PATIENT AND NURSE PERSPECTIVES ON LOSS TO FOLLOW-UP IN HIV CARE

By
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A thesis submitted in the fulfilment of the requirement for the degree of Doctor in Philosophy in the Department of Psychology at the University of Venda

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Submitted on : April 2019

Declaration

I, Mahlatse Briggite Modipane, hereby declare that this thesis titled “**Patient and nurse perspectives on loss to follow-up in HIV care”** for the Doctor of Philosophy degree at the University of Venda, hereby submitted by me, has not been previously submitted for a degree at this or any other university, and that it is my own work in design and execution and that all reference material contained therein has been duly acknowledged.

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Signature	Date

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I give thanks to the Almighty God who lifted me from nowhere and made me what I am today. It was not an easy journey. He gave me strength and guided me throughout my studies. He is truly the best.

I also thank my mother for her guidance, support, love, and encouragement to never give up despite the challenges I came across. Most importantly, thank you for taking care of my gorgeous princess Bohlale when I was at school studying.
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Abstract

Background: South Africa has world’s highest prevalence of HIV-positive people with approximately 7.06 million HIV-positive people with 110 000 HIV- related deaths reported by Statistics South Africa in 2017. South Africa has expanded access to anti-retroviral therapy services, from urban centers to resource-constrained rural communities. The rate of loss, however, to follow-up for patients on anti-retroviral treatment continues to increase.

Aim of the Study: The aim of this study was to determine patient and nurse perspectives on loss to follow up among HIV-positive patients in Sekhukhune District of Limpopo Province, South Africa. The findings of the study guided the development of a proposed strategy to decrease loss to follow up among HIV-positive patients.

Method: A qualitative research design was used with non-probability purposive sampling and with probability systematic sampling. The sample of patients comprised 30 HIV-positive people classified as lost to follow-up from clinics with high prevalence rates of lost to follow-up patients. Eight nurses, four from clinics with high rates and four from clinics with low lost to follow-up rates comprised the sample of nurses. Semi-structured interviews were conducted using the study research questions as a guide. Eight interviews were conducted with nurse clinic managers and 30 with the patients. Content analysis was used to analyze the data.

Results: The key themes that emerged from the study included patients' and nurses` perspectives on factors contributing to loss to follow up among HIV- positive patients; and Patients' and nurses' perspectives on strategies that would address barriers to loss to follow up among HIV- positive patients. Sub-themes on patients' and nurses' perspectives on factors contributing to loss to follow up among HIV- positive patients included: Lack of understanding of anti-retroviral treatment; fearful to disclose HIV status; lack of confidentiality; negative side effects; use of traditional medicine; self-transfer from one clinic to another. Patients' and nurses' elicited the strategies that would assist patients to remain in care and to take antiretroviral treatment consistently. The strategies included: providing patients with health education; working as a team; implementing social support group programme; providing nurses with in-service education on ethics and ethos. Informed by various intervention models in HIV care: Information Motivational Behavioural model; Health Belief Model; Social Action Theory and Social Cognitive Theory; I proposed a strategy that may reduce the rate of non-adherence and loss to follow up among patients with HIV in Limpopo Province.

Keywords: Loss to follow up, HIV-positive patients, health care workers, compliance, defaulters, HIV care, retention in care, antiretroviral therapy, strategy development.

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List of Abbreviations and Acronyms

AIDS: Acquired Immune Deficiency Syndrome
ARV: Anti-retroviral
ART: Antiretroviral Therapy
BCUR: Baccalaureus Curationis
CD4: Cluster of differentiation 4
DOH: Department of Health
HBCs: Home Based Carers
HBM: Health Belief Model
HIV: Human Immune Virus
HSRC: Human Sciences Research Council
IMB: Information-Motivation-Behavioural Model
LTFU: Loss to follow up
NRF: National Research Foundation
PHC: Primary Health Care
SANC: South African Nursing Council
SAT: Social Action Theory
SCT: Social Cognitive Theory
STATS SA: Statistics South Africa
UNAIDS: Joint United Nations Programme on HIV/AIDS
WHO: World Health Organization

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CHAPTER 1: OVERVIEW OF THE STUDY

1. Introduction

This chapter presents the overview of the study. The background of the study discusses the different perceptions of loss to follow up in HIV care globally. This chapter also presents the problem of the study, the significance of the study, the study aim and research questions. It also gives a brief outline of the different psychological models that guided the development of the proposed strategy in chapter 6.

1.1. Background of the study

Worldwide, HIV has affected a high proportion of the population with 36.7 million people living with HIV (UNAIDS 2016). Of these, over 25 million HIV-positive people are from Sub-Saharan Africa, and this means that 75% of people living with HIV inhabit Sub-Saharan Africa (UNAIDS, 2016). South Africa is a country with the highest prevalence of HIV-positive people world-wide. Approximately 7.06 million people in South Africa are HIV- positive out of a population of 56 million (Statistics South Africa, 2017). There has been a significant increase of people living with HIV in South Africa from 4.94 million in 2002 to 7.06 million in 2017 (Statistics South Africa, 2017). That means that 12.6 % of the South African population is infected with HIV.

Approximately one-fifth of South African women in their reproductive ages (15-49 years) are HIV positive. HIV prevalence among the youth aged 15– 24 has declined over time from 7,3% in 2002 to 4,6 in 2017. Since the beginning of the epidemic, more than 70 million people have been infected with the virus, and about 35 million people have died of HIV (Human Sciences Research council, 2014). The spread of HIV has enormously affected parts of South Africa, especially the KwaZulu-Natal Province (Human Sciences Research council, 2014). KwaZulu-Natal Province continues to lead South Africa in HIV prevalence at 16.9%; the Mpumalanga Province follows at 14.7%, and Free State Province at 14.0%. Other rates include North West Province (13.3%); Gauteng Province (12.4%); Eastern Cape Province (11.6 %); Limpopo Province (9.2%); and Northern Cape at 7.4%. The Western Cape has the nation`s lowest HIV prevalence at 5.0 % (Human Sciences Research Council, 2012). In addition, in response to this overwhelming HIV burden, large-scale programmes to provide antiretroviral treatment (ART) for HIV-positive people have expanded in Sub-Saharan Africa with South Africa comprising the largest ART rollout programmes worldwide (UNAIDS, 2014). It has approximately 3 0785 70 people receiving ART (UNAIDS Spectrum HIV estimates, 2014). Antiretroviral therapy (ART) is a lifelong commitment that requires patients to adhere to their schedule of daily medication doses and to making frequent clinic visits for their care. People living with HIV can live healthy long lives when retained on antiretroviral therapy (Rosen, Fox & Gill, 2007). Some HIV- positive patients are lost to follow up, and are therefore at high risk of illness and death due to HIV-related conditions (Rosen et al., 2007). For instance, a systematic review of patients who initiated ART across Sub-Saharan Africa found that approximately 25% of HIV-positive patients were no longer in care one year after ART initiation, and this rose to 40% after two years (Rosen et al., 2007). It is evident that not everyone eligible for ART is initiated into care, and not all ART patients are retained in HIV care. In order to evaluate the effectiveness of HIV care in South Africa, it is important to understand the reasons behind these rates (number of HIV-positive people, number of people initiated on ART, number of patients retained on ART, and number of LTFU patients). *Figure 1* illustrates the most recent South African engagement in HIV care for 2012/2013 (Sekhukhune Annual District Report, 2014). The figure shows that only 39% of people living with HIV are on ART, and only 70% of those on ART are retained in care. This means that one of the goals set for the National Strategic plan 2012-2016 by the South African government to initiate at least 80% of eligible patients on ART, has not been achieved. In addition, only 70% of ART patients were retained in care, with 20% LTFU HIV-positive patients.

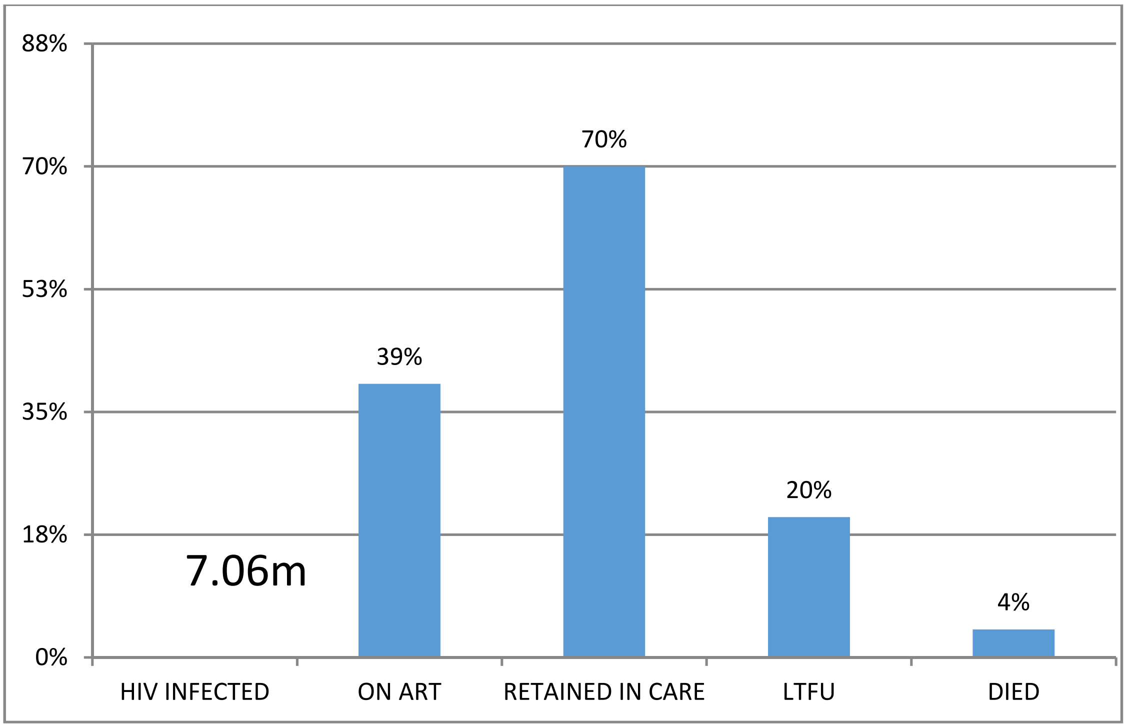


Figure 1. South African health review 2012/2013 (Health System Trust, 2013)

The South African Department of Health`s vision is to retain all HIV positive-patients on ART to promote longer, healthy lives and reduce HIV-related deaths in South Africa (Sekhukhune Annual District Report, 2014). Despite this goal, *Figure 2* illustrates the most updated South African LTFU in 2012/2013. It shows that LTFU rates increase with time for all nine provinces. For instance, in Limpopo Province, at three months on ART, 19.9% of patients were lost to follow-up; at six months on ART, the rate of LTFU increased to 25.4%, and at 12 months on ART, the rate increased again to 35.4%(South Africa Global AIDS Response Progress Report, 2015).

HIV- positive patients experience complex and multidimensional factors throughout their journey of HIV care, and these experiences may provide useful information. HIV-positive patients drop out of care for various reasons. In South Africa, the most common reported reasons for LTFU in care included transportation costs, long clinic waiting times, stigma and discrimination, unsatisfactory treatment by service providers as well as shortage of medication (Maskew, MacPhail, Menezes, & Rubel, 2007). These South African findings were consistent with other Sub-Saharan African findings. Consequently, some patients opt for alternative therapies such as faith healing and traditional healing (Miller, Ketlhapile, Rybasack-Smith, & Rosen, 2010). On the contrary, in the United States, inconvenient opening hours were found to be the significant reason for patients LTFU. Most commonly reported findings, however, do not address the village structures, clinic structures, poverty, and unemployment in the villages of rural communities such as Sekhukhune District of Limpopo Province in South Africa.

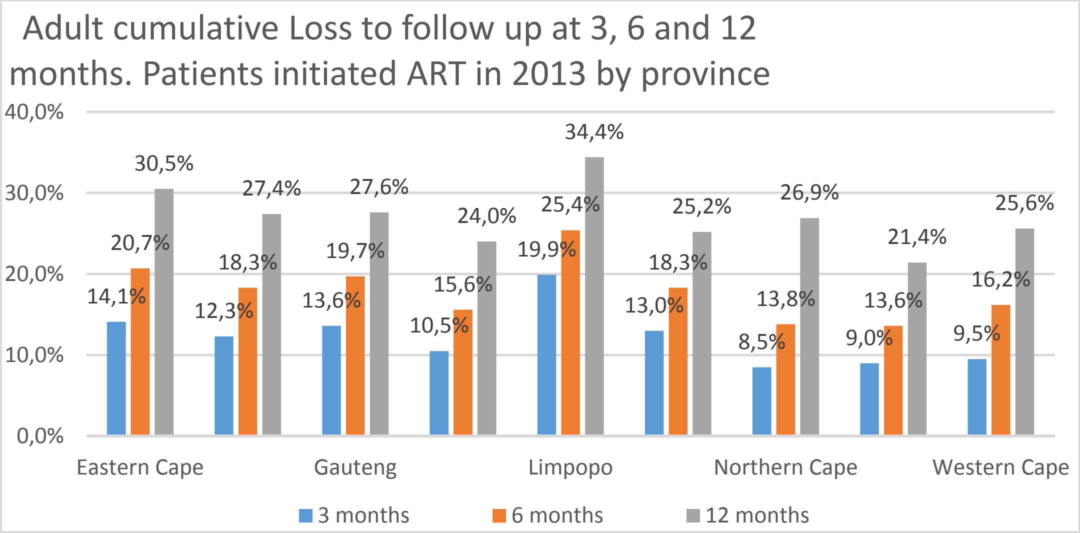


Figure 2: Adult lost to follow-up at three, six, and 12 months, full calendar year 2013, by province (South Africa National AIDS Council Trust, 2015)

UNAIDS‘s five-year vision initiated in 2011 of getting to zero new infections, zero HIV related deaths, zero discrimination against HIV positive people by 2016 has not been achieved, with 140,000 AIDS related deaths in 2014(UNAIDS Spectrum HIV/AIDS estimates, 2014). Many people are still getting infected with HIV each day with 270,000 new HIV infections in 2016 (UNIAIDS, 2017), and many are still dying of AIDS related deaths. *Figure 3* illustrates the most current percentage of AIDS related deaths as of 2011 to 2015. There has been a decrease of deaths from 320,000 deaths in 2010 to 140,000 deaths in 2014; however, we are striving to get to zero AIDS related deaths as a country. It is important, therefore, to retain all HIV-positive people on ART; this will reduce AIDS related deaths and improve health outcomes such as CD4 count and viral load.

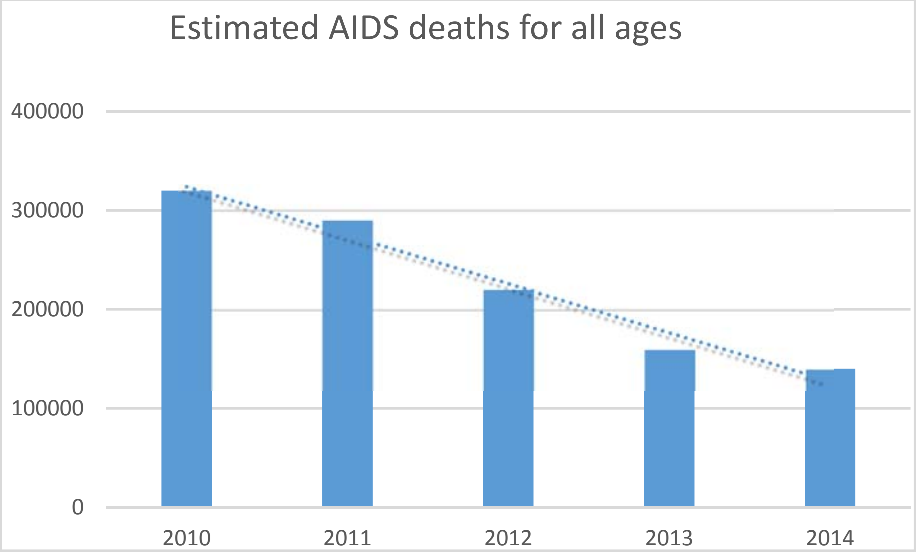


Figure 3. Estimates of AIDS deaths in South Africa, 2011-2014 (UNAIDS Spectrum HIV estimates, 2017).

1.2. Problem statement

Despite the South African government`s efforts to expand access to antiretroviral therapy services, from urban centres to resource-constrained rural communities, with the vision of zero new infections, and zero HIV- related deaths, there were 140,000 HIV- related deaths in 2014 (UNAIDS Spectrum HIV estimates, 2014). Moreover, loss to follow-up care among HIV-positive people who are on antiretroviral treatment continues to be a significant problem. Furthermore, it is expected that the longer patients take antiretroviral medicines, the longer they will adhere to ART, be retained in care, and achieve high viral load suppression, which will lead to improved health and reduced mortality rate. In the Sekhukhune District of South Africa, some sub-districts contain residents who live further than five kilometers from their nearest clinic, which inhibits patients` access to clinical therapy; however, there are patients who live within walking distance to the clinics. For instance, Elias Motsoaledi Sub-District enjoys the greatest access, as 64% of the population can reach a clinic within a five kilometre radius. In Fetakgomo sub-district 51% of residents have nearby access to clinics. In Greater-

Tubatse sub-district at 45%. Makhuduthamaga sub-district stands at 48%, Ephraim Mogale sub-district at 47%. Sub-districts where clinic access is farther from residents' homes may pose challenges to patients' access to ART and may lead to patients` LTFU in HIV care (Sekhukhune Annual District Report, 2014).

