (2012). *Research Methods for Business Students*, 6^{ed}. Pearson Education Limited.
- Sekoni AO, Obidike OR and Balogun MR. (2012). Stigma, Medication Adherence and Coping Mechanism among People Living With HIV Attending General Hospital, Lagos Island Nigeria. *African Journal for Primary Health Care Family Medicine*. 2012;4(1), Art. #417.
- Skovdal M, Campell C, Nhongo K, Nyamukapa C and Gregson S. (2011). Contextual and Psychosocial Influences on Antiretroviral Therapy Adherence in Rural Zimbabwe. *International Journal of Health Planning and Management*. 26(3). Doi:10.1002/hpm.1082.
- Sokoya T. (2012). Occurrence and Treatment Failure in Antiretroviral Therapy at Tshwane District Hospital. Unpublished. Master of Science in Pharmaceutical affairs Dissertation. Johannesburg: University of Witwatersrand.
- The MERCK Manual of Medical Information (1997). Home edition. New Jersey: The Merck publishing group Rahway.
- Tod A. (2006). *The Research Process in Nursing*, 5th ed. Edited by Gerrish K and Lacey A. Hong Kong: Blackwell.

- Trotta MP, Cozzi-Lepri A, Ammassari A, Vecchiet J, Cassola G, Caramello P, Vullo V, Soscoia F, Chiodera A, Ladisa N, Abeli C, Cauda R, Buonomi AR, Antinori A and Monfort A. (2010). Rate of CD4+ cell count increase over periods of viral load suppression: Relationship with the number of previous virological failures. *Clinical Infectious Diseases*: Volume 51 <https://doi.org/10.1086/6551551> (accessed November 2017).
- UNAIDS (2012). Global Report on AIDS Epidemic. Geneva Switzerland, joint United Nations Programme on HIV/AIDS (UNAIDS).
- Uzidike N, Ross A and Harbor O. (2015). Adherence by Primary Healthcare Clinic in Kwazulu-Natal to the National HIV Guidelines, *South African Family Practice*, DOI: 10.1080/20786190.2014.976945
- Visser M, Mundell J, De Villiers A, Sikkema K and Jeffery, B. (2005). Development of Structured Support Groups for HIV Positive Women in South Africa. *Journal of Social Aspects of HIV/AIDS*: 2 (3): 213-8.
- Wasti SP, Simkhada P, Randall J, Freeman JV and van Teijlingen E. (2012). Factors Influencing Adherence to Antiretroviral Treatment in Nepal: A Mixed-Methods Study. *PLoS ONE* 7(5): e35547. doi:10.1371/journal.pone.0035547
- Watson S. (2018). Antiretroviral HIV Drugs: Side effects and adherence. <https://www.healthline.com/health/HIV-aids/antiretroviral-drugs-side-effects-adherence> (accessed March 2018).
- World Health Organisation (WHO) (2008). *Adherence to Long Term Therapies- Evidence for Action*. Geneva. WHO.
- World Health Organisation (WHO) (2010). *Antiretroviral Therapy for HIV Infection in Adults and Adolescents*. Geneva: WHO.
- World Health Organisation (WHO) (2015). *Global Update on HIV Treatment: Results, impact and opportunities*. Geneva, Switzerland.

ANNEXURES

Annexure A: Ethical Clearance Certificate from TREC



University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2306, Email:noko.monene@ul.ac.za

**TURFLOOP RESEARCH ETHICS
COMMITTEE CLEARANCE CERTIFICATE**

MEETING: 31 August 2017
PROJECT NUMBER: TREC/284/2017: PG

PROJECT:

Title: Experience of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo, Limpopo Province, South Africa
Researcher: MP Maphakela
Supervisor: Mr MP Kekana
Co-Supervisor: Dr E Maimela
School: Health Care Sciences
Degree: Masters in Public Health


PROF. TAB MASHEGO

CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol.
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

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Annexure B: Request to Conduct Study

**APPENDIX 5: APPLICATION TO CONDUCT STUDY AT THE STUDENT HEALTH
AND WELLNESS CENTRE**

From: Maphakela M.P.