The rate of LTFU in the Sekhukhune district in Limpopo Province is 23%, which is greater than the South African National LTFU rate of 20% in the financial year 2013/2014 (Sekhukhune District Annual Report, 2014) . Therefore, this project focused on this district.
Figure 4 illustrates the most updated LTFU prevalence among HIV-positive patients on ART within five sub-districts of the Sekhukhune District LTFU.

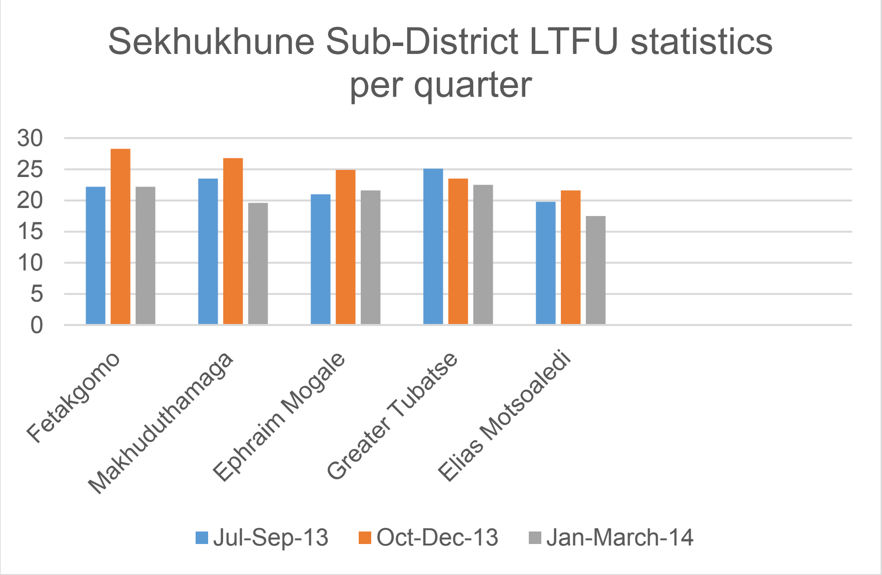


Figure 4. Sekhukhune Sub-District LTFU statistics per quarter (Sekhukhune District Annual Report, 2014)

This Figure illustrates the prevalence of LTFU for three annual quarters of 2013-2014, beginning in 7/1/2013, 10/1/2013, and 1/1/2014. The majority of the sub-districts experienced the highest rate of LTFU in the quarter Oct-Dec compared to other quarters, with the highest LTFU rates at Fetakgomo at 28.3% and Makhuduthamaga at 26.8%. There was, however, an improvement in the following quarter (Jan-March), and all the sub-districts' LTFU rate decreased, including at Fetakgomo at 22.2%; Ellias Motswaledi at 17.5 %, and Makhuduthamaga at 19.6 %. It is noteworthy that October-Dec 2013, the overall rate for the Sekhukhune district was 25%, while for the quarter Jan-March the rate decreased to 21%. This demonstrates a 4% decrease of LTFU rates in the Greater Sekhukhune District in those two quarters. Unfortunately, this decrease is not successful enough, with over 15% of all district patients still LTFU, which is inconsistent with South Africa`s health system vision to retain all HIV-positive patients on ART in care.

Figure 5 illustrates the most recent statistics of the clinics’ LTFU rates in the Sekhukhune District of Limpopo Province. It is important to note that the clinics presented in the graph are only some of the 124 health facilities (including 117 clinics and 7 hospitals) in the Sekhukhune District. However, in this figure it is evident that patients are increasingly lost to follow- up in care. In some clinics, such as Motetema clinic and Marble hall Clinic, LTFU prevalence is higher, compared to other clinics. In contrast, there are clinics with no LTFU of patients at all. Several awareness campaigns have been conducted to help people realize the importance of adhering to antiretroviral treatment and retention in care. Despite these campaigns, many patients have become lost to follow-up, putting their health and that of their communities at risk. It is worth noting that the higher the rate of LTFU, the higher the prevalence of HIV-related deaths. Furthermore, given the significant negative impact that default from treatment has on HIV- positive people and their families, the need to conduct this study was essential.

Notably, the results of this study provide a better understanding of factors contributing to LTFU of HIV- positive people on ART, especially in the clinics with higher prevalence of neglected care. Information from the patients’ and nurses’ perspectives, combined with theories of health behaviour informed the development of the strategy to help HIV positive people to re-engage and remain in care.

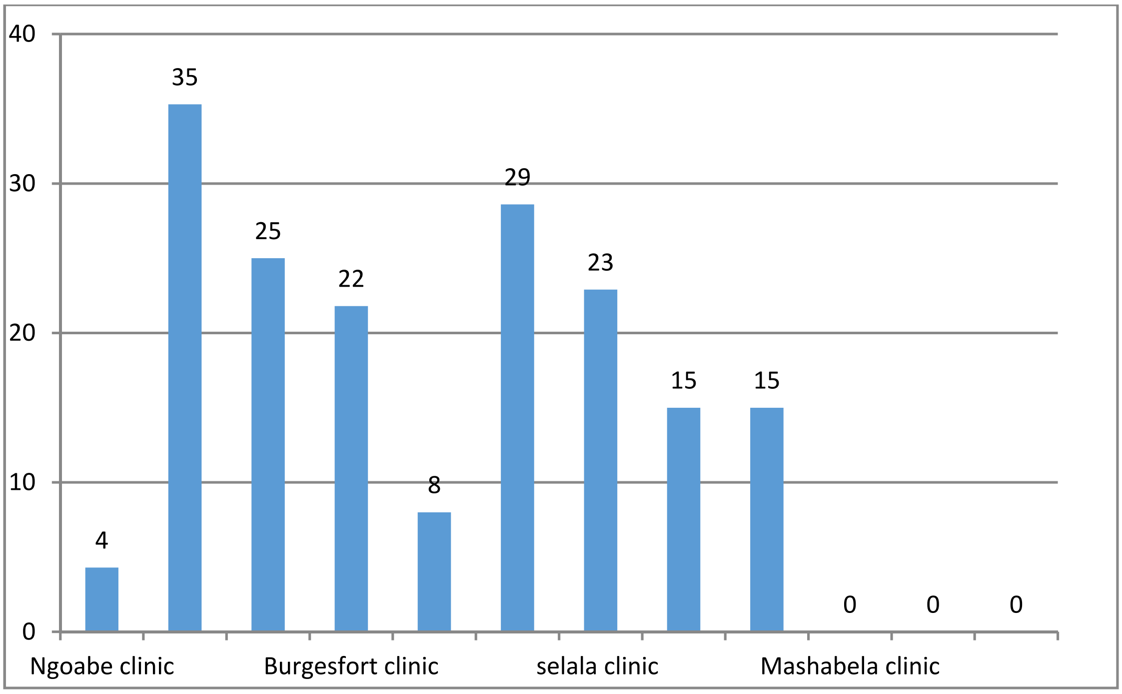


Figure 5. Clinic LTFU at 3 Months (Q1) January to March 2014 in Sekhukhune District, (Sekhukhune District Annual Report, 2014)

1.3. Aim of the study

The aim of this study was to investigate patient and nurse perspectives on LTFU among HIV-positive patients in Sekhukhune District of Limpopo Province, South Africa. The findings of the study guided the development of a proposed strategy to decrease LTFU among HIV-positive patients. The study sought to answer the following research questions:

1.4. Research questions

- What are the factors contributing to LTFU among HIV- positive patients from their perspectives?
- What are the factors contributing to LTFU among HIV- positive patients from nurses' perspectives?
- What are the strategies from patients' and nurses' perspectives that would address barriers to LTFU among HIV-positive patients?

1.5. Significance of the study

The proposed strategy derived from this study may help HIV-positive patients re-engage and remain in care. The study can be most beneficial with HIV education, skills building, and outreach programme strategies, this will in turn increase knowledge needed to better attract and retain HIV-positive patients in care within respective clinics in all the sub-districts. The study could also be beneficial to the Greater Sekhukhune District as the intervention strategy developed in the study may help decrease the overall LTFU rate, AIDS related deaths and increase the rate of patients retained in care within the respective district. Below is, in detail, how the study will benefit HIV-positive patients, nurses, Home Based Carers as well as families and communities as a whole.

1.5.1. Significance to PHC nurses

The nurses will be well equipped with skills on how to motivate, counsel and encourage HIV-positive patients who are already in care about the importance of adherence. This will help to avoid patients defaulting out of care, and in turn, this may results in low LTFU for their respective clinics. The study could also equip the nurses with skills on fast tracking HIV-positive patients before they are identified as LTFU. They may be able to fast track their patients as soon as they miss one or two appointments. They study intervention may also assist them to be cautious about basic ethics, such as patient confidentiality and privacy. As this may be one of the reasons patients default, they lack trust in the nurses. These skills will help nurses to earn the trust of patients.

1.5.2. Significance to the home based carers

The proposed strategy could equip the Home Based Carers (HBCs) with basic counseling skills needed to counsel and educate LTFU patients about the importance of remaining in care. The study can also help the HBCs to be better equipped with the basic ethics skills such as confidentiality and respect for patients. These skills will enable them to be trusted by patients.

1.5.3. Significance to HIV-positive patients

The proposed strategy may help HIV-positive patients re-engage and remain in care. During the strategy implementation, the nurses and HBCs will be well informed, and educated on how to properly counsel, support, motivate and encourage HIV-positive patients to adhere to their medication. As a results of knowledgeable nurses and HBCs, patients will, in turn, be well informed and well educated about ART. Therefore, due to the knowledge passed to them by nurses and HBCs, they could be re-engaged and adherent to their medication. This behaviour will have positive health outcomes on HIV-positive patients such as suppressed or undetectable viral load, less opportunistic infections and healthier long lives.

1.5.4. Significance to the community and families

The communities and families may also benefit from the proposed strategy. When patients are adherent, they will have positive health outcomes such as suppressed viral loads, less opportunistic infections, and will live healthier long lives with their families. Through health education given by nurses at the primary health care settings, the community will be knowledgeable about HIV, stigma, and ART adherence.

1.6. Theoretical framework

The proposed study was guided by various models namely: Information Motivation Behaviour Skills (IMB); Health Belief Model (HBM); Social Action Theory (SAT); and Social Cognitive Theory (SCT) as briefly explained below. The primary theoretical framework IMB is important because it is the foundation from which all knowledge is constructed for the research study. It serves as the structure and support for the rationale of the study, the problem statement, the purpose, the significance of and the research questions (Bowleg, 2012). It provides the background that supports the investigation and offers a justification for the study of a research problem. Therefore, without the theoretical framework the structure, the vision of the study is unclear (Bowleg, 2012). All these models are briefly detailed below and will be fully discussed in detail in chapter 6.

1.6.1. Information Motivation Behaviour Skills (IMB) Model

Fisher, Amico, Fisher and Harman (2008) have proposed an IMB model that speculates that information, motivation, and behavioural skills are principle determinants of health related behaviour (Amico,Toro, Alfonso,& Fisher, 2005). In this study context, this model holds that HIV-positive people who are well-informed through adherence education, motivated to act, and possess the behavioural skills that enable them to act effectively, will remain in care and adhere to ART. Conceptualization of the model to the study results and literature will be fully discussed in chapter 6.

1.6.2. Health Belief Model (HBM)

Health Belief Model attempts to explain and predict health behaviours. This is done by focusing on attitudes and beliefs of individuals. This model addresses problem behaviours that evoke health concerns like high risk sexual behaviours and the possibility of contracting HIV (Croyle, 2005). The HBM views humans as rational beings who behave in certain ways to minimize what they perceive as threats (e.g., non-adherence to medication) and enhance what are perceived as benefits (e.g., adherence to ART). This model is comprised of several interactive states of belief, which collectively affect ART adherence and, therefore, is of relevance for adopting this study. Full details of the model and its relevance to the study will be fully detailed in Chapter 6.

1.6.3. Social Action Theory (SAT)

SAT identifies and eliminates factors that contribute to negative health behaviours, which are detrimental to good health, and introduces positive health behaviours, which will enhance good health (Reynolds, et al., 2010, Ewart, 2009). Social Action Theory (SAT) further suggests the need to expand individually-focused action state concepts by including interdependence with others as a determinant of continued behaviour change. This model and its applicability to the study will be fully discussed in Chapter 6.

1.6.4. Social Cognitive Theory (SCT)

Social Cognitive Theory acknowledges that both the knowledge of health risks and the benefits of treatment are necessary to the patients' performing health behaviours. Self-efficacy and outcome expectation are additional self-influences that are necessary to achieve changes that will result in the desired health behaviour. Self -efficacy means the belief in one's ability to execute a given behaviour and is a known predictor of health behaviour in patients with chronic medical conditions; it has also been shown to influence adherence to ART. An outcome expectation is the belief that a particular behaviour will result in a specified outcome, and outcomes can be either positive or negative. The SCT suggests that an individual will choose an action that he or she believes will maximize positive outcomes and minimize negative outcomes (Bandura, 1977). The detailed relevance of this model to the study will be discussed in detail in Chapter 6.

1.7. Definition of key terms

Loss to follow up (LTFU) means not keeping ART refill appointments for a period of 90 days or longer from the last booked refill appointment date (Cornell, et al., 2014). In the context of this study project, it refers to LTFU patients who have received HIV care services from clinics of the Sekhukhune District.

Nurse is a health care professional who ensures that individuals, families, and communities achieve optimal health by improving their quality of life. In the context of this study, a registered professional nurse applies. They hold a diploma or degree and perform physical exams before making critical decisions; provide health promotion, counseling and education; administer medications and other personalized interventions; and coordinate care, in collaboration with a wide array of health care professionals (SANC, 2008).

Patient is a person under health care, the person may be waiting for this care or may be receiving it or may have already received it (SANC, 2008). This study included HIV-positive individuals who are LTFU.

Strategy refers to a plan of action designed to achieve a major or overall aim. In the study a strategy is a unique set of activities that I will propose to clinics to put in place in order to help HIV-positive patients stay in care and adhere to their ART medications. (MedicineNet).

Anti-retroviral treatment (ART) is a drug therapy used to treat HIV. ART function slows down the replication of the virus and reduces its impact on the body (Cornell, et al., 2014).

1.8. Conclusion

Taking into consideration the 90-90-90 world–wide treatment target to help end the AIDS epidemic, which especially states that by 2020, 90% of all people diagnosed with HIV will receive sustained antiretroviral therapy, and of all people who are on antiretroviral treatment, 90% should have a suppressed viral load (UNIAIDS, 2014). Given the high prevalence of HIV in South Africa and the rate at which patients are dropping out of care, there is a dire need for the strategy proposed in the study to be shared with the relevant individuals. The strategy was guided by incorporation of various psychological models, international literature as well as the results of the study. This will guide the clinics in the Sekhukhune district on what they could do to reduce their rates of loss. . The proposed strategy not only would be useful to the Sekhukhune district but also to the Limpopo Province at large. The subsequent chapters include literature review, which evaluates scholarly research articles and other relevant sources that are related to the current research; research methodology, which describes the research methodology applied in the current study; results of the study, which provide detailed information on how data was analysed along with detailed patients' and nurses' responses; discussion of the findings, which discusses the results of the study in detail and compares the findings with relevant literature; and the proposed strategy, which explores the intervention models in HIV care that might be relevant to guide the strategy development to retain patients in HIV care.

CHAPTER 2: LITERATURE REVIEW

2. Introduction

This review examines previous studies on the present topic, and it also summarizes, compares and contrasts, and evaluates scholarly research articles and other relevant sources that are directly related to the current research.

Reviewing this literature has assisted the researcher to understand what barriers contribute to patients defaulting out of care in South Africa and globally. Consequently, the following literature was systematically reviewed, and reliable sources such as PubMed and Science Direct were consulted to inform the literature below. South African studies are included in the literature and supplemented when needed by international studies.

Various aspects of LTFU of patients on ART have been widely researched, both internationally and in South Africa (Miller et al., 2010). The detailed literature review below provides an overview of the empirical evidence about loss to follow-up (also known as poor retention in HIV care) and about use of alternative treatments among HIV-positive patients worldwide. Thus, the review will identify the factors contributing to LTFU among HIV-positive patients from an international perspective, then specifically within South Africa. In addition, this review will examine the various intervention strategies that help HIV-positive people remain in care. Noteworthy, information pertaining to patients' perspectives on factors contributing to LTFU among HIV-positive patients and intervention strategies that help HIV-positive people remain in care is voluminous. However, information on the nurses' perspectives on factors contributing to LTFU among HIV-positive patients was not found. At the end of the literature review is a table indicating all the themes and sub-themes in the presented literature and articles retrieved from each.