Student Number: 201415805

Mobile: 0826978813

E-mail: Mahlodi.maphakela@ul.ac.za

To: Director Health and Wellness Centre, University of Limpopo.

Subject: **REQUEST TO CONDUCT STUDY.**

Dear Sir

I am undertaking my masters in public health (MPH) studies at the University of Limpopo (UL). As fulfilment for that I am required to complete a research project. I intend to do a study on Experiences of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo.

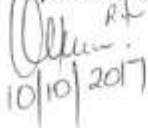
The proposed study requires the following variables: date of initiation, follow up viral load and CD4 count, follow up weight and only patients who are more than 1 year on treatment. Data sources is existing in the Student health and wellness centre records and the participants for the interview are also available at the centre.

Therefore I am requesting for permission to conduct the study, it is quite significant not only to my academic benefit but also for identifying the causes of immunological and virological failure.

The issue of ethics has been seriously considered and permission from TREC has been granted, see attached. All data will be handled confidentially and will be de-identified from patient identifiers before it is transferred outside the health centre.

Sincerely

Maphakela M.P.



10/10/2017

Annexure C: Permission from Health and Wellness Manager



University of Limpopo
Student Health and Wellness Centre
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3726, Fax: 0865145967, Email:norman.letebele@ul.ac.za

12/10/2017

PERMISSION TO CONDUCT RESEARCH AT THE HEALTH & WELLNESS CENTRE

Dear Me M Maphakela

Kindly be informed that permission is granted to you to conduct research at the Student Health & Wellness Centre entitled: "experience of students with immunological and virological failure on antiretroviral drugs at the University of Limpopo".

We wish you the best with your academic journey

Warm Regards



.....
NORMAN LETEBELE

DIRECTOR: HEALTH & WELLNESS CENTRE



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Annexure D: Informed Consent Form

CONSENT FORM

PROJECT TITLE:

EXPERIENCES OF STUDENTS WITH IMMUNOLOGICAL AND VIROLOGICAL FAILURE ON ANTIRETROVIRAL DRUGS AT THE UNIVERSITY OF LIMPOPO, LIMPOPO PROVINCE, SOUTH AFRICA

PROJECT LEADERS/SUPERVISORS: Mr MP Kekana and Dr E Maimela

I, hereby voluntarily consent to participate in the following project:

EXPERIENCES OF STUDENTS WITH IMMUNOLOGICAL AND VIROLOGICAL FAILURE ON ANTIRETROVIRAL DRUGS AT THE UNIVERSITY OF LIMPOPO, LIMPOPO PROVINCE, SOUTH AFRICA

I realise that:

1. The study deals with
2. The procedure or treatment envisaged may hold some risk for me that cannot be foreseen at this stage.
3. The Ethics Committee has approved that individuals may be approached to participate in the study.
4. The research project, i.e., the extent, aims and methods of the research, has been explained to me.
5. The project sets out the risks that can be reasonably expected as well as possible discomfort for persons participating in the research, an explanation of the anticipated advantages for myself or others that are reasonably expected from the research and alternative procedures that may be to my advantage.
6. I will be informed of any new information that may become available during the research that may influence my willingness to continue my participation.
7. Access to the records that pertain to my participation in the study will be restricted to persons directly involved in the research.
8. Any questions that I may have regarding the research, or related matters, will be answered by the researcher/s.

9. If I have any questions about, or problems regarding the study, or experience any undesirable effects, I may contact a member of the research team or Ms Noko Shai-Ragoboya.

10. Participation in this research is voluntary and I can withdraw my participation at any stage.

11. If any medical problem is identified at any stage during the research, or when I am vetted for participation, such condition will be discussed with me in confidence by a qualified person and/or I will be referred to my doctor.