2.1. Factors contributing to Loss to Follow-up among HIV-positive patients from the patients perspectives globally

Various factors contribute to HIV-positive patients becoming lost to follow-up once they are initiated into care. Below is a detailed review of what is known about why HIV-positive patients default from their ART; structural factors (financial constraints and long distance to the clinic, food insecurity); system factors (long waiting times in the clinic, unsatisfactory treatment by service providers, medication shortage, termination of disability grants); psychological factors (fear of HIV stigma and discrimination, negative side-effects and feeling better physically); and cultural/behavioural factors (Traditional beliefs, religious faith).

2.1.1. Structural factors

Structural factors responsible for patients’ non-retention in care are different for all HIV-positive patients. This may be related to the economic system in the patients` countries. There are various structural factors that prevent HIV-positive patients from remaining in care. The factors may include inconveniences and financial constraints, such as long distance to the clinic, food insecurity, and transportation costs. Below is detailed literature on structural factors responsible for patients’ non-retention in care world-wide.

2.1.1.1. Financial constraints and long distance to the clinic

Most health care facilities in Sub-Saharan Africa are located far from patients’ homes. This makes it difficult for patients with fewer financial resources to reach the clinics. It is therefore important to note that some patients travel long distances to access the clinic for their ART refills. Unfortunately, because of this burden, some patients discontinue their HIV treatment (Roura, Wringe, Busza, & Nhandi, 2009; Mukumbang Mwale J& van Wyk, 2017).

For instance, in Nepal, semi-structured interviews were conducted among 34 participants to elicit contributing factors for patients who ceased treatment. The study found that long distance to the clinic was one of the contributing factors to LTFU in care. Some patients reported walking more than one and a half days to receive their HIV treatment. As a result, they decided to discontinue their HIV care (Wasti, Simkhada, Randall, Freeman & Teijlingen, 2012) . A similar cohort Ugandan study also found that long distance to clinics was one of many reasons for not returning to the clinic for medication refills (Geng et al., 2010). In addition, in a Tanzanian qualitative study, patients reported that the distance to their clinic was a barrier to clinic attendance due to the inconvenience and expense of travel (Roura et al., 2009 ; Tomori, et al., 2014).

Moreover, various studies demonstrated that patients perceive financial constraints as a barrier to continuing their ART treatment. Financial constraints can be related to several factors, including low income and unemployment. Most patients pointed to those financial constraints that make it difficult for them to afford transportation to the clinic, and yet many clinics are not within walking distance (Tweya et al., 2013, Bezabhe et al., 2014, Balcha, Jeppsson, & Bekele, 2011).When a patient is unemployed or has a low wage, it may be almost impossible to afford transportation to the clinics.

In support of this assertion, a qualitative study in India showed that finances emerged as the greatest barrier to ART adherence. Interviewees often did not have the money for transportation to health facilities for their HIV medication refill, and as a result, they discontinued their HIV medication (Wasti et al., 2012; Sangaramoorthy, Jamison, & Typhanye, 2017). Similarly, in a study conducted in Malawi, 62% of traced patients who stopped ART reported that travel and lack of transport, were the primary causes of their discontinuation of HIV treatment care (Tweya et al., 2013). Additionally, an Ethiopian qualitative study exploring barriers to sustained treatment and follow-up of ART among HIV patients found that although ART was free at the point of use, participants reported that several costs were associated with the treatment. Patients implied that the cost of transportation was a hindrance to follow-up because they could not afford it (Balcha, Jeppsson, & Bekele, 2011; Tiruneh, et al., 2016). Similarly, in another study in Ethiopia, 24 were interviewed. It revealed that lack of transport money prevented patients from returning for their HIV medication refills; this impaired retention of ART. In this study, half of patients who had been lost to follow-up after the initiation of ART were either unemployed, daily labourers or waiters working for low wages (Bezabhe et al., 2014).

A similar study conducted in Nigeria, Tanzania, and Uganda examined missed clinic visits and subsequent disengagement among patients enrolled in HIV treatment and care programmes in these three countries. In the study, 91 patients were interviewed. Lack of support from family and community in the form of failure to provide transportation money was a factor for these HIV patients to discontinue their HIV treatment (Ware et al., 2013). Correspondingly, 35 semi-structured interviews were conducted in a Ugandan qualitative study and revealed that transportation costs reduced adherence to a regular medication schedule. Individuals who missed doses cited problems finding transportation money as a key reason for not returning to the clinic for refills. The patients explained that they could not afford to travel to the clinic (Tuller et al., 2010; Bezabhe, 2014). A South African study examined factors relating to LTFU of patients on antiretroviral therapy. Telephone interviews were conducted among 182 LTFU patients, and it was discovered that the most frequently reported cause of failure to follow up was financial struggle. About a third (34%) of the patients cited transportation costs as the biggest obstacle to obtaining HIV treatment (Maskew et al., 2007, Geng et al., 2016).

South Africa's unemployment rate increased from 25.6% in 2011 out of a population of 51,777,560 to the rate of 26.4% in 2015 out of a population of 53,491,333. In Sekhukhune District of Limpopo Province, 51% of 1,076,840 of the district population are unemployed (Statistics South Africa, 2011). When HIV-positive unemployed patients cannot afford transport costs to the clinic, this leads to LTFU of patients, which will later increase HIV-related deaths. Therefore, to prevent loss to follow up and HIV-related deaths due to transportation issues, the high rate of unemployment should be given more attention in South Africa and globally. Lastly, LTFU is a serious concern in areas with high unemployment, such as South Africa. For instance, in the Greater-Sekhukhune District of Limpopo Province, the unemployment rate is at 51%, (Statistics South Africa, 2011). Based on the findings reported in previous studies, it can be predicted that the higher the unemployment rate, the fewer chances there are of affording transport costs to the clinics.

2.1.1.2. Food insecurity

Food insecurity is defined as the state of being without reliable access to sufficient quantities of affordable nutritious food. Food insecurity was found to be associated with LTFU of patients on ART. For instance, in a Congolese study, a multivariate analysis examined factors related to LTFU care. Food insecurity was strongly associated with non-retention in care. Specifically, food-insecure participants were two times more likely to discontinue taking their HIV medication compared to those who had sufficient food. Patients reported that they needed nutritious food (which they could not afford) in order to take their ART medication (Musumari et al., 2014).

In a qualitative Ethiopian study, some ART patients reported requiring more nutritious diets than a ‘‘normal’’ person. They stated that they had to change to a richer balanced diet. Participants tried to justify their view and reported that ARV medications ‘‘were too strong’’ to take along with the routine diet of Ethiopians. Others asserted that ART medications were completely different from conventional medicines. Half the Ethiopian patients in the study reported that they stopped taking their medication because they did not have the balanced diets that would go with ART medication (Balcha et al., 2011; Colasanti, Stahl, Farber, del Rio & Armstrong, 2017).

Structural factors found to be barriers to ART have shown to affect most of the countries in Sub-Saharan Africa (Musumari et al., 2014). This may be because most clinics in Sub-Saharan Africa are located long distances from patients’ homes; this makes it difficult for patients without substantial financial resources to reach the clinics (Roura et al., 2009). As a result, some patients discontinued taking their HIV treatment (Geng et al., 2010). In South Africa, unemployment is the most highly related factor to financial constraints, with the current unemployment rate of 26.7% and 51% in the Sekhukhune District, where the proposed study will be conducted (Statistics South Africa, 2011). This means that more than half of the population in the district is unemployed. When a patient is unemployed or has a low wage, and the clinic is too far away, it may be difficult to afford transportation to reach the clinics. The distance to the clinic and the financial constrains are intertwined. Most patients pointed out that those financial constraints, combined with transportation costs, make it difficult for them to afford getting to the clinic, and yet many clinics are situated so that patients can reach them on foot (Tweya et al., 2013).

2.1.2. System factors

System factors refer to the health facilities, practices and delivery of health care services in different communities. The literature below will outline in detail various global system factors that may be responsible for patients defaulting in care. The factors include long waiting times in the clinic, unsatisfactory treatment by service providers, medication shortages as well as termination of disability grants.

2.1.2.1. Long waiting times in the clinic

Long waiting times have been a concern to most patients, especially in Sub-Saharan Africa (Dahab et al., 2008). This factor was frequently identified in studies as one of the contributing reasons for patients LTFU. It is common in South Africa for patients to wait up to four hours in the clinic before receiving their medication refills (Dahab et al., 2008). Consequently, patients become discouraged about returning to the clinic, anticipating another long wait or lost day of work. For example, in a South African study, several subjects reported abandoning treatment because of long clinic waiting times (Dahab et al., 2008). Other issues reported in the study were difficulty in booking appointments and the large number of patients that exceeded the capacity of the clinic (Miller et al., 2010). Another corresponding South African qualitative study also found that most patients who were LTFU reported that clinic waiting times were too long, and that the delay was the reason they stopped going to the clinic to refill their medication (Dahab et al., 2008; Napúa, 2016).

It is noteworthy that in many South African clinics, each clinic caters to a high volume of patients (Sekhukhune District Annual Report, 2014). For instance, in Sekhukhune District, on average there is one clinic for every 17,000 people within the district. As a result, by the time the clinic opens, hundreds of patients are already queuing at the gate. Without a clinic structure of scheduled appointments, patients have no choice but to wait for hours to get service.

Moreover, most HIV clinics operate from 9:00 am to 17:00 pm worldwide. Clearly, these are the times when most patients are at their workplaces. As a result, patients must take time off from work in order to go to the clinic for their ART care and medication refills. This poses a challenge to many full-time employed HIV positive patients. For instance, in a South American study conducted in Bolivia, patients reported that limited schedules and distant locations of clinics providing ART treatment were significant barriers to their retention in care.

Many participants stated that the clinics closed too early at night or opened too late in the morning for them to schedule doctor appointments or pick up medications without conflicting with their work schedules (Palar, Martin, Camacho, & Derose, 2013). It is also worth noting that in Limpopo Province of South Africa, most clinics operate from 9:00 am to 17:00 pm weekdays. In general, when patients go for medication refills, they are given their next appointment date by the health worker. However, it is a challenge for most HIV-positive patients who are employed full-time to return for their set refill appointment dates, especially at clinics that operate for only eight hours a day.

It is especially difficult for patients to leave their workplace and go to the clinic for their medication refills because most patients do not disclose their HIV status to their employers. This means that every time the full-time employed patients must go to the clinic for medication refills, they are required to explain their reasons for leaving work. Consequently, patients may hesitate and fail to return to the clinic at all (Palar et al., 2013).

2.1.2.2. Dissatisfactory treatment by service providers

Negative treatment from staff also discouraged patients from going to the clinic for their refills (Layer et al., 2014). Patients were denied service for being late for their appointment at the clinic after traveling hours to get there(Layer et al., 2014). Arriving late is expected considering the long distance patients travel from their homes to the clinic and the scarcity of public transport in non-urban areas. Most HIV clinics operate from 9:00 am to 17:00 pm. These are the times when most patients are at their workplaces. As a result, some patients hesitate to take time off every time they have to go to the clinic for their ART care and medication refills (Palar et al., 2013). Some studies have reported that patients with HIV state that negative treatment by personnel at the health facilities made them default from their HIV treatment. In support of this, a Tanzanian study conducted interviews among HIV positive patients to understand their reasons for dropping out of care. The study discovered that one of the barriers to retention in HIV care was disrespectful and abusive treatment by health care workers. Participants in this study reported having encountered negative experiences where they were shouted at, or ‘‘punished’’ by one or more health care workers (Layer et al., 2014).

Negative interactions often occurred when a client disobeyed rules set by providers, most commonly arriving late or missing an appointment. When clients returned to the clinic on a day other than their assigned clinic day, they were often either denied services completely or forced to wait until the end of the day as ‘‘correction’’ for their behaviour. This harsh and disrespectful treatment was a common reason for HIV-positive clients to disengage from care (Layer et al., 2014). Similarly, a Malawian cross-sectional study designed to investigate the reasons for patients defaulting from ART care showed that 34% of ART patients defaulted from their HIV medication because of dissatisfaction with the care or staff behaviour (McGuire et al., 2010; Lam, 2016). Similarly, a study in Kenya among 219 HIV-positive individuals investigated their reasons for disengaging in care, and found that 73% of the patients reported that they were afraid of being “scolded.” Additionally, 43% of patients reported that staff members were not friendly. For patients, these were genuine reasons for discontinuing care (Rachlis et al., 2015; Yu, 2016).

2.1.2.3. Medication shortage

Medication shortage (or stock-outs) is defined as the unavailability of ARV drugs in the clinics. Frequent medication shortages mean that patients are likely to be turned away without the needed medications, even after making long trips to the clinic. Evidence supporting this idea was found based on semi-structured interviews in a study conducted in Bolivia. Some participants also reported that at times, the pharmacy was unstaffed during business hours, or lacked specific medications needed by the client. In these cases, patients had to return another day, requiring additional cash and yet another round of permission from work or absence from important livelihood activities. Some patients were sometimes turned back twice before medication was available. Some patients reported that they discontinued ART because of this (Palar et al., 2013; Moriarty, Genberg & Norman, 2018).

Second , a South African qualitative study conducted in Limpopo and Gauteng Provinces showed that HIV-positive patients reported that they stopped taking ART due to the perception of a constant shortage of HIV medication at the clinics (Miller et al., 2010). In fact, these perceptions are often accurate. South Africa has recently been experiencing ART stock-outs or medication shortages. In 2013, 52% (242) of South African clinics experienced such shortages. In Limpopo Province, 41% of clinics sustained shortages, and the highest figure of 54% clinic ART shortages occurred in Free State Province. In Limpopo Province, the stock outs improved massively with 29% in 2014, 12% in 2015). However, in the Free State, a large increase was noted between 2014 (28%) and 2015 (36%) in the percentage of facilities reporting stock outs.(2015 Stop Stock-out National Survey, 2016). Such shortages present a risk factor for HIV-positive patients to default from HIV treatment.

2.1.2.4. Termination of disability grants

According to the Department of Social Development, disability grants are available to adult South African citizens and to permanent residents who are incapacitated and unable to work due to illness or disability. A number of people living with HIV/AIDS access disability grants once they have fulfilled the criteria set down by the Department of Social Development. In South Africa's highly unequal society, the disability grant often operates as the only source of income for poor families. This has created an untenable situation as there is a disincentive to attain health by taking ART. A grant is terminated when one's health outcomes, such as CD4 count and viral load, improves.

Therefore, HIV positive people may choose to default by failing to take life-saving medication (ART), ensuring that their CD4 count deteriorates and viral load increases so that they could continue receiving their disability grant. The disability grant is usually the only means of survival and is thus regarded not merely as social assistance but as legitimate income. Termination of disability grants is interconnected with both financial instability and food insecurity. When HIV positive patients lose the disability grant, they start having financial problems and cannot afford basic food. Studies have shown that losing the grant has implications for HIV positive people because a healthy diet may no longer be accessible/affordable, which in turn undermines adherence to ART (Woolgar & Mayers, 2014).

Few studies have been conducted in South Africa to determine the relationship between the disability grant and ART adherence. Those conducted so far seem to indicate that the conflict between health and the disability grant may not be leading to non-adherence. For example, a qualitative research study explored the perceptions and experiences of HIV positive people on ART concerning the disability grant and its contribution to their health and well-being. Three focus groups, with 15 selected participants who attended a primary care clinic in the Western Cape Province, showed that the disability grant was considered an essential source of income and, for some, the only means of survival. In that sample, participants valued their health more than the income, however, and, despite the risk of losing the grant, they remained adherent to ART.

Therefore, the disability grant was seen as a great benefit for the participants, and it assisted them in affording basic necessities such as food and to adhere to the medication regime. So, the disability grants did contribute to the good health outcomes of patients. A grant facilitated good physical and mental health, enabled participants to meet their basic needs, and reduced stress. Regardless of the participants' employment status, social and/or disability grants played a major role in survival and wellbeing by alleviating poverty (Woolgar & Mayers, 2014). Another Western Cape study explored -from the perspectives of both PLHIV and their doctors- whether people living with HIV (PLHIV) reduced or stopped treatment to remain eligible for the disability grant. .The results showed that unemployment and poverty were the primary concerns for PLHIV, and the disability grant was viewed as a temporary way out of this vicious cycle. Loss of the disability grant significantly affected the wellbeing of PLHIV, but they did not discontinue ART (Manuela de Paoli, Mills, & Gronningsaeter, 2012). In the same study, 42% of the respondents had experienced losing their disability grant. Ninety percent of those, for whom the disability grant had been terminated, reported that it had a substantial impact on the household economy. The interviews revealed that the loss of disability grants have a negative impact on HIV positive peoples' wellbeing because, when the disability grant is terminated, patients can no longer afford a healthy diet, and in this way adherence to ART is undermined.

There are various structural factors that have been reported that undermine ART adherence worldwide. As pointed out above, factors such as long waiting times, medication shortages, and termination of disability grants undermine ART adherence worldwide. Long waiting time has been mostly reported as a barrier to ART adherence in Sub-Saharan Africa (Dahab et al., 2008). This may be caused by a high volume of patients that each clinic caters to with limited clinic staff. For instance, in Sekhukhune District of South Africa, each single clinic caters to nearly 17,000 people within that district (Sekhukhune District Annual Report, 2014). Medication shortages have also been reported to be the contributing factor to ART non-adherence with a reported figure of 52% medication stock-outs in South African clinics (SSP Stock- out National Survey, 2013). When patients go to the clinic and find no medication, they get discouraged and not motivated to go back the next time (Palar et al., 2013). It is worth noting that termination of disability grants is interlinked with financial instability. When HIV-positive patients lose the disability grant, they start having financial problems and cannot afford basic food and transportation to the clinic (Woolgar & Mayers, 2014).

2.1.3. Psychosocial factors

Psychosocial factors are those that affect patients psychologically and socially and often trigger patients to default from ART. They may include stigma and discrimination, negative side effects, and feeling better physically. Below is detailed literature on how psychosocial factors cause patients to be retained in care.

2.1.3.1. Fear of HIV stigma and discrimination

The phenomenon of HIV stigma and discrimination refers to prejudice, negative attitudes, and abuse of people living with HIV. Many patients living with HIV discontinue ART due to their fear of the negative reactions of family members, friends, colleagues or community members. Patients fear that if they are attending HIV care clinics or taking ARV medication, they will be stigmatized and discriminated against.

To investigate this, a South African qualitative study was conducted at four health facilities. The study sought to assess the rate and reported reasons for loss to follow-up among stable patients on ART. In this study, patients pointed out that they opted to discontinue taking ART because they were afraid that if their employer discovered their HIV status, they might discriminate against them and dismiss them from work. In addition, patients discontinued attending HIV clinics for their ARV medication refills because they did not want to request time off from work to collect their medication. They pointed out that requesting time off meant they had to disclose to their employer their reasons for absence (O'Connor, Osih, & Jaffer, 2011; Atanga, 2017).

In a Malawian study, 221 participants were interviewed individually to investigate their reasons for defaulting from ART. The authors found that the primary reason for patients' defaulting was stigma. Many (43%) of the patients defaulted from ART because of fears of being stigmatized (McGuire et al., 2010).Another similar qualitative study was conducted in Kenya among 27 HIV-positive youth (15-21 years) to explore reasons for LTFU among that age cohort. The study revealed that HIV-related stigma, both at school and at home, was the main factor leading to LTFU of youth living with HIV. Youth participants described their fears that family members might discover their HIV status as the reason why they discontinued HIV treatment (Wolf et al., 2014). A qualitative study in Vietnam interviewed 48 participants (including HIV- positive individuals and their relatives). Experiences and fears of HIV-associated stigma were widely acknowledged by participants of both genders. Most HIV-positive participants reported fear that taking their medication would reveal their HIV status to family members, friends, neighbours, or co-workers. This was the main reason for discontinuation of medication (Tama, Pharrisa, Thorsona, Alfvena, & Larssona, 2011; Doherty, 2017).

Concurrently, in an Indian study, a meta-synthesis method was used to summarize findings from qualitative studies to identify the relationship between ART adherence and HIV-related stigma. In this review, patients experienced stigma when self-identifying as HIV-positive, including discrimination and acts of hostility. In such settings, many participants opted neither to go to HIV care clinics nor to take ART medications (Katz et al., 2013; Lambert, 2018).

2.1.3.2. Negative side-effects

Anti-retroviral therapy may have side effects for HIV-positive patients; the side effects include dizziness, nausea, headaches, and fever. Most of these side effects can be prevented or managed proactively. Some studies found that patients default from their ART due to the negative side effects mentioned above. For instance, a qualitative study in Lima, Peru found that 74% of the patients reported side effects as a barrier to their retention in care (Curioso, Kepka, Cabello, Segura, & Kurth, 2010). A prospective cohort study was conducted in South Africa to better understand the reasons why patients default from ART programmes. Some participants defaulted due to the medication's side effects. Of the 14 interviewed defaulters, two women reported body shape changes, such as enlargement of breasts as contributing factors for defaulting from treatment (Miller et al., 2010; Buregyeya, 2017). A cohort study in Malawi analysed mortality, LTFU, and retention on ART in the first year of therapeutic initiation across all age-groups in the Malawi national ART programme. Overall, side effects were the most frequently discussed barrier to adherence by participants. Side effects reported included both negative symptoms which the participants attributed to the ART regimen, and the side effects anticipated due to the ART regimen. Patients reported that ART caused unwanted changes to their bodies; as a result, they were reluctant to adhere to their ART regimen (McGuire et al., 2010; Koirala , Deuba , Nampaisan , Marrone & Ekström, 2017).

2.1.3.3. Feeling better physically

It is common for patients on ART to feel physically better and stronger than before their ART initiation. Unfortunately, some HIV-positive patients stop taking their HIV treatment when they feel physically well. For instance, a study conducted in Kenya to evaluate outcomes of patients lost to follow-up found that other reported reasons why patients disengaged from care was a sense of physical health (Rachlis et al., 2015). As a result, patients decided to stop HIV care. A longitudinal follow-up study in New York sought to locate LTFU persons living with HIV and assist them with linkage to care, and also to investigate the reasons for LTFU (Ndeaga, Webster, Bocour, Michel, & Shepard, 2013). In this study, among 161 LTFU patients, 41% reported their reason for LTFU was that they felt positive about their health and therefore decided to cease their HIV treatment. They felt that medical treatment was no longer necessary for them.

Patients' traditional and religious beliefs also influence their retention in HIV care. Some patients believe that HIV is a result of witchcraft, and they consider traditional medicine as a more appropriate HIV treatment than ART (Rachlis et al., 2015). On the other hand, some patients claim that God cured them, and therefore believed that they no longer have HIV. In both cases, patients stop taking ART because they believe that they were cured or that they will be cured (Wringea et al., 2009). Both beliefs have been found to be common in Sub-Saharan Africa (Rachlis et al., 2015).

Patients also reported to have stopped taking their ART due to side effects such as dizziness, nausea, headache, and fever. Most patients, however, lacked the knowledge that these side effects could be prevented or managed proactively; thus, they were discouraged from continuing their ART medication (Curioso et al., 2010). Typically, HIV patients on ART feel physically better and stronger than before their ART initiation. Unfortunately, some HIV-positive patients stop taking their HIV treatment when they feel physically well, which is also due to lack of knowledge. They believe that since they feel physically stronger, they are cured and see no need to continue with the treatment (Rachlis et al., 2015).

2.1.4. Cultural and behavioural factors

Cultural and behavioural factors encompass the set of beliefs, moral values, and traditions, (or rules of behavior) held in common by a nation, a community, or other defined group of people (Dahab et al., 2008). Due to different beliefs that people have , some HIV-positive patients default from their HIV treatment and opt for alternative therapies such as traditional medication, faith water, and prayer (Dahab et al., 2008). Below, is a detailed review of cultural and behavioural factors that influence LTFU HIV-positive patients.

2.1.4.1. Traditional beliefs

Traditional beliefs may include beliefs in spirits, traditional healers, or other practices as medicine. Sometimes patients who are already initiated on ART default from their therapy and opt for traditional medicine as an alternative treatment (Rachlis et al., 2015). This means that patients' traditional beliefs may influence their retention in HIV care. Many patients believe that the HIV virus is a result of witchcraft. As a result, traditional medicines seem a more appropriate HIV treatment than ART (Rachlis et al., 2015; Mukumbang, Mwale & Van Wyk, 2017). This belief was identified in a study conducted by Wringea et al. (2009). In this study, 42 interviews and 4 focus group discussions were conducted to explore factors influencing attendance at HIV clinic appointments among patients in northwest Tanzania. Results showed that local beliefs that the HIV virus was attributable to witchcraft and could be cured had a negative effect on patients` clinic attendance. In this study, patients discontinued their ART and resorted to traditional medication in the belief that they would be treated and cured of HIV.

Furthermore, related findings were revealed in a Kenyan study that was conducted in one of Africa's largest informal urban settlements, Kibera, in Nairobi. The objective of this study was to explore the influence of traditional medicine and religion on discontinuation of antiretroviral therapy (ART). Semi-structured, face-to-face interviews were conducted with 20 patients discontinuing ART due to issues related to traditional medicine and religion. Patients described a decisional process, prior to the actual drop-out from the ART program, that involved a trigger event, usually a specific religious event, or a meeting with someone using traditional medicine who influenced them to take the decision to stop ART (Unge, et al., 2011; Wanyama, 2017). A 2008 South African study showed similar findings. In this study, interviews were conducted among 12 key informants to assess patients' reasons for LTFU; the main reported reason for LTFU was patients` use of traditional medicine. Respondents believed that ART and traditional medicine should not be used concurrently and therefore ceased ART for the period during which they utilized traditional medicine (Dahab et al., 2008).

2.1.4.2. Religious faith

In other cases, patients claimed that God had cured them, and therefore denied that they still had the HIV virus. Consequently, they stopped taking ART because they believed that they were cured. One ART patient who stopped attending the clinic for several months attributed his ‘‘cure’’ to his religious faith (Wringea et al., 2009). Similarly, a qualitative Tanzanian study was conducted in which 42 semi-structured interviews were held to investigate the diversity of factors underlying attendance at ART clinics. The authors revealed that patients reported discontinuing taking their HIV medication because they believed that HIV is caused by witchcraft and therefore can only be cured through spiritual healing (Roura et al., 2009).

A Nigerian retrospective cohort study was conducted in two hospitals to investigate patients' reasons for LTFU. The most common reason they reported for stopping treatment was patients` switch to alternative HIV treatment options. The majority of patients (75.3%) reported that alternative HIV treatment options could lead to an HIV cure. These HIV treatment options included the use of herbal medicines and visiting a prayer house (Onoka et al., 2012). The same Nigerian study revealed that patients who reported having a personal relationship with and trust in God were more likely to drop out of ART care. The majority of those respondents, who identified themselves as Christians, testified about how being ‘‘born-again’’ and their ‘‘personal relationship’’ with God had healed them. They therefore saw no need to continue with antiretroviral treatment (Onoka, et al., 2012; Atanga, 2016). Moreover, 17 in depth interviews were conducted in an Ethiopian study among people living with HIV. It was discovered that the use of holy water was considered by HIV-positive patients to be an alternative and complementary treatment for HIV (Berhanu, 2010). Contradicting findings in a study conducted in the US among Latino immigrants revealed that religious belief provided a source of hope and optimism for HIV-positive patients (Levison, 2017).

2.2. Literature review implications

Despite all the informational programming available throughout the world, the fear surrounding the HIV epidemic that emerged in the 1980s persists today. In the early phase of the epidemic, lack of knowledge led people to discriminate and to stigmatise HIV-positive individuals due to their fear of being infected. This stigma around HIV makes HIV- positive patients fear that their HIV status might become known if they adhere to ART (McGuire et al., 2010). As a result, patients defaulted from treatment to avoid being discriminated against and stigmatized and to prevent their HIV status from being discovered (Wolf et al., 2014). The evidence that medication shortages undermine engagement in HIV care implies that HIV medication should be given priority by the South African government to ensure that medication is provided and is available at all times in the clinics. Disability grants are provided to HIV-positive patients who are very ill and are unable to work. The grant is terminated, however, when patients’ health outcomes improve and they feel better. So, it is a disincentive for patients who receive the disability grant to adhere to their medication and improve their health outcomes because they are afraid to lose the grant. As a result, they intentionally stop treatment so that they remain ill and continue to receive the disability grant . It is also worth noting that South Africa has an enormous shortage of nurses and a high volume of patients, therefore with limited staff, patients may wait a long time in the clinics to receive care (SANC Annual Report, 2017). This waiting might cause patients to hesitate to return to the clinic for their next visit due to feeling disrespected, being inconvenienced, and incurring costs for transportation, etc. South Africa has a high rate of people whose religious faith and traditions may lead patients to believe that they can be healed by either God or by traditional medications. Finally, based on the above mentioned findings on factors that contribute to patients LTFU, it is reasonable to expect that most of these barriers among HIV-positive LTFU patients, especially in Sub-Saharan Africa, may also be the same barriers that contribute to patients LTFU in the Sekhukhune District of Limpopo Province in South Africa.

2.3. Conclusion

Based on the above findings, it is evident that many patients in Sub-Saharan Africa experience many challenges that are beyond their control. The literature also points out important areas of improvement for the future to improve the rates of LTFU. These findings indicate that a new strategy to improve patient care is needed. Chapter 3 will describe all the research methods applied in this study.

CHAPTER 3: METHODOLOGY

3. Introduction

The previous chapter outlined the literature on patient and nurse perspectives regarding loss to follow-up in HIV care. The present chapter focuses on the research methodology applied in the study. It describes the research design; the study methods undertaken (which include study setting, study population, sampling methods). This chapter further explains the research instrument used in the study and also illustrates how trustworthiness was established. Moreover, the chapter demonstrates how the research instrument was pre-tested; the data collection process; how the data was analysed as well as the ethics considered during the study. Lastly, this chapter illustrates how the strategy to enhance ART adherence and promote retention in care was developed. The study was conducted to answer the following research questions:

- What are the factors contributing to LTFU among HIV- positive patients from their perspectives?
- What are the factors contributing to LTFU among HIV- positive patients from nurses' perspectives?
- What are the strategies from patients' and nurses' perspectives that would address barriers to LTFU among HIV-positive patients?

3.1. Research Design

The present study applied a qualitative research design. Qualitative design is a way of obtaining or gaining insight through discovering meanings (Cresswell, 2013). The qualitative research design was the most appropriate design to the research questions posed for several key reasons (Cresswell, 2013). During the interviews, participants' responses were not limited; that is, the interviews allowed for an open-ended flow of information from respondents. Secondly, participants had an opportunity to elaborate on their answers. Thirdly, the observational nature of qualitative design allowed me to further describe the thoughts and actions of the participants, using rich details and broad themes and using the respondents' own words (Cresswell, 2013).

Qualitative design is also inter-subjective; I was physically involved in the entire process of data collection and therefore able to observe participants' non-verbal gestures (Cresswell, 2013). Lastly, qualitative design is relevant for the study as it appreciates differences among respondents and attempts not to generalize its findings. Qualitative design considers that people think differently from each other and that each individual's circumstance is equally important in understanding reality (Cresswell, 2013). This design is further relevant to my study because it allowed patients and nurses to share their perspectives on LTFU in more detail during the interviews. This design also allowed me to probe for more information and also allowed the participants to elaborate their answers and ask for clarity if needed.

3.2. Study setting

The study was conducted in the Sekhukhune District located in the Limpopo Province, the northern-most part of South Africa. This district lies in the South-Eastern part of the province and is comprised of five local sub-districts: Elias Motsoaledi, Ephraim Mogale, Fetakgomo, Makhuduthamaga, and Greater Tubatse. The district has a population of 1,076,840 people, of these 55% are female, 45% are male, and 83% of the population speak Sepedi as their mother tongue. The district also comprises of 740 villages, and of these, 394 are without health facilities. There are 117 clinics and seven hospitals in the district, of the 117 clinics in the district, one serves at least 17,000 patients daily, on average (Sekhukhune District annual report, 2014). All the 117 clinics in the district offer ART; patients decide to go to whichever clinic is convenient for them. Most of the patients go to the nearest clinic to their homes. However, some of the patients prefer clinics farther away from their homes due to fear of non-confidentiality in their nearest clinics. Unfortunately, these patients usually end up defaulting from care due to lack of transportation fares to travel to the clinic of their choice. Figure 8 and Figure 9 below show where Sekhukhune district is located in the Limpopo Province and where all the sub-districts of Sekhukhune districts are located in the district. Table 1 shows the population of all districts of the Limpopo Province, and table 2 shows the population of all sub-districts in the Sekhukhune district.

Figure 6. Limpopo Province map: Districts of Limpopo Province (Sekhukhune Annual District Report, 2014).

Table 6.1. Estimated population for Limpopo province by district, (Stats SA, 2011)

District	Population
Capricorn	1,261,463
Greater Sekhukhune	1,076,840
Mopani	1,092,507
Vhembe	1,294,722
Waterberg	679,336

Figure 7. Sekhukhune District map (Sekhukhune Annual District Report, 2014).

Table 7.1. Estimated population for Sekhukhune district by sub-district/municipality, 2016 (Stats SA, 2016).

Sub-district	Total estimated population
Elias Motswaledi	168,256
Ephraim Mogale	127,168
Greater Tubatse	393, 713
Makhuduthamaga	283,956

3.3. Study population

A study population refers to the entire group of people that meet a designated criteria (De Vos, 2005). This definition is substantiated by Burns and Grove (2009) who define population as all elements, individuals, objects, events, or substances that meets the sample criteria for inclusion in a study. These authors further differentiated between accessible and target populations of participants available for a particular study or accessible to the researcher. A target population refers to the total group of subjects about whom the researcher is interested and about whom research findings can reasonably be generalised. Accessible population comprises cases from target populations that are accessible to the researcher as a pool of subjects (Burns & Grove, 2009). Thus, in this study, my target population was all HIV-positive LTFU patients and nurses in the clinics with both high and low rates of LTFU in the Sekhukhune District. Sekhukhune districts was a choice of study because of its high rate of LTFU. Thus, the accessible population in the study was the selected participants who are a subset of the target population. Sekhukhune district of Limpopo Province was the study area choice due to its high rate of LTFU. The rate of LTFU in the Sekhukhune district of Limpopo Province is 23%, which is greater than the South African National LTFU rate of 20% (Sekhukhune District Annual Report, 2014).