12. I indemnify the University of Limpopo and all persons involved with the above project from any liability that may arise from my participation in the above project or that may be related to it, for whatever reasons, including negligence on the part of the mentioned persons.

SIGNATURE OF RESEARCHED PERSON

SIGNATURE OF WITNESS

SIGNATURE OF PERSON THAT INFORMED
THE RESEARCHED PERSON PARENT/GUARDIAN

SIGNATURE OF

Signed at _____ this ____ day of _____ 2015

Annexure E: Semi-structured Interview Guide

- 1) What are your experiences as a student and having to take ARVs?
 - How do you experience taking ARVs as a student?
 - Are there any factors that you experience as a student that could affect you taking ARVs?
 - Are you in a relationship at the moment?
 - Does your partner know about your HIV status, if not why?
 - Are any of your schoolmates or roommates aware of your HIV status and your taking of ARVs?
 - Are you receiving any support from family and friends about your HIV status and in taking ARVs?
 - How is your experience with your follow-up visits and collection of treatment?
 - Are health-care providers having an influence in determining your treatment outcome, if so how?

- 2) Do you think HIV is still stigmatised around campus and in the society as a whole and if so why do you think that?
 - Do you find it easy to collect your treatment like any other person who collects their medication, if not what is different in your case?

- 3) Is there any other factor that you would like to mention that affects you taking treatment besides the mentioned?

Annexure F: Examples of Transcripts as Narrated Verbatim by Participants

Respondent: 2

Q: What is your experience of being HIV positive and having to take ARVs as a student, like how does it affect your student life?

A: *"I think from the beginning, with my experience it was a per challenge concerning taking arvs, because the health centre it was not providing the medication and I had to go to Mankweng hospitals to que for the whole day and whatever but after all when the health centre was providing the medication things become easier, and the more reasonable to take medication".*

Q: Are there any obstacles or challenges that you are encountering more over that you are a student concerning taking of ARVs?

A: *"ya, there is cause sometimes, when you start taking the medication at the beginning you get dizziness, you get hallucinations(hallucinations) and so on, but in the long run you get used to the medication and the medication gets used to you and then it becomes easier".*

Q: Does taking ARVs affect your student life and how?

A: *"yes, it can affect a student life and career wise remember if ever you are taking the medication you have to read, and at the same time you cannot your highest learning or you get dizzy and so on. You end up like not studying and you just sleep and then at the end of the day it can harm your career and performance."*

Q: Are you in a relationship at the moment?

A: *"I decided to abstain to just like stay alone since I discovered that I'm HIV positive."*

Q: Is it because of your HIV status that you decided to abstain and why?

"I think maybe because of a bad experience that I got with the HIV status it makes me to be cautious and say no, what else is in the person I'm going to be who is going to understand me as a man, a person who is normal, who's going to give a life, a love life in a full or is the person that I'm going to be involved could re infect

me if ever the person is not aware of his or her status, so I had to be cautious about that, so is one of the elements to make me say let me sit back and understand the what elements that I should consider to be involved in relationships.”

Q: But you are not dead and being HIV positive does not mean you do not have to be in a relationship?

A: *“no is not like that....”*

“no is not the defining thing cause really I conducted some research about the HIV now there is a new element whereby we can use truvada if ever I can have a partner who's HIV negative and then we can enjoy life and start a family we can able to grow..”I think the genes will be passed, somehow somehow.

Q: Do any of your schoolmates or roommate know about your HIV status and you are taking ARVs?

A: *“My schoolmates and my roommate doesn't know anything about my HIV status, but the group that I'm involved in especially like the support group, they know about me and I'm too vocal on that, so I hope in the near future I'll be able to stand up and then disclose it and able to speak whole concerning HIV.”*

Q: How do you go about taking treatment when they are around?

A: *“Due to my conditions cause I'm having eye problems I've been allocated a single room, so then I don't have, is in favour I don't have a roommate, so I stay alone, and it's not a problem for me to take medication..”*

Q: So do you think if your schoolmates knew about your status they would have a problem with that?