3.4. Sampling procedures and sample

The accessible sample population came from eight clinics in the district. The sample of patient participants is comprised of 30 HIV-positive people classified as “lost to follow-up”. The nurse participants’ sample is comprised of eight nurses, four from clinics with high rates of LTFU and four from clinics with low rates of LTFU. HIV-positive participants included 18 females and only two males in four sub-districts of the Sekhukhune district. Only people who are 18 years and older were included in the study because, in South Africa, people 18 years of age and above can give legal consent. Trochim (2006) defines sampling as a process of selection of units (e.g., people, organisations) from a population of interest, so that by studying the sample one may fairly generalise the results back to the larger population. It is important to ensure fairness during participant selection because the selection can affect the risks and benefits of the study as well as the results (Emmanuel, Wandler & Crady, 2000).

In this study, patients were sampled through a non-probability purposive sampling method and a probability systematic sampling method. Non-probability purposive sampling is a sampling method in which only relevant participants are chosen to fit the requirement for the purpose of the study, whereas probability systematic sampling is a sampling method involving the selection of elements from an ordered sampling frame (Crepaz & Marks, 2002). In this method, the researcher first randomly picks the first item or subject from the population. The researcher then selects each n'th subject from the list (Crepaz & Marks, 2002).

3.4.1. Sampling of clinics

The clinics were sampled through a non-probability purposive sampling method. This sampling method was chosen because it enabled me to actively select the most productive sample to answer the research questions. Only clinics identified as those with both high and low LTFU rate were sampled. A non-probability purposive sampling was used to sample two clinics from each sub-district, one with the highest rate of LTFU patients and one with the lowest rate of LTFU. This helped to maximise an equal representative of all the sub-districts in the Sekhukhune district. It also minimised bias and enabled the results of the study to be generalizable to the district as a whole. The clinics were sampled because of their high rate of LTFU, while others were sampled because of their low/zero LTFU rate. For instance, Mashabela and Motetema clinics were selected because of their high rate of LTFU in their respective sub-districts whereas Mankotsane and Moeding clinics were selected due to their low rate of LTFU.

3.4.2. Sampling of HIV–positive LTFU patients

A probability systematic sampling was used to select the patients from the selected clinics. Every 5th patient on the LTFU clinic register was selected. Thirty patients who have been identified as lost to follow-up in the whole district were sampled from all the four sub-districts in the clinics with high rates of LTFU experience. To fill the gap of those who were not interested in participating, other patients from the LTFU list provided by the clinic were systematically selected and contacted until the data saturation was reached. This sampling method was chosen to reduce bias and gave every participant an equal opportunity to participate in the study.

3.4.3. Sampling of nurses

Non-probability purposive sampling was used to select the clinic nurses. This sampling method was chosen because it enabled me to actively select the most productive sample to answer the research questions. Only nurses from selected clinics with both the highest and lowest LTFU rate in the district were sampled to participate in the study. This technique was less time-consuming and less expensive, as it involved smaller search costs (Crepaz & Marks, 2002).

3.5. Research instruments

The data was collected through the use of a semi-structured interview guide (refer to appendix C, D and E) that I prepared prior to the collection of data and before conducting the interviews with the participants. The semi-structured interviews were conducted to obtain a comprehensive illustration of participants' perceptions on LTFU. The semi-structured interview guide questions were derived from the research objectives of the study to address the research questions of the study. It consisted of two sections: Section A gathered participants' demographic information (age, gender, marital status, educational status) and Section B focused the interview on areas that the study sought to explore. The areas of focus included factors contributing to LTFU among HIV-positive patients and strategies to retain HIV-positive patients on ART.

3.6. Pre- test

Pre-testing is the trial administration of the newly developed research instrument on a small sample of the respondents before a full scale study to identify any problems such as unclear wording on the instrument. A study of this nature requires pre- testing because it provides the opportunity to assess the suitability of the measuring instrument which in this study is the semi-structured interview guide (Cresswell, 2013). The semi-structured interview guide was pretested before the main study to assess if the researcher's questions were answerable and all the interview questions were clear to the respondents. Pre-testing checked if adaptations on the interview guide were required. For the pre-testing, two HIV-positive patients (LTFU) and two clinic nurses were individually interviewed following the procedures for the actual study. Those three patients and two nurses who participated in the pre-testing of the instrument were not included in the larger study. Pre-testing assisted me to improve the instrument and rephrase some of the questions. This made the instrument a reliable and valid measure for the issues under investigation.

3.7. Data Collection

Qualitative researchers primarily collect data, which are narrative explanations. These narrative descriptions may be obtained by having conversations with the participants and by making notes about how participants behave in naturalistic settings (Pilot & Beck, 2010). In this study, patients and the nurses were interviewed individually face to face. The individual interviews involved verbal communication between myself and the participant, during which information was provided to me. I used a semi structured interview guide to ask the questions, and participants responded to the questions. I chose to conduct interviews in this study because interviews allow me to explore more in-depth of meaning than other techniques. Also, most of the participants had a low level of reading and writing ability and may possibly have failed to complete questionnaires (questionnaires requires reading and writing). Therefore, interviews were appropriate in this regard. Since the interviews were face to face, I was able to probe further and obtain more information from participants and also ask for elaboration where needed.

I co-operated with the clinic managers of the selected clinics to choose relevant clinics and participants from the LTFU patient register. The selected patients were traced from their homes with the assistance of the Home Based Carers from the selected clinics. During the visits, I explained more about the study and received consent from interested patients. For patients who were not interested, other patients from the LTFU register were selected and traced. LTFU patients who consented to participate in the study were individually interviewed at their choice of place of meeting; however, the location of the interview was quiet, comfortable, and private. The nurses were also interviewed in a quiet, private room in their clinics. All interviews lasted for about 40 minutes to 60 minutes.

There are various processes that were followed for the study to be a success. I received approval letters from the DOH provincial and district office which gained me access to the sub-district managers. The sub-district managers in the district alerted clinic managers of my visit, and therefore the clinic managers were well prepared for the visit. Upon my arrival at the clinics, I explained the purpose and what help and support I would need from the clinic. The clinic managers were very co-operative during the interviews and also offered any assistance I might need during the study period. The clinic managers of clinics with a high rate of LTFU in the respective sub-districts shared with me a list of HIV-positive patients who were recorded as LTFU; the list had the contact numbers and the physical address of the patients. So, with the help of Home Based Carers (HBCs), we traced those patients in the villages.

The Home based carers knew the patients very well and their houses, so they showed me all the houses of patients on the list given by the clinic manager. Given that during the pre-testing, patients emphasized that they did not trust the HBCs and therefore felt uncomfortable around them, I visited the patients' houses alone without the HBCs during the actual study to make them feel comfortable to engage in the discussion with me. During the visit in the patients homes, I explained the purpose of the visit and asked for permission to interview them. Most of the traced patients agreed to be interviewed except one, who totally denied that she was not the person I was looking for. I contacted patients who were not located at their homes by telephone and made an appointment to see them to conduct a face to face interview. Only a few patients who were not located at their homes preferred a phone interview.

An audio recorder was used to record all interview sessions. In addition to audio recording, I took brief notes (words and phrases) in order to keep abreast with what transpired during the interviews. Brief notes were preferred during interviews to avoid loss of focus and its effect on participants' responses (Barbie, 2012). Data was collected until data saturation was reached. The interviews were conducted in Sepedi to assure comfort during interviews, because 83% of the population in the district speak Sepedi as their first language (Sekhukhune District annual report, 2014). All semi-structured interviews were translated into English by a qualified language translator who has years of experience in translation.

3.8. Data Analysis

Data analysis is conducted to organise and give meaning to the collected data. It refers to a systematic organisation and synthesis of research data and testing of the research hypotheses using the data collected (Pilot & Beck, 2010). The main purpose of data analysis is to reduce, organize, provide structure to, and elicit meaning from research data (Pilot & Beck, 2010). In the current study, content analysis was used to analyse collected data . Content analysis is a research tool used to determine the presence of certain words or concepts within texts or sets of texts. Researchers quantify and analyse the presence, meanings, and relationships of such words and concepts; they then make inferences about the messages within the texts (Pilot & Beck, 2010).

To conduct a content analysis on such text, the text is coded, or broken down, into manageable categories on a variety of levels, word, phrase, sentence, or theme and then examined using one of content analysis' basic methods: conceptual analysis or relational analysis. So, during coding, I was guided by the study research objectives to examine the text for salient categories of information supported by the text from the interviews.

Audio recorded individual interviews were listened to and transcribed word by word; this was considered raw data. Collected data was audio recorded and additional information and observations were documented on paper. Transcripts from the recordings produced immense amount of data that filled many sheets. Thus, due to the amount of data obtained, the data was classified into themes and sub-themes as guided by the study objectives in order for the data to be manageable and provide meaning from the data.

3.9. Strategy development

The proposed strategy was developed with the aim to improve medication adherence in HIV care. As a result, I applied the analysed findings of the study, suitable psychological models and literature to contribute to the design of a more effective strategy to promote adherence to HIV medication. Literature was also provided regarding the efficacy of all specific models in improving ART adherence in HIV care. Each model was reviewed to determine whether it was appropriate to tackle certain barriers and improve ART adherence and retention in care.

3.10. Trustworthiness

It is essential for researchers to have their findings reflect the truth, be accurate, unbiased/fair, and adequately represent the true experiences of the target group. Qualitative researchers use different criteria compared to quantitative researchers to evaluate the quality of the study. On one hand, quantitative researchers use reliability and validity to measure the quality of the study. On the other hand, qualitative researchers discuss methods of trustworthiness of the study`s results to evaluate the quality of the study (Pilot & Beck, 2006). Trustworthiness is when the study accurately represents how the researcher convinces her audience that the findings are worth taking note of. Trustworthiness can also be considered as the degree of confidence that qualitative researchers have in their data, and it is evaluated using the criteria of credibility; transferability; dependability; and conformability (Pilot & Beck, 2006). Below is a detailed discussion on how this criteria of trustworthiness was ensured in the study.

3.10.1. Credibility

Credibility refers to whether the researcher has established confidence in the truth of the findings from the participants (De Vos, 2005). It establishes whether the research findings represent plausible information drawn from the participants' original data and is a correct interpretation of the participants' original views. A research study is considered credible if it presents an interpretation of human experience that people who shared that experience would immediately recognise. In this study, credibility was ensured through techniques such as prolonged engagement, triangulation, clarifying of researcher bias, peer debriefing, and in-member checks (Cresswell, 2013). All these techniques are detailed below and explained how they were ensured:

3.10.1.1. Prolonged engagement

Qualitative research data collection requires the researcher to immerse him or herself in the participants' world (Bitsch, 2005). This helps the researcher gain an insight into the context of the study, which minimizes the biases of information that might arise due to the presence of the researcher in the field. The researcher's extended time in the field improves the trust of the respondents and provides a greater understanding of participants' culture and context (Onwuegbuzie & Leech, 2007). So, this is where I went to meet with the participants before the interviews and spent time with them in order to build a trusting relationship. This helped participants to feel more comfortable around me and to share their perspectives freely without fear.

3.10.1. 2. Triangulation

Triangulation “involves the use of multiple and different methods, investigators, sources and theories to obtain corroborating evidence” (Onwuegbuzie & Leech, 2007). Triangulation helps the investigator reduce bias, and it cross- examines the integrity of participants’ responses. Here, I consulted with multiple sources including reference books, research articles from professional journals; I also made use of different types of field notes to get corroborating evidence.

3.10.1.3. Peer debriefing/ review

According to Guba (1981), peer debriefing provides inquirers with the opportunity to test their growing insights and to expose themselves to searching questions (Guba, 1981). A qualitative researcher during this process is required to seek support from other professionals willing to provide scholarly guidance, such as members of academic staff, the postgraduate dissertation committee and the department. Feedback from peers also helps the researcher improve the quality of the inquiry findings. This means that a qualitative researcher, when writing his/her report, should present his/her study findings to peers to receive their comments. In other words, a researcher should obtain the perceptions of peers in developing the conclusion of the study (Bitsch, 2005). Such an investigator looks at background information, data collection methods and process, data management, transcripts, data analysis procedure, and research findings (Pitney & Parker, 2009). Thus, I had a peer reviewer who went through background information, data collection methods and process, data management, and data analysis. The peer reviewer was candid with me and asked questions about everything she investigated, including the methods, meanings, and interpretations in order to verify concepts found in the analysis.

3.10.1.4. Clarifying researcher bias

Researcher bias was clarified so that the reader understands the researcher’s position and any biases that may have occurred during the study. During this clarification process, the researcher commented on past experiences, biases that are likely to have shaped the interpretation and approach to the study (Lincoln & Cuba, 1985). To clarify researcher bias, I commented on past experiences during the study and biases likely to shape the interpretation of the study. I then sought participants’ views on the credibility of the findings and interpretations. During this time, data analysis, interpretations, and conclusions were taken back to the participants and shared with them; they reviewed the research findings, making changes as needed to satisfy these participants that their perspectives had been captured accurately.

3.10.1. 5. Member checks

Another strategy for improving the quality of qualitative data is allowing member checks. Member checks mean that the “data and interpretations are continuously tested because they are derived from members of various audiences and groups from which data are solicited” (Guba, 1981). Member checks is a crucial process that any qualitative researcher should undergo because it is at the heart of credibility (Lincoln & Guba, 1985; Onwuegbuzie & Leech, 2007). Researchers are required to include the voices of respondents in the analysis and interpretation of the data. The purpose of doing member checks is to eliminate researcher bias when analyzing and interpreting the results. This means that the analyzed and interpreted data is sent back to the participants for them to evaluate the interpretation made by the inquirer and to suggest changes if they are unhappy with it or because they had been misreported. Informants may reject an interpretation made by the researcher, either because it was socially undesirable or because of the way in which it was presented by the researcher (Schwandt et al., 2007; Anney, 2014)).

As a result, I went back to the district to seek participants’ views of the credibility of the findings and interpretations. I took the data, analysis, interpretations, and conclusions back to the participants, and they judged the accuracy and credibility of the study (Lincoln & Cuba, 1985).

3.10.2. Transferability

Transferability refers to the degree or extent to which the findings from the data can be applied to other contexts and settings. It is the ability to generalize the findings to a larger population. Transferability was attained through comprehensive descriptions of research methodology. In this technique, I described in detail the participants or setting under the study. With such detailed information, the readers will be able to transfer the information to other settings and to determine whether the findings can be transferred because of shared characteristics. A purposive sampling strategy was also applied; I purposively selected the locations and informants that could be obtained from and about the context. Participants and setting of the study along with detailed information were described in detail, so that readers will be able to not only utilise the information in other settings but also determine whether the findings can be relied upon.

3.10.3. Dependability

Dependability refers to “the stability of findings over time”. Dependability involves participants evaluating the findings and the interpretation and recommendations of the study to make sure that they are all supported by the data received from the informants of the study (Cohen, Manion, & Morrison, 2011; Tobin & Begley, 2004). The study is considered to be dependable if it can provide its audience with evidence that if it were to be repeated with similar respondents, in the same context, its findings would be similar.

Dependability was achieved through an auditing of research processes. Here, an auditor (peer reviewer) examined documentation of critical incidents (documents and interview notes) and products such as research findings, interpretations, and recommendations and confirmed that all these products were supported by data.

3.10.4. Confirmability

Confirmability refers to the degree to which the results of an inquiry could be confirmed or corroborated by other researchers (Baxter & Eyles, 1997). Confirmability is “concerned with establishing that data and interpretations of the findings are not figments of the inquirer’s imagination, but are clearly derived from the data.”

Conformity was established through the involvement of experienced promoters (independent coder) who reviewed the products, the findings, and interpretations in order to test conformability.

Moreover, a peer reviewer assisted me by asking focused questions about the methods, meanings, and interpretations in order to verify the study`s concepts.

3.11. Ethical Considerations

Ethics in research refers to a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal, and social obligations to the study participants (Polit& Beck, 2006). Hence, it is important for a researcher to consider ethical issues before conducting research. Ethical requirements aim to minimise the possibility of exploitation by ensuring that research subjects are not merely used, but treated with respect while they contribute to social good (Emmanuel et al., 2000). The following ethical issues were therefore considered in this research:

3.11.1. Permission to conduct the study

Approval to conduct the study was obtained from the University of Venda Higher Degrees Committee (see appendix F). After obtaining permission from the UNIVEN Higher Degrees Committee (UHDC), permission was obtained from the Provincial Limpopo Department of Health and the Sekhukhune District Department of Health (see appendix G). Furthermore, permission was obtained from the sub-district managers of all the respective sub-districts in the Sekhukhune District where the study was conducted.

3.11.2. Confidentiality

Confidentiality means that all participants` personal information should be secured, and only the researcher and the research team can identify the responses of individual subjects and will have access to the participants' information. In the study, participants` names were not used in the report. Each participant's responses were treated with confidentiality. This was ensured by numbering the audio recorder and informing participants that myself and my promoters would have sole access to their answers. Participants were assured that the audio recorder would be used only for the purposes of the study, and the recordings would be kept in a safe locked place where only I would have access to.