A: *“Yea, my perceptions is yes, because some of the things we discuss in maybe in maybe we discuss in class like in class there is the discussions concerning information sharing, you find that people they speak much bad about HIV information statistics and so on, so it's clear to my mind it does say, if people can able to understand or know about my status maybe they'll stigmatise me or they'll run away from or be disassociated with me , so it's one of the other challenges*

that most of the students they come across , so they unable to disclose because of the peer pressure within their schoolmates.”

Q: How do you experience your follow-up visits when you have to collect medication or take bloods at the health centre, does it make life easy for you as a student?

A: “Not necessarily because with the relationship that is within the health centre, it makes it is easier to talk about anything and with the support group it makes it very easier to come back and to remember everything even the dates know when I’m going to take medication how I’m going to take the medication on a daily basis. And even the blood, when you are supposed to take the blood and all those criteria that have been formulated for medication and blood are all in a visible places and then we talk about them in the support group, so it is not something that is challenging.”

Q: So as I listen you mean if one is in a support group it makes life easier?

A: “Yes, it makes it live very easier and even to understand much better about the HIV and how it’s supposed to be treated and especially when it come to the daily medication I carry it you have to understand ok what time are you going to take your medication and what is the repercussions if ever you are not adhering to your medications.”

Q: Do you think HIV is still stigmatised around campus and in the community?

A: “Yes, it’s still stigmatised in a, a certain way because people they still believe that HIV is the end of life, death sentence, while they are not actually acquiring about the HIV and how it works so it is make it in very difficult for the community to understand I think most of them outreaches is for the information to be delivered to most of the students it can make them to understand, that HIV is not a death sentence, yes is manageable under chronic diseases that are out there.”

Q: What would you recommend as a recipient of ARVs, how do you think could be done to make life easy as a student?

A: “Ya! let me, I will just say, I think the proper of to recommend something is to look at the negative of them and I’ll say with the negative of them the, the strategy of

you are taking the medication, every day, every day, every day. Every day it becomes a challenge some of the people they easily forget. if ever they come up with a strategy were you can take medication maybe once in a month, once in a month then it can be easier for one to remember that no ok this day I take this medication and one of the other thing is the memory loss if ever you are using the medication and some of the people they are taking it for nyaope and so on and so on.

People get robbed and so because of the perceptions of say maybe ARVs are good for being in a higher whatever but it makes people to be vulnerable and being robbed for the medication besides that I think the ARVs are playing a very important role in our lives. You can see I'm glowing good but ya no one can realise that I'm having HIV so the medication is playing a very important role and I can recommend that people should adhere to their medication and also adhere to the time that they take their medications and also revisit the clinic in the given time that they should revisit the clinic and take the blood and so on and so on and make sure that everything that it is instructed they follow it,"

Q: Any other element that has always been at heart that I didn't mention about taking ARVs as a student?

A: "I think one of the other things that will make it our concern is to formulate groups, especially in chronic diseases whereby we can talk about everything and then highlight each and every chronic diseases including HIV and aids, where people can able to understand HIV better and then to minimise the stigmatisation because the moment they understand the treatment of HIV and how it works and how they can be able to manage their own life it will be better and substance abuse, alcohol abuse, reinfection issues and also thereby they need to be touched concerning in those supporting groups so with those supporting group they can be useful."

Thank you for participating, I really appreciate it.

Respondent: 10

Q: What are your experiences as a student and having to take ARVs, like how does taking ARVs have an impact on your student life, any challenges that you are facing because you are a student?

A: "Yes, there are some challenges that I raised like for instance like now during the exams uhn, you find that I take the long time studying at the library, lose control of time the next thing then I realise that I have only, maybe 5 minutes to take my pills and I do not bring it with me to the library and walking from the library to my place is quite a distance so that's one of the things that I find challenging and the fact that I don't. my friends here at campus don't know that I'm infected and I don't have that one person yet that which I can say will help remind me every day that I should take my pills apart from my parents who call me now and then of course but they are times that I just forget even if they reminded me that I should cause I focus, I try to focus too much on my studies that the fact that I have to, that I'm infected."