3.11.3. Voluntary participation.

Voluntary participation means that participants are fully informed about the research study and give their voluntary agreement to take part in the study. There was neither implicit nor explicit pressure from me. Participation in the study was free of any coercion or inflated promise of benefits from participation. Participation in the proposed study was completely voluntary. No participant participated in the study against their will. They were informed that they may withdraw from the study at any stage if they experience discomfort and were assured that no one will punish them in any way should they decide to withdraw.

3.11.4. Informed consent.

Informed consent means that participants have the right to be informed about the nature and consequences of the research in which they are involved. Participants' agreement was based on full and open information. The subjects were told the duration, methods, and possible risks of participation in the study. In the present study, there were no risks involved. In this study, participants gave informed consent to participate in the study and signed the informed consent form prior to participation. The purpose of the research was explained to them, and informed consent was obtained before participants started answering questions. Consent for the use of a an audio recorder was given by participants.

3.12. Conclusion

The above discussion show that all the necessary research protocols were followed by the researcher to successfully carry out the study. All the involved people in the study process such as DOH, patients and nurses were fully co-operative during the whole process. As a result, the proposed strategy was developed after all the data; literature and psychological models were fully incorporated and critically analysed. The proposed strategy is hence fully discussed in chapter 6. The next chapter provides detailed information on how data was analysed as well as detailed results on patients' and nurses' perspectives on factors that contribute to LTFU and strategies that can help retention in HIV care.

CHAPTER 4: RESULTS

4. Introduction

The previous chapter outlined the research design and methodology used in this study. This chapter provides detailed information on how data was analyzed and also discusses the results of the study in detail. During data analyses, themes and sub-themes were developed from the raw data, which was collected through the use of semi-structured interviews with participants. The data was collected in four sub-districts and not five sub-districts as initially proposed; this was because data saturation was reached during interviews with participants in the first four sub-districts. As a result, I saw no need for further investigation.

Data that was collected from participants is presented below. This section also highlights the demographic information of all the patient and nurse participants who were interviewed individually. It gives a full description of participants in the demographic information and also their responses when they were interviewed regarding their perspectives on factors contributing to LTFU among HIV- positive patients; as well as full descriptions on the strategies that would help them address barriers to remain in care and take ART consistently. The demographic information of participants who were interviewed are presented in below.

4.1. Demographic information of nurse participants

All the nurses were over the age of 40, with the oldest being 63 years of age. All the interviewed nurses were female. The majority of the nurses held a nursing diploma; however, one of the nurses held a Bcur degree. Of all the nurses, only two were married and the rest were single.

4.2. Demographic information of patient participants

All the patient participants were ages 25 and above, with the oldest being 54 years old. The patients were predominantly female with only 2 males. The highest qualification that patients held was a grade 12 certificate; this qualification was held by only one participant. Majority of the patient participants did not complete secondary school. Only one patient was employed, the rest of the patient participants were unemployed.

Guided by the semi-structured interview tool, the findings of the study were clustered. **Table 3** indicates the themes and sub-themes extracted in the study. The Overall participants identified 12 barriers that contribute to patients' loss to follow up in care and 8 strategies to help re-engage and retain patients in care.

Table 3: Themes and sub-themes

Theme 1	**Sub-themes patients**	**Sub-themes nurses**
Patients' and nurses' perspectives on factors contributing to LTFU among HIV- positive patients.	• Patients feel strong physically. • Lack of understanding of ART. • Fearful to disclose their HIV status to their partners. • Nurses and home based carers do not have confidentiality. • Experience of negative side effects. • Nurses are rude and unwelcoming. • Use of traditional medicine for cure. • Difficulty taking time off from work during weekdays for clinic visits. • Lack of funds to travel to the clinic.	• Feeling physically strong. • Ignorance about the significance of ART. • Anxious to disclose HIV status to family members. • Worried that the HBCs will not keep their HIV status confidential. • Patients' self-transfer from one clinic to the other. • Traditional and religious beliefs contribute to denial. • Patients intentionally default from treatment. • Denial that one is HIV-positive

Theme 2	**Sub-themes patients**	**Sub-themes nurses**
Patients' and nurses' perspectives on the strategies that would assist patients to remain in care and take ART consistently.	• Health education is vital for improving knowledge on HIV and ART. • Confidentiality assurance regarding their HIV status is essential. • Social support gives patients courage.	• Health education enhances the understanding of ART. • Team work improves quality patients' care. • Development of social support groups is essential for patients support. • Giving those who are compliant medication that will last them for few months. • In-service education on ethics and ethos.

4.3. Detailed results

The interviews were conducted with nurses whose clinics have lower rates of LTFU and also with nurses whose clinics have the highest rates of LTFU in their respective sub-districts. HIV-positive LTFU patients were also interviewed individually in their respective homes. Various similarities and differences in the responses were well established during the discussions with the nurses and patients on factors contributing to LTFU as well as strategies that may help to re-engage and retain patients in care. Noteworthy, the results from the nurses' and patients' perspectives from this study will be analyzed concurrently. Below are all the findings that were incorporated to demonstrate the important information and the strengths of the current study.

4.3.1. Theme 1: Patients' and nurses' perspectives on factors contributing to LTFU among HIV- positive patients

Patients outlined various reasons that contributed to their decision to discontinue HIV treatment. The reasons included feeling well physically, non-disclosure, lack of confidentiality, negative side-effects, traditional/ religious beliefs, lack of understanding of ART, difficulty taking time off from work and lack of enough medication. Over and above the reasons elicited by patients, nurses perceived traditional/religious beliefs, patients self-transfer, fear of lack of confidentiality, lack of understanding of ART, disability grant, feeling better physically as the contributing factors to LTFU. Noteworthy, there are similar reported factors by nurses and patients such as: feeling well physically, fear of disclosure, lack of confidentiality, traditional/ religious beliefs as well as poor understanding of ART. There is also, however, a unique barrier that was only identified by nurses, which is the disability grant. Nonetheless, patients also identified different barriers that were not mentioned by nurses, such as difficulty taking time off from work during weekdays for clinic visits, lack of funds to travel to the clinic, and the experience of negative side-effects. Thus , all these identified factors are detailed below.

4.3.1.1. Lack of understanding of ART and Feeling well physically

Both patients and nurses mentioned lack of understanding of ART and Feeling well physically as barriers to their continuing with ART. Patients indicated that they had discontinued taking their medication because they believed that they did not need it since they felt well. They believed that one should be on medication only if they felt sick and weak; therefore, since they felt strong, they did not see the need to adhere to their medication. Patients seemed really surprised that they should have returned to the clinic for a medication refill subsequent to the treatment initiation. They were intrigued by the information I gave them that ART was a lifelong treatment and about the advantages of medication adherence. They afterwards promised to re-engage back into care.

Patients emphasized that the nurses did not clarify that the medication was lifelong; therefore, they assumed that when they completed the first dose of medication, there was no need to visit the clinic for refill. One of the patients was under the impression that she was on ART medication only to protect the baby from being infected since she was initiated on ART during pregnancy. She did not understand that the medication was also to help her live a longer healthy life. She confidently emphasized that the nurses never explained that the medication was lifelong. She sadly reflected that since she gave birth to a still born baby she felt that there is no need to continue with the medication. This is supported by these statements from some of the patients:

"I just thought that since I am feeling strong physically and I am also condomising, there is no need for me to continue taking medication".

"I don't feel any pains in my body, I don't need medication".

"The medication was to protect the baby during pregnancy, so, I have lost my baby, I don't need medication anymore".

Nurses had the same perspective as the patients had, as mentioned above. Looking concerned, nurses highlighted that patients' default from care due to lack of understanding of the importance of ART and feeling strong physically. They assumed that due to lack of understanding of how ART work, patients defaulted from care when they felt well and strong physically. The nurses said: ***"Patients default from care due to lack of understanding of how ART works, the moment they feel well in their bodies, they stop taking the medication".*** Yet, nurses confidently confirmed that they explained to the patients in detail about ART and HIV, especially that ART was a lifelong treatment and that HIV cannot be cured. They also assured me that they gave them immense information on general health education regarding HIV, ART, and opportunistic infections during the initiation of treatment. They further emphasized that every morning they gave health education in the patients' waiting area on HIV, ART and other important health topics such as TB and cancer. Moreover, nurses further acknowledged that the LTFU rate was alarming; therefore, they would strengthen their health education on ART and HIV to enhance patients understanding on these topics.

4.3.1.2. Fearful to disclose their HIV status to their partners.

Fear of disclosing one 's HIV status was reported to be a barrier by nurses and patients. However, nurses mentioned fear of disclosing private information to family members as this hinders patients from remaining in care, whereas patients said that the reason they discontinued taking their medication was because they were afraid to disclose that information to their partners. Patients calmly mentioned that they have unprotected sex with their partners and were afraid to suddenly demand condom use. To the patients, demanding condom use automatically meant one should disclose their HIV status to their partner. The partner would demand to know the reasons for sudden condom use. Furthermore, patients emphasized that condom use demand and disclosing their HIV status would make their partners angry and cause the end the relationship. These patients are very aware of how ART works. Hence, they revealed that it is not helpful to adhere to treatment and still continue having unprotected sex because the medication will not be effective. Consequently, they defaulted from their HIV treatment. Patients' knowledge of ART confirms what was said previously by some of the nurses that they must explain to the patients how ART works. Some of the patients said: **"*The father of my baby refuses to use a condom, and I am afraid to disclose my HIV status to him, so I don't see the need to take medication since it won't be effective".***

"My partner does not know that I am HIV positive, so he will be surprised if I suddenly request a condom especially because he wants a baby so its useless for me to continue with the medication" .

Patients gave the impression that they value their relationship with their partners more than their health. Surprisingly, patients were aware of the consequences of non-retention in care, that they will get weaker and sicker. When probed further to ask why they are more adamant on protecting their relationship than adhering to medication regardless of the consequences, they explained that they did not want to lose the relationship because they sorely depend on their partners financially. Financial dependence on partners is expected due to the high rate of unemployment in the Sekhukhune district; of all the patient participants, only one is employed. This means that fear of rejection by partners/struggling financially is a big hindrance to retention in care; hence patients are fearful both to disclose and to adhere.

Nurses looked concerned about the patients when they gave their responses on this. They cited that patients' fear of disclosure to their family members is the reason for default as opposed to fear of disclosure to sexual partners as mentioned by patients. Nurses assume that patients default because they think that if they continue taking the medication at home, family members will be suspicious that they might be HIV-positive since they are taking pills on a daily basis. When further probed if they encouraged patients to disclose their HIV status, they responded positively that they always encouraged patients to disclose to at least one family member they trust. They said that they explained all the advantages and disadvantages of disclosure to the patients. They mentioned that patients were assured that disclosure may help them acquire the social/emotional support they need from their family. They also said that they explained to the patients that, should it happen that they were unable to collect their medication, a trusted family member they disclosed to could come on their behalf. The nurses said:

" Our patients default because they are scared to disclose to their family members, they are afraid that family members will speculate that they might be HIV-positive if they continue taking pills on a daily basis"

4.3.1.3. lack of confidentiality by nurses and HBCs

Patients emphasized that they have defaulted from care due to lack of confidentiality by nurses and home based carers; they fear being stigmatized if their HIV status was to be exposed to the people around them. Patients furiously pointed out that the home based carers and the nurses disclosed patients' HIV status to other people in the community. The following statements were highlighted by patients: "***The nurses and home base carers tell other people in the village that I am HIV -positive and that I take HIV medication".***

"When home based carers tell people that I am HIV- positive and I take medication, everyone in the village will believe them since they work in the clinic. So this means I will just see myself die from HIV since I am afraid that if I go to the clinic everyone in the village will know that I take HIV medication".

"I can never go to the clinic because the nurses and home based carers gossip about my HIV status in the village".

When probed on how they know that there is no confidentiality among the nurses and the home based carers, patients further explained that they were informed by some of the home based carers that other people in the village are HIV-positive and taking HIV medication. So due to this experience, they are certain that their confidentiality will also be compromised. This is illustrated in the following statement:

"I know of other people that are HIV-positive and taking HIV treatment through the home based carers. Therefore, I am sure that they will tell other people about my HIV status. It is very painful when someone from the village just tells me that I am HIV-positive and yet I was not the one who informed them".

The nurses with concern confirmed that patients' fear of lack of confidentiality might certainly be the reason for their defaulting. The nurses further confirmed that the majority of the nurses and all home based carers are from the same village as the patients. The nurses and the home based carers are patients` neighbours and therefore well known to the patients. Subsequently, patients fear that their HIV status will be known to other people in the village if they continue going to the clinic for HIV care. One of the nurses illustrated that: ***“Our patients default because most of the nurses in our clinic are from this village, so patients feel uncomfortable. They are fearful that we might disclose their HIV status and the fact that they are taking HIV medication to other people in the village”.***

Nurses further explained assertively that they do assure patients that everything will be kept confidential by talking to them about confidentiality during initiation of treatment. They emphasize that patients just disbelieve and distrust them because they are from their village not because they were not assured that they HIV status would be kept confidential.

One way that patients’ confidentiality was proven to be compromised was that in some clinics HIV-positive patients’ files are marked. Thus, by looking at the patients’ files, one would recognize that the file belongs to a HIV-positive patient. In this way, patients are afraid that their confidentiality is compromised, hence they default from HIV care. However, the nurse said that, as a clinic they have realized that this system is pushing patients out of care, therefore, they are in the process of discontinuing it. One nurse supported this statement by saying that: ***“The files of HIV-positive patients are different from all other patients’ files; they are marked so that we can retrieve them easily when patients come for their consultation. So I think patients are aware of this system as a result they default because other patients can easily see that their files are for HIV-positive patients”.***

4.3.1.4. Experience of negative side effects

Experience of negative side effects was only identified as a barrier by patients; none of the nurses mentioned it. Patients highlighted that they have stopped taking their medication due to negative side effects experienced, such as nausea and dizziness. They also highlighted that these side-effects draw unnecessary attention from the family members and can make those close to them suspicious that they are not well. Patients said: ***“I stopped taking the medication because it makes me vomit all the time”.***

“The medication makes me feel dizzy, I feel very sick after taking the medication, it is too much I could not take it anymore”.

Patients further stated that they were not aware of the possible side effects; nobody at the clinic explained the possibility of the side-effects during the initiation of treatment. As a result, they stopped taking the medication because they observed that they experienced these side-effects immediately after taking the medication. When I explained to them that it is normal for the medication to have such negative side-effects, they seemed surprised and mentioned that they thought medication was not supposed to make one feel sick but better. They, however, showed a sign of relief when I mentioned that the side-effects were only temporary. They stated that they could bear the side-effects if they were only temporary. The patients appreciated the information and assured the nurses that they would re-engage in care after our conversation.

4.3.1.5. Unwelcoming and rude behaviour by nurses

Patients furiously mentioned that they have defaulted from care due to rude conduct towards them by nurses. A patient highlighted that nurses are not welcoming and are rude to them during their visits; he cited that one Afrikaans nurse was racist and harsh towards black patients. He emphasized that he could not stand to be spoken to like a child, this is reflected in the following statement: ***"There is an Afrikaans nurse in the clinic who is rude to most patients, she does not treat me well every time I visit the clinic especially if I missed one appointment. Therefore, I decided to avoid her by not visiting the clinic anymore".*** On the contrary, none of the nurses mentioned unwelcoming behaviour by clinic staff as a possible reason for patients default.

4.3.1.5. Traditional/religious beliefs

Use of traditional medicine was less frequently mentioned as a barrier in the current study; however, it was reported by both nurses and patients. Some nurses also reported faith healing as a possible barrier for non-retention in care. Moreover, one participant calmly mentioned that she defaulted from ART medication because she resorted to traditional medication. She sounded hopeful and believed that she could be healed through the use of traditional medicine. She asserted that HIV virus is only the dirty blood that can be easily cleansed by traditional medicine. The patient confirmed that she was using traditional medication as an alternative therapy. The patient said: ***"I am using traditional medication to fight what I have in my body; the traditional medicine will clean my blood then I will be HIV free***". The patient boldly referred to other people whom she knows in the village that have been cured of HIV by the same traditional medicine. She further explained that the dirty blood in her body was caused by a spiritual animal that has sex with her. She affirmed that since the cause of dirty blood (referring to HIV) is spiritual, therefore, the cure will be traditional and not western. She further mentioned that the nurse explained to her that HIV cannot be cured but she assured her that she will return to the clinic for ART medication if she doesn't receive the help she hopes for from the traditional healer.

This corresponds to some of the nurses' responses; nurses indicated that some of the patients default from care due to traditional or religious beliefs though none of the patients mentioned religious beliefs as the reason for default. The nurses emphasized that some patients default from treatment because they believe that they can be healed by either God or traditional healers. One of the nurses said: ***"Some of the patients tell us that they were instructed by a traditional healer to stop taking their HIV medication and focus only on the traditional medication".*** Nurses clearly explained that they tell the patients everything they need to know during initiation of treatment; they also emphasized that patients are told that HIV is a life long treatment, and it's not curable by anyone or any medication including ART. They explained that regardless of their emphasis to the patients that HIV cannot be cured, patients still replace ART with traditional medicine or holy water. Due to their traditional or religious beliefs that God can heal all illnesses, they still seek help from pastors and traditional healers with the hope of being cured. Some of the nurses reckon that some of the patients might be using both ART and traditional medicine; however, they highlighted that patients always deny this when they are confronted with it. Although with these patients, their clinical outcomes will not improve; the viral load and the cd4 count will worsen even though the patient seems to be an adherent and attends all their clinic visits.