Q: Are any of your schoolmates or roommate aware of your HIV status or you taking ARVs, like even initially when you started, was it easy to take them in front of everyone?

A: "Naah, unless if maybe she is suspecting but I don't think she knows I've never told her and with my school mates there's just this one girl only who we aaah interacted though certain group here on campus and I found comfort in her through the way she talking to me and she...it's a ladies' club, ya, so I met her through the ladies' club so she's just one of those people who is just supportive she also tries to remind me there and there. Ya."

Q: Since you say your roommate is not aware of your status, what happens when it's time to take your ARVs and she is there?

A: "Believe or not I would take the pack and I would take the bottle of ARVs, put them in my bag, go outside as though I'm meeting someone to give them the laptop or something at the gate..."

Q: So you do that every day if she is there?

A: "Sometimes I try to just open the bottle like eh, silently because it makes a lot of noise if you just take it out and put like I would try to open in, it just goes chekge, chekge, chekge...and since well she's not even someone who likes music threw at a time I tried to manipulate the situation by playing music so that she cannot hear what was happening on my side, but then I realised that sometime I'm invading her space because she likes the silent place...eish... it's quite challenging, it's quite challenging, but I think one day I'm gonna have to gather strength and tell her maybe.."

Q: How is your experience with your follow-up visits and collection of treatment at the health centre?

A: "The experience here it's quite great it's quite good because for starts from the reception then, I don't need to mention out loud to the filling admin that I'm here to collect treatment. Ummmhh, They give us this small paper that we should tick on to show what is it that I'm here for, only the filling admin sees it and myself and also from that they just tell me which room I should go to and the consulting room do not specify that I'm going to, I'm going for ARVs, or I'm going to consult or whatever... it's quite good, its welcoming, it's comforting in a way."

Q: Is it different from the other places where you collect your treatment like in the community?

A: "Eish, ya I can say so since well I've just, I've been the bad news like a few months back, when you had closed or winter recesses I just went to the clinic back at my village, I was just walking around just to see what is it I should expect that when I come back in December, so I realised that people who collect ARVs they have a certain place they have one office at the corner, right next to the one that they test for HIV, and everyone knows that that particular consulting room is for ARVs treatment collection, so it's something that disturbed me and somehow I even wished that if it was possible I can get treatment for the whole year so that I don't have to go there lie every month or after 3 months like whatever the case would be so, ya its quite different from ,there is, the, like , the experience here at campus."

Q: Do you think HIV is still stigmatised around campus, like do students still see a student who is HIV positive as an alien or so?

A: *"I would say and no. it depends with the , I think we still have this thing of being like cultures, different cultures, not to be a tribalist or an afro phobic but , I've noticed that as most south Africans we are trying to be more welcoming to people who are living with HIV, however there's a particular group of people like students from Zimbabwe that which I know, the moment you talk about HIV, the moment you talk about male medical circumcision like you are invading their property like it's like taboo for them it's still something not to be talked about, so its disturbing cause for someone like I still love tell people although I don't go around telling them that this is my status but I love to hear how people think about situations, so, ya."*

Q: Do you think if your friends knew about your status they would treat you differently or shut you out?

A: *"No... I'm sure they will shut me out on the spot I'm sure I will never be their friends again."*

Q: Is there any other thing that I did not ask that you always had at heart or any recommendation that would make a student who is on ARVs life easy?

A: *"Ok, the noisy container, chokgo chokgo chokgo, you see I've realised that pills or tablets come in different packages, so there is this one of, the ones that they use for contraceptives the one that they pack them individually in a simple pack, plastic pack, I mean that one when you open it it's like you are opening a sweet, even if you open it in front of people it's rare that someone that someone will ask what is that, you can even cut it out and take piece out and then you go wherever that you have to be with it and then at the right time you take your tablet, but the container its very much disturbing for me , so I think that's one thing that needs to be looked into and also the fact that the local clinics, this thing of saying people should go, those who are collecting ARVs should go to a certain office, those who are doing what what should go...it creates this stigma, it creates this discrimination amongst the community on its own like, instead of getting support from them, instead they just, you know they, they, withdraw themselves from us people who are living with HIV, so. ...ya."*

Annexure G: Co-Coder Certificate

Coding Report from independent coder for Ms M P Maphakela

RESEARCH TITLE: EXPERIENCES OF STUDENTS WITH IMMUNOLOGICAL AND VIROLOGICAL FAILURE ON ANTIRETROVIRAL DRUGS AT THE UNIVERSITY OF LIMPOPO, LIMPOPO PROVINCE, SOUTH AFRICA.

By Ms PM Mamogobo

The storyline is that of PLHWA and are students in a rural community where they have to cope with the diagnosis, treatment and side-effects of antiretroviral treatment. Disclosing HIV status to others including fellow students and roommates is a challenge and a complex decision, as it may leave one vulnerable to a number of possible responses. Some of the study participants shared and said:

“yea, my perceptions is yes, because some of the things we discuss in maybe in maybe we discuss in class like in class there is the discussions concerning information sharing, you find that people they speak much bad about HIV information statistics and so on. So it’s clear to my mind it does say, if people can able to understand or know about my status maybe they’ll stigmatise me or they’ll run away from or be disassociated with me. So it’s one of the other challenges that most of the students they come across, so they unable to disclose because of the peer pressure within their schoolmates.”

“No, my roommate and even friends don’t know about my status. Yes I remember this other day I visited my friend and it was halve past eight, so I had to take my medication, I just pretended as if I was taking a tissue and I put that pill there, I pretended as if I wanted to spit out something and I took my medication and drink water, they did not know that I took the pill.”

Disclosing and living with HIV as a university student is challenging with multiple ways adopted by students to cope with the diagnosis and adjusting and adhering to antiretroviral treatment.

Data analysis method used: Tesch's data analysis method as described in Creswell (2009) was used using the following steps: - Tesch's eight steps of a systemic process of analysing verbatim data was used to assist the researcher in shaping and reducing data collected as cited in Creswell (2009). The data analysis method used involved the following steps:

- The researcher read the transcripts to get sense of the whole, by reading all transcribed data and jotted down ideas on the margins as they come to her mind on each transcript;
- The researcher then picked the most interesting of the transcribed data from the rest of the pile, carefully read the transcript to make sense of the meaning of the information collected, and further wrote down meanings on the margins of each transcripts;
- The researcher then wrote down list of all topics based on the collected data and grouped similar topics together and organised such topics into columns of either major topics, unique topic and those that could be classified as left overs;
- The research went back to the verbatim transcripts with topics written in columns to organise them into codes and will write the codes next segment of the transcribed text and further related these to the research topic. The researcher also checked if there are any new codes that emerge as codes were allocated to the data collected;
- The researcher had to find wording that best describe wording of topic and reduced total list of topics, wording of topic list were then turned into categories by grouping the topics that relate to each other. The researcher subsequently drew lines between categories to show the interrelationship between these categories;
- The researcher then made a final decision on each category and wrote them alphabetically;

- The researcher further assembled each belonging category and then started performing preliminary analysis of collected data; and
- The researcher was able to recode the existing data as the need arose to relate them to the phenomenon under study.

The following are themes that emerged as the research coder read the transcripts:

TITLE: EXPERIENCES OF STUDENTS WITH IMMUNOLOGICAL AND VIROLOGICAL FAILURE ON ANTIRETROVIRAL DRUGS AT THE UNIVERSITY OF LIMPOPO, LIMPOPO PROVINCE, SOUTH AFRICA.