4.3.1.6. Difficulty taking time off from work

Both nurses and patients declared that difficulty taking time off from work is a possible barrier to discontinuing of treatment. Looking frustrated, patients indicated that they have stopped taking their medication because the clinic does not give them enough medication to last them for longer periods, and they have difficulties taking time off to visit the clinic monthly. One of the patients stated: ***"I stopped taking the medication because the clinic only provides me with medication that will only last me for a month and I cannot take leave from work monthly to visit the clinic".*** Furthermore, they shared that if possible, they would visit the clinic in the morning and report late for work afterwards. Unfortunately, their seniors at the workplace would not allow late reporting to work especially on a monthly basis, hence they would appreciate being provided with medication that would last them for a longer period. Other patients revealed that their seniors expect them to disclose the reason for regular time off, and they are not prepared to disclose their HIV status at work due to fear of stigmatization***.***

Notably, the clinics do provide patients with medication that will last them for two to three months (three month apply); however, not all the patients qualify for this. This only applies to patients with positive health outcomes such as a suppressed/low viral load and higher cd4 count. Nurses stated that the reason for this is because they are certain that patients with positive health outcomes are responsible enough to manage on their own for longer period without visiting the clinic. This was highlighted by one of the nurses who said: ***"Only patients who have a suppressed /low viral load qualify to get a three months apply (medication for three months***").

Moreover, the findings regarding inability to take time off from work were verified by nurses' responses. They stated with concern that some patients work during weekdays and are unable to visit the clinic since most clinics do not operate on weekends. The nurses seemed enthusiastic about operating on weekends but it is difficult due to shortage of staff. Some of the nurses in specific clinics, however, indicated that they will begin operating on weekends once the nurses that are on leave return to work in a few months. The nurse highlighted: "***our clinic currently operates only on weekdays and some patients are unable to visit the clinic due to the inability to take off from work.*** The nurses further outlined that since most of the patients have not disclosed their HIV status to anyone at home, they are thus unable to send any of the family members to collect their medications on their behalf when they are at work. The nurses additionally outlined that during the initiation process, they encourage the patients to disclose to one of the family members for this reason. The nurses clarified that they assure patients that they can send any person they trust if they are for any reason unable to collect the medication themselves.

4.3.1.7. Lack of funds to travel to the clinic

It is important to note that lack of funds to travel to the clinic was infrequently reported as a barrier to non-retention in care. Only few patients cited that they are unable to attend their regular clinic visits due to lack of money for transportation. These were patients who preferred attending clinics further from their homes. None of the nurses mentioned lack of funds as a possible contributing factor to patients' non-retention in care. One of the patients stated that: ***"I stay far away from the clinic and at times I cannot afford to travel to the clinic, that is the main reason I stopped going for my medication"*** .

The reason for infrequent report on lack of funds for transportation as a barrier may be that all the clinics that I visited in the Sekhukhune district are located within the patients' communities, hence patients do not need any transport to travel to the clinics. All the clinics are within a walkable distance from the patients' homes. Except if one prefers to attend a clinic further away from their village, then they will need transport to travel to that clinic. Looking worried, some of the patients in the study clearly indicated that they prefer to attend clinics further away from their homes due to fear of stigma and confidentiality. However, this compromises their adherence in care because they can't always afford to travel to the more distant clinic. This is reflected in the statement below: ***"I will never return to this clinic in the village, the HBCs are gossipers, I will rather go to a further located clinic".***

4.3.1.8. Patients self-transfer

The most common reason reported by nurses was patients' self-transfer. This was reported mostly by nurses whose clinics serve patients that work in the mines, farms, as well as college students. The nurses emphasized that patients relocate from the village where the clinic is located without obtaining an official transfer-out letter from the clinic. The nurses assume that patients transfer themselves out because they have completed their studies (students), they have started working at a new farm or mine, or they have relocated to their home country (immigrant mine and farm workers). As a result, those patients are labeled as LTFU in their records. Notably, nurses cited that they trace patients as soon as they miss one appointment, but they are also untraceable because their contact numbers are discovered to be invalid. The nurses confirmed that the patients are aware that they should obtain a transfer letter from the clinic if they decide to attend another clinic, but they leave without notice anyway. Some of the nurses said: ***"Most of our patients are immigrant farm workers, they don't inform us when they are moving to another farm or returning to their home country. Thus, in our system they are recorded as loss to follow up".***

"They also give us wrong telephone numbers, if we try to call, the phone number is invalid".

"Majority of our patients study at the FET college nearby, so when they complete their studies, they self-transfer themselves to the clinics at their homes. They relocate without notifying the clinic, then in our records they are LTFU".

4.3.1.9. Disability grant

Disability grant was mentioned by one of the nurse participants as a barrier that encourages patients to default from treatment. The nurses were worried that patients prioritize the grant over their health. The nurse illustrated that some of the patients default from treatment intentionally so that they would get weaker and sicker to quality for a disability grant. She further said that some of the patients confessed to her that they need to get weaker so that they may qualify for the grant. She emphasized that patients thought getting a disability grant was a better option since they have financial difficulties. She also confirmed that she encouraged those patients to stay on ART to live a healthy longer lives. Nonetheless, patients insisted that the disability grant is the only option for them to be financially independent and to take care of their family. She narrated that patients said unless they got a job then they could re-engage back in care. This was reflected by one of the nurses as follows: ***"some patients intentionally default from treatment because they want to get sick, weaker and qualify to get a disability grant".***

In this study, however, none of the patients confirmed that receiving a disability grant encouraged them from defaulting from care. All the patient participants confirmed that they did not receive a disability grant. Unexpectedly, all the patients interviewed were not aware that there is a disability grant that one may receive if they get weaker from HIV or other HIV related illnesses.

4.3.1.10. Denial

Nurse participants reported that some of the patients stop taking their medication because they do not believe that they are HIV-positive. Some of the patients are thought to be in denial that they are HIV-positive and that it is a chronic illness which requires lifelong treatment. This is confirmed by some of the patients' responses. When I interviewed some of the patients, in the beginning of the interview, they insisted that they have tested HIV negative at a different clinic hence they defaulted from care. When I went further to explain that I would request the nurses to call the clinic in question to confirm whether they have indeed visited the clinic and that they are HIV negative. The patients then confessed that they lied when they said they went to a different clinic; they further explained that they did not believe that they were HIV-positive. Some of the nurses said:

"Some patients deny that they are HIV positive and therefore don't take their medication".

***"Few patients insist that they have tested at a different clinic and the results came back HIV negative, they are convinced that they are not HIV-positive"*.**

4.3.2. Theme 2: Patients' and nurses' perspectives on the strategies that would assist patients to remain in care and take ART consistently

During the conversations with the patients and nurses, they gave their opinions on different strategies to assist HIV-positive patients stay in care. Noteworthy, the nurses whose clinics have zero/ low rate of LTFU also shared the strategies that they use to retain their patients in care. The strategies included team work, health education, social support, and in-service education on ethics and ethos. Patients mentioned health education and confidentiality assurance about their HIV status as possible strategies that could encourage them to re-engage and stay in care. Moreover, nurses whose clinics have high rate of LTFU also suggested strategies that may work for them to keep patients in care; their strategies included development of social support groups, giving those who are compliant medication that will last them for a few months and health education. Significantly, health education was found to be a commonly mentioned strategy by both patients and nurses. All these strategies are discussed in detail below:

4.3.2.1. Health education and confidentiality assurance

Patients voiced their opinions on approaches that could assist them to re-engage back in care and assist patients to stay in care. The outlined approaches included health education and confidentiality assurance. With concerned faces, patients felt that they were not well informed about the importance of ART and how it worked . They also believed that health education would enrich them with the knowledge they need to encourage them to re-engage and remain in care. They mentioned that if they were well educated on the advantages of ART adherence and the dangers of dropping out of care, they would certainly remain in care. This is what the patients indicated: ***"It will be helpful if nurses educate us about ART, this will help us understand the importance of taking treatment".*** Patients indicated that delegating nurses to visit them (defaulters) at their homes to motivate them about the importance of ART adherence would encourage them to re-engage in care. They also emphasized that talking to someone not only motivated them but also demonstrated that someone cares for their health. The patient said:

"They staff at the clinic should educate us more about HIV and the importance of ART".

Moreover, majority of the patients felt that they would be re-engaged and retained in care if their HIV status and the fact that they are on HIV medication would be kept confidential by the clinic staff (nurses and home based carers). Looking upset, the majority of the patients put emphases on assurance of confidentiality, that it was important for them to be assured that their HIV status would be kept confidential. In this way they would gladly re-engage and remain in care. They also pointed out that nurses and home based carers should receive in-service education on ethical issues, especially confidentiality. They reckon that the training will assist the staff to keep patients' information confidential. This is what some of the patients shared: ***"The home base carers should be taught to be confidential about our information and not disclose our private matters in the village".***

When probed further to understand how much knowledge patients have on ART, some of the patients explained that the medication helps one to gain strength. However, some of the patients said once a person gains strength from taking ART, taking medication continuously becomes unnecessary. Nonetheless, there are patients who had a great understanding of how ART works, they stated that ART helps one to live a healthy long live. Noteworthy, all the patients had no understanding on health outcomes such as viral load and cd4 count. They pointed out that no one explained to them what the numbers meant on the blood test results. The above mentioned responses concur with the responses from the nurse participants whose clinics have high rate of LTFU. Nurses gave their opinions on what they thought could be done to retain patients in care, and the most frequently mentioned strategy was health education. They believe that if patients are equipped with the knowledge on HIV and ART, they will remain in care, and those who have defaulted may re-engage back into care and be retained. This is what the nurses said about health education: ***"Adherence counseling during pre-ART counseling would help patients to understand the importance of adherence and therefore not default from treatment".***

"Our patients need proper health education, so that they understand the importance of ART".

Nurses assertively indicated that they currently provide health education in the waiting room and consultation room during ART initiation. They acknowledged, however, that the time they have with one patient in the consultation room is limited as they have many patients to attend to daily. As a result, they suspect that patients do not fully understand the importance of ART adherence. Nurses also concurred with the patients that they may need to visit defaulters at their homes to educate and motivate them to re-engage back in care. Nurses were hesitant on sending home based carers to do the motivation talk due to lack of trust patients have on home based carers.

Nurse participants, whose clinics have achieved low rates of LTFU, concurred with the above reported findings by patients, and with nurses whose clinics have high rate of LTFU. They highlighted health education both at the waiting area and consultation rooms as one of the strategies that help them to achieve low rate of LTFU. They outlined that patients' health education should be more in depth in the consultation room because it is private and patients feel comfortable to ask questions and to seek clarity when they do not understand. They mentioned that in the waiting room patients are shy to ask questions in the presence of everyone, hence they prefer health education to be emphasized in the privacy of the consultation rooms. The nurse said: **"one *strategy that has helped us to retain patients in care is by educating the patients about HIV and ART during initiation in the consultation rooms because there is privacy there unlike the waiting area".***

Some of the nurses also shared that the reason they are able to retain their patients is through collaboration with the traditional healers in the village. They cited that they educated the traditional healers about HIV and ART, how the two worked. In this way, when patients visit the traditional healers for HIV healing, the healers already are equipped with knowledge on HIV and ART. For instance, that HIV cannot be cured, about the symptoms of HIV related illnesses. Through this knowledge, traditional healers are able to advise and refer such patients to the clinic if they recognize the symptoms.

4.3.2.2. Team work

The other commonly identified approach that was highlighted by the majority of nurses whose clinics achieved low LTFU rate is team work. They emphasized that the reason they achieve low/zero rates of LTFU is because they co-operate and work as a team. They stated that even if one of the duties is not part of their job description, such as tracing patients, they do so when there is a need. For instance, if for some reason, there is no one to assist with the tracing or the patients is not cooperative when traced by home based carers, nurses go to the community and trace the patients. This is what some of the nurses said about team work:

"*Team work helped us to succeed in retaining HIV-positive patients in care"*

***"We work as a team to achieve a lot, when there is a need, I, as the clinic manager put admin work on hold to go to trace a patient*"**

None of the nurses whose clinics have high LTFU rate mentioned team work as a possible strategy that could assist keeping patients in care. Also none of the patients mentioned team work as a strategy that could assist them to stay in care.

4.3.2.3. Social support

The majority of the nurses at the clinics with high rate of LTFU thought reaching out to the patients might help them to re-engage and retain patients in care. Other nurses reported that having family support may also help in having someone a patient can delegate to collect medication on their behalf if need be. They emphasized that this mostly applied for those patients who have difficulties taking time off from work for medication collection.

The nurses whose clinics have low LTFU rate also concurred with certainty that social support has assisted them in retaining patients in care over the years. They cited that, as clinic managers, at times they put administrative work aside and traced the patients who had missed their appointments, to encourage them to return to the clinic. They confirmed that they usually visit the patients if they have missed many of their appointments after home based carers already traced the patients without success of returning them to the clinic. They illustrated that the reason they at times take responsibility to trace the patients is because patients have no trust in the home based carers and do not welcome them in their homes. The nurses also established that patients who have family support send their family members to collect medication on their behalf if they are, for any reason, unable to. This makes the nurses assured that social support is helpful in retaining patients in care and taking ART consistently. The following extract by nurses reflect the above results:

"We support our patients as much as we can, if home based carers trace the patients without success, I go to trace the patients myself and educate them about the importance of ART adherence".
"The patients do not trust the home based carers, therefore they do not co-operate when they are visited by them, so I visit the patients myself to encourage them to return back in care".
"Most of my patients who are unable to visit the clinic during weekdays send family members to collect medication on their behalf".
" peer supporters in our clinics encourage and offer support to other HIV-positive patients and this has really helped us to retain our patients".

Moreover, patients corresponded with the nurses' responses. They pointed out that they will re-engage and retain in care if they received support from the nurses. They mentioned that nurses should visit them at their homes to educate them on all they need to know about ART. This way they will feel appreciated and encouraged. One of the patients said:

"I think nurses should make home visits and motivate us about the importance of retaining in care, it really helps talking to someone".

4.3.2.4. Providing medication that lasts for longer periods

Patients highlighted that since they have difficulties taking time off from work during weekdays, they pointed out that it would be helpful to be provided with medication that would last for two to three months. In this way, they wouldn't have to visit the clinic every month. However, the nurses clearly emphasized that patients should meet requirements for a three months apply (medication that lasts for three months) such as suppressed viral load and high cd4 count. This way they are definite that the patient can manage on his own for a few months without visiting the clinic. If the patient is not compliant, they do not qualify for a three month supply . One of the patients stated***: "I suggest that the clinic gives me medication to last me for a few months because I can't visit the clinic on weekdays".***

4.3.2.5. In service education on ethics and ethos

Both nurses and patients suggested in-service education on patients' confidentiality as one of the strategies that could assist in keeping patients in care. Nurses whose clinics have low rate of LTFU indicated that they practice all ethics issues as expected. Patients' confidentiality is one of the main ethical considerations that helps them retain patients in care. They also illustrated that confidentiality assurance helps the patients feel encouraged and comfortable to stay in care. When confidentiality is assured, patients trust the nurses enough to stay in care. Therefore, due to patients' confidentiality, patients also feel comfortable to get home visits by the home based carers that they usually avoid. Nurses further highlighted that their clinics ensure that home based carers are unaware of patients' HIV status. In this way, they are unable to gossip about patients' HIV status in the village. When home based carers trace the patients, they are not told why the patient is needed in the clinic, thus only nurses know the HIV status of the patients and that they are on ART. Nurses in turn keep patients' HIV status confidential.

The nurse further stated that their home based carers trace patients with all chronic illnesses, therefore they can't tell which patient has TB, HIV, or diabetes. As a result, this assurance of confidentiality makes it easier for patients to remain in care. Patients confidentiality assurance encourages them to remain in care and be assured that no one will disclose their HIV status. Additionally, when patients do not overhear gossip about another persons' HIV status in the village, then they will be convinced that their HIV status will also be kept confidential. In this way, it makes it easier for them to stay in care. This is narrated below:

" Our *patients are assured confidentiality and are retained in care because we keep their health matters confidential from everyone including the home based carers".*

Furthermore, nurses stated that they treat patients politely and this encourages patients to stay in care; they feel supported and appreciated. This way, patients do not feel discouraged and scared to visit the clinic. One of the nurses highlighted:

"Our clinicians are welcoming to patients so patients are comfortable and feel encouraged to come back to the clinic for their medication".