INTERPRETATION AND PRESENTATION OF FINDINGS

THEMES	SUB-THEMES
1. Disclosure is still a problem among student peers making it difficult to take treatment when amongst them.	1.1 Lack of disclosure among student's roommates which makes it difficult for one to adhere to treatment. 1.2 Inability of students to disclosure to family members affecting treatment taking when at home. 1.3 There is fear of rejection from partner following disclosure of HIV status. 1.4 Disclosure to peers leads to stigma and perceived death. 1.5 Once the students have disclosed it becomes easier to adhere to treatment and receive social support.
2. ARV packaging too noisy and somehow perceived as indirectly disclosing one's status.	2.1 ARV container perceived as disclosing one's status 2.2 More improved ways of containing ARVs as they are perceived as being different from other treatments. 2.3 Students on treatment seek discreet ways to take treatment which lead to poor

	compliance.
3. Side effects of ARVs affects studies.	<p>3.1 Students are unable to adhere to ARVs as they put their studies first.</p> <p>3.2 Side effects of antiretroviral drugs also make time schedule different to adhere to with afterhours study.</p> <p>3.3 Missing doses when having to write tests or exams due to side effects.</p>
4. HIV is still stigmatised around campus and society.	<p>4.1 HIV still perceived as a death sentence amongst students.</p> <p>4.2 Students are unable to adhere to treatment in the presence of peers due to perceived stigma related to diagnosis.</p> <p>4.3 Societies at large still view someone who is HIV positive as promiscuous.</p> <p>4.4 Education needed to students about HIV and ARVs.</p> <p>4.5 Self-stigmatization about diagnosis and treatment taking.</p>
5. Strict medication schedule makes it difficult to adhere to medication.	<p>5.1 Daily routine of treatment schedule makes it difficult to adhere when having to study.</p> <p>5.2 Adjusting to social life vs treatment schedule as a student.</p> <p>5.3 Use of cell phone alarms also stigmatise indirectly.</p> <p>5.4 Having disclosed to a partner makes it easy to adhere to treatment.</p>
6. Service delivery affects adherence to ARVs.	<p>6.1 Isolated or secluded rooms for HIV positive clients stigmatise users of the service.</p> <p>6.2 Attitude of health-care providers affect follow-up visits and treatment outcome.</p>

	<p>6.3 Supermarket approach reduces stigma in HIV clients.</p> <p>6.4 Competence of health professionals at the health centre in delivering comprehensive service delivery.</p>
<p>7. Being part of a support group encourages compliance and adherence.</p>	<p>7.1 Support from people in a similar situation makes it easier to accept status.</p> <p>7.2 Support group for other conditions to reduce stigma.</p> <p>7.3 Sharing of challenges in the support groups improve knowledge that assist with adjustment to challenges related to the diagnosis.</p> <p>7.4 Support groups enhance positive consideration on disclosure of the status.</p>

Data saturation based on the verbatim scripts was achieved. The limitation to the study is that the researcher used guiding question to open and guide the conversation with study participants with prepared probing question, but however they assisted in obtaining information related to the topic under study. I can confirm that the coded themes were in line with what I discovered and consensus was reached after sitting down with the incumbent and giving conclusive codes presented in the research.

Ms PM Mamogobo

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Date 10 May 2018

Department of Nursing Science University of Limpopo

Annexure H: Editor's letter

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16 August 2018

To Whom It May Concern

EDITING CONFIRMATION: Ms MP MAPHAKELA'S STUDY

This letter is meant to acknowledge that I, MM Mohlake, as a professional editor, have meticulously edited the dissertation of Ms Maphakela Mahlodi Phildah (Student Number 201415805) entitled "Experiences of Students with Immunological and Virological Failure on Antiretroviral Drugs at the University of Limpopo, Limpopo Province, South Africa".

Thus I confirm that the readability of the work in question is of a high standard.

For any enquiries please contact me.

Regards



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