Nurses from the clinics with high rate of LTFU also gave different opinions on this. They emphasized that patients are assured confidentiality but still default from care. Nurses outlined that patients always assume that home based carers are aware of their HIV status hence they are not welcoming to them in their homes. Nurses further illustrated that patients always assume that since home based carers are sent by the nurses to trace them, they are aware of their HIV status. Nurses pointed out that despite the fact that they assure the patients during initiation that everything will be confidential, they still disbelieve them. This is illustrated below:

"**HIV-*positive patients are very sensitive, they are always suspicious that people are talking behind their back about their HIV status, they also assume that we tell the home based carers that they are HIV-positive".***

It is clear that confidentiality means a lot to the patients. They also concurred with the nurses' responses, saying that they will re-engage and stay in care if they could be assured confidentiality. They firmly mentioned that if their HIV status and the fact that they are on ART could be kept confidential, they will remain in care without any fear that people in the village will know their health matters. In-service education on ethics and ethos will enhance and strengthen nurses and HBCs knowledge. This is illustrated in the extract below:

"I will return to the clinic for HIV care only if my HIV status could be kept confidential, otherwise I will rather not take medication".

Moreover, nurses from other clinics pointed out that tracing patients before they are classified as LTFU may help them in care. They also highlighted that it is always helpful to trace patients as soon as they miss one or two appointments; in this way, they easily come back to care. With early tracing, patients feel supported and that there is someone who cares for them and their health. The nurses confidently explained that immediately when the patient misses their appointment once or twice, they contact the patient. They do not wait for patients to be loss to follow up. They further highlighted that all of the patients they contact for missed appointments do re-engage in care because they feel cared for by the clinic. This is illustrated below:

"We contact those patients who have missed their appointments for a month or two before they are classified as loss to follow and the patients usually successfully re-engage back in care".

"We usually don't wait for a patient to be recorded as a loss to follow by the system. If a patient miss two appointments, we follow up with them immediately **".**

4.4. Conclusion

There are similarities and differences in responses by nurses and patients in the study. They shared the same thoughts on some of the factors, such as on lack of understanding of ART and fear of disclosure as barriers that hinder retention in HIV care. Also, they both thought that education on ART will enhance patients' understanding of ART and other health related matters. They, however, had different views in some instances because none of the nurses mentioned unwelcoming and rude behaviour by nurses as a possible barrier; most of the patients, however, outlined it as one of the top barriers that hamper retention in care. These responses demonstrate that it was of importance to explore both nurses' and patients' perspectives in this regard, given the unique thinking and experiences every individual has. The table below summarizes the patients' and nurses' agreements in responses and the unique responses among nurses and patients on factors contributing to LTFU among HIV-positive patients as well as strategies that would assist patients to remain in care and to take ART consistently. The next chapter discusses the results of the study in detail and compares the findings with relevant literature.

Table 4: Examples of patients' and nurses' agreements on factors contributing to LTFU among HIV-positive patients

Lack of understanding of ART and feeling well physically	**Patients response**	**Nurses response**
	"There is no need to take the medication because I feel very health". *" I am still able to perform my daily house chores, what do I need medication for?"* *"Look at me, I am perfectly fine I don't need any pills".* *"I just thought that since I am feeling strong physically and I am also condomising, there is no need for me to continue taking medication".*	*"Patients default from care due to lack of understanding of how ART works, the moment they feel well in their bodies, they stop taking the medication".* *"Our patients stop taking treatment when they feel strong physically".* *"Patients believe that medication is meant for people who are admitted in hospitals only".* *"As long as they are able to perform their daily activities, they don't think they need to take pills everyday".*

Fearful to disclose their HIV status to their partners.	*“The father of my baby refuses to use a condom, and I am afraid to disclose my HIV status to him, so I don’t see the need to take medication since it won’t be effective”.* *“Disclosing to my boyfriend is risky because he might leave me”.* *“ I can’t take a chance of my boyfriend finding out my HIV status, so I stopped taking the pills”.*	*“Our patients default because they are scared to disclose to their family members, they are afraid that family members will speculate that they might be HIV-positive if they continue taking pills on a daily basis”.* *“ Patients stop taking their medication because they are afraid to disclose to their family members and they get tired of hiding the medication”.* *“Most of our female patients depend of their boyfriends financially so they don’t want to scare them off by disclosing their HIV status and they end up dropping out of care”.*

Lack of confidentiality by nurses and HBCs	*"The home- based carers are the worst gossipers, they tell everyone in the village about I am on HIV treatment".* *"The nurses and home base carers tell other people in the village that I am HIV -positive and that I take HIV medication".* *" I expected nurses to be professional but they share our health issues with people from our neighborhood".* *"The home based carers should just get fired because they tells everyone who cares to listen patients HIV status and that they are on medication".*	*"Patients assume that the home based carers will disclose that they are on treatment to other people, so they stop visiting the clinic for medication".* *"Our patients default because most of the nurses in our clinic are from this village, so patients feel uncomfortable. They are fearful that we might disclose their HIV status and the fact that they are taking HIV medication to other people in the village".* *Patients stop taking treatment because they believe that we will tell other people in the village that they are on HIV treatment".* *"HIV-positive patients are sensitive and paranoid, they are always suspicious that nurses will disclose their HIV status to other community members".*

Traditional/religious beliefs	*"I am using traditional medication to fight what I have in my body; the traditional medicine will clean my blood then I will be HIV free*".	*"Some of the patients tell us that they were instructed by a traditional healer to stop taking their HIV medication and focus only on the traditional medication".* *"Pastors promise patients that they can cure HIV, so patients stop treatment and run to those pastors".*
Difficulty taking time off from work	*"I stopped taking the medication because the clinic only provides me with medication that will only last me for a month and I cannot take leave from work monthly to visit the clinic".* *"It is very difficult when you work in the farm to take time off, it has been a long time since I was able to go to the clinic for my medication".* *"I get paid based on the number of hours I worked so I cannot risk losing money by wasting time and going to the clinic".*	"*our clinic currently operates only on weekdays and some patients are unable to visit the clinic due to the inability to take off from work".* *" Most of our patients are farm workers, so it is almost impossible to get time off to come to the clinic".* *"Patients who work on weekdays don't have time to come to the clinic for their medication".*

Table 5: Examples of responses that were only mentioned by patients on factors contributing to LTFU among HIV-positive patients

Experience of negative side effects	**Patients** *"I could not take it any longer, I got sick every time I took the pills".* *"I can't tolerate the medication, I feel very nauseous after taking it".* *"Medication is not supposed to make me sick but better, so I stopped taking it".* *"The medication makes me feel dizzy, I feel very sick after taking the medication, it is too much I could not take it anymore".*
Unwelcoming and rude behaviour by nurses	*"Nurses speak to us in a very disrespectful manner, I am not a child".* *"I will rather discontinue care that be treated like a nobody".* *"There is an Afrikaans nurse in the clinic who is rude to most patients, she does not treat me well every time I visit the clinic especially if I missed one appointment. Therefore, I decided to avoid her by not visiting the clinic anymore".*

Lack of funds to travel to the clinic	*“I did not plan to stop going to the clinic, I stopped because I cannot afford a taxi to go to the clinic” .* *“I stay far away from the clinic and at times I cannot afford to travel to the clinic, that is the main reason I stopped going for my medication” .* *“I prefer going to another clinic which is far from here, so sometimes I can’t afford transport fare”.*

Table 6: Examples of responses that were only mentioned by nurses on factors contributing to LTFU among HIV-positive patients

Patients self-transfer	**Nurses** *“our patients never inform us when they relocate, they just leave and start taking medication elsewhere”.* *“Patients who are college student always return to their home towns after graduating and don’t let us know”.* *“Most of our patients are immigrants farm workers, they don’t inform us when they are moving to another farm or returning to their home country”.*

Disability grants	*“Sometimes patients don’t want to get better because they are afraid to forfeit the disability grant they receive”.* *“some patients intentionally default from treatment because they want to get sick, weaker and qualify to get a disability grant”* .
Denial	*“Patients sometimes find it hard to accept their HIV-status so they don’t visit the clinic any longer”.* *“some of the patient refuse to believe that they are HIV-positive so they don’t come for treatment at all”.* *“Some patients deny that they are HIV positive and therefore don’t take their medication”* .

Table 7: Examples of patients’ and nurses’ perspectives on the strategies that would assist patients to remain in care and take ART consistently.

Health education	**Patient responses**	**Nurse responses**
	“It is better if we are well informed on the benefits of adhering to medication”. *“I think nurses should educate us on the importance of taking these pills every day because we don’t know”.* *“I am not aware of why I should take the medication and I think I should be taught”.* *“It will be helpful if nurses educate us about ART, this will help us understand the importance of taking treatment”.*	**“***We educate patients on the importance of ART, that is how they are able to stay in care”.* *“Patients in our clinic are aware that HIV is their life, we educate them very well”.* *“Our patients need proper health education, so that they understand the importance of ART*”. “one *strategy that has helped us to retain patients in care is by educating the patients about HIV and ART during initiation in the consultation rooms because there is privacy there unlike the waiting area”.*

Social support	*"I am always feels encouraged when I am motivated by a knowledgeable professional like a nurse".* *" I would appreciate it if our nurses run health education programs in the community, I will feel encouraged and loved".* *"I think nurses should make home visits and motivate us about the importance of retaining in care, it really helps talking to someone".*	*" when we notice that a patients has missed two appointment, I go to their homes personally, and they always return to care after the visit".* *"Most of my patients who are unable to visit the clinic during weekdays send family members to collect medication on their behalf".* *" peer supporters in our clinics encourage and offer support to other HIV-positive patients and this has really helped us to retain our patients".*

Table 8: Examples of responses that were only mentioned by patients on the strategies that would assist patients to remain in care and take ART consistently.

Confidentiality assurance	***Patients*** *"I will return to the clinic for HIV care only if my HIV status could be kept confidential, otherwise I will rather not take medication".* *"I don't have a problem with returning to care as long as my health issues are not spread in the whole village".* *"it will be safe to keep on visiting the clinic only if the home based carers can stop gossiping about our HIV-status and telling everyone that we take HIV-medication".*
Providing medication that lasts for longer periods	*"I suggest that the clinic gives me medication to last me for a few months because I can't visit the clinic on weekdays".* *" I wish I could have medication to last me for long to avoid asking for time off from work to visit the clinic".*
In-service-training on ethics and ethos	*"Nurses and Home based carers should be trained and taught on how to keep our health issues confidential".* *"These nurses should know how to respect us and not treat us like dirt".* *"Home based carers should be taught on how to be professional and keep our business confidential".*

Table 9: Examples of responses that were only mentioned by nurses whose clinics have less rate of LTFU on the strategies that would assist patients to remain in care and take ART consistently.

Team work	*Team work helped us to succeed in retaining HIV-positive patients in care"* *"working as a team always help us to retain our patient"* *"we help each other where we can, in this way no patient drops out of care"* .

CHAPTER 5: DISCUSSION OF FINDINGS

5. Introduction

This study adds to the few studies in South Africa that have explored the barriers faced by HIV-positive people in accessing ART. While the study only focuses on Sekhukhune district of the Limpopo Province, South Africa, it reveals a number of findings that should be given attention. The majority of our study participants were unemployed, while some were farm workers, mine workers, and college students. Furthermore, the majority of the participants were women who tested HIV-positive during their pregnancy. This might be because women are obliged to test for HIV during pregnancy and are immediately put on HIV treatment if tested positive for HIV. Notably, the study consists mostly of HIV-positive women and fewer men. This might be because the prevalence of HIV is higher among women. Patients face many barriers that challenge their retaining in care; nonetheless, they have suggested strategies that might assist them to re-engage and retain in care.

This study examined patient and nurse perspectives on factors contributing to LTFU as well as strategies that may help to retain HIV-positive patients in care. While there is extensive literature on patients' perspectives, the literature on the nurses' perspectives is limited. Consequently, in this discussion, some of the results on nurses' perspectives will be supported by literature on patients' perspectives. Below is a preview of the findings that were incorporated to demonstrate factors that contributed to patients' LTFU , strategies that may help to re-engage and retain HIV-positive patients in care, as well as global relevant literature for each reason and strategy. This discussion will assist in establishing if the literature contradicts or supports the findings of the study. Moreover, the findings presented in this study highlight an urgent need for strategies to address various barriers to ART access.

5.1. Theme 1: Factors contributing to LTFU among HIV- positive patients from patients' and nurse's perspetives

There are various factors, which were described by nurses and patients as obstacles that hinder patients from retaining in HIV care. Patients also feel that some of the obstacles are beyond their ability to overcome. The reasons outlined by patients and nurses included feeling well physically, fear of disclosure, lack of confidentiality, negative side-effects, unsatisfactory treatment by staff, traditional/ religious beliefs, and difficulty taking time off from work, lack of enough medication, financial constraints, patients' self-transfer, disability grant, and denial. All these barriers are discussed in detail below.

5.1.1. Lack of understanding of ART/ Feeling physically strong

Some patients felt that they should discontinue taking their medication because they feel strong physically. They believe that an HIV infected person should feel pain, be weak and unable to carry on with their daily routine activities. These perceptions are due to limited understanding of how HIV and ART work. Patients do not understand that ART is a lifelong treatment and that a HIV-positive person on treatment can live a normal healthy life like everyone else. Nurses also attested to what patients reported that they believe that patients discontinue taking their medication when they feel strong physically. They also reckon this might be due misinterpretation of how ART works.

The above mentioned results are not far off from the findings in some of the studies in Africa. For instance, in an East African conducted study (Uganda, Tanzania and Kenya), it was found that one of the most common reasons for non-return in care were “felt well and therefore did not see any reason for coming to the clinic” (Geng, Odeny, Lyamuya, Nakiwogga-Muwanga, Diero et al., 2016). Interestingly, it is not only adults who reported feeling well as the reason for default. In a study conducted among adolescents, they also acknowledged “not feeling sick,” as one of the numerous barriers to non-retention (Kunapareddy, Nyandiko,Inui,Ayaya, Marrero, & Vreeman, 2014).

It was revealed in the current study through participants’ responses that their lack of understanding of ART and HIV was the main cause of non-retention in care. Findings revealed that the greatest barrier cited at the health system level was that of unclear information provided by health facility staff; patients cited that they did not understand most of the basics about ART and HIV, how both work; this is consistent with previous studies (Schechter, Bakor, Kone, Robinson, Lue, & Senturia, 2014). In addition, consistent findings showed that some of the patients reported to have defaulted from treatment because they did not understand how ART works. Patients expressed discouragement when they were informed about clinical outcome results. Patients did not understand why their clinical health outcomes were not improving although they made major efforts to take their ART; hence, they stopped visiting the clinic for medication (Krummenacher, Spencer, Pasquier, Bugnon, Cavassini et al., 2014).

Furthermore, to support that patients had limited information about HIV and ART, an Ethiopian study reported a number of misconceptions about HIV and ART that were identified by patients. In the study many HIV-positive individuals felt that HIV was a death sentence and were unaware that ART can help patients remain healthy and live long lives (Lifson, Demissie, Tadesse, Ketema, May, et al., 2012).

5.1.2. Fear of disclosure and stigma

Patients mentioned that they discontinued taking their medication because they are afraid to disclose their HIV status to their partners. They also assume that if they disclose their HIV status, partners will end the relationship. They also felt that demanding condom use may make their partners suspicious that they are HIV–positive and still end their relationship. As a result, they did not disclose their status and continued having unprotected sex. They confirmed that they defaulted from their medication because the medication would no longer be effective due to unsafe sexual intercourse. However, patients shared with me their desire to disclose their HIV status to their partners with the hope of receiving support to adhere to their medication.

The fear of rejection by partners has been reported to be a hindrance to retention in care. For example, in a study by Nabukeera-Barungi, Elyanu, Asire, Katureebe, Lukabwe, et al. (2015) non-disclosure to partners was found to be a hindrance to adherence and retention in care. These results are also consistent with the results found in an Ethiopian study which revealed that fear of HIV status disclosure was a considerable barrier to remaining in care. Participants across groups were discouraged by stigmatizing attitudes towards HIV if they were to disclose their HIV status (Tiruneh, Galarraga, Genberg, & Wilson, 2016, C`roome, Ahluwalia, Hughes, & Abas, 2017).

Relatedly, an Ugandan study also identified fear to disclosure of one’s HIV status to partners, and HIV stigma as major barriers to ART adherence and encouraging completely missing clinic appointments. Most participants mentioned experiencing disclosure difficulties and consequently struggling to adhere to their treatment (Buregyeya, Naigino, Mukose, Makumbi, Esiru et al., 2017). Further findings in a review aimed to identify facilitators and barriers to HIV retention in care interventions, fear of HIV status disclosure increased clinic avoidance behavior among individuals living with HIV (Hall, Sou, Beanland, Lacky, Tso, et al., 2017).

Furthermore, many patients do not want to be seen receiving HIV care at a nearby clinic by neighbours or friends due to fear of stigma; some instead opt to go to far distant clinics where there is less chance of being recognized. Distance to these clinics, however, can be a major barrier to retention in care, especially for those from rural communities and those with limited funds for transportation. (Lifson, et al., 2012).

Additionally, a US study by Sevelius, et al., (2014), discovered that participants also described not wanting to access HIV care at agencies known for providing such services because they feared being seen entering or leaving the building, or running into people they knew. Consistent results in a different study disclosed that the commonly cited barrier by women participants was fear of stigma, which occurred within both families and the community.

Women described stigma and discrimination as prevalent in their communities, and this makes them default from care (Schechter, et al., 2014). Moreover, in a study conducted among lost to follow ups in 14 clinics in Uganda, Tanzania, and Kenya. It was found that 27% of the patients defaulted from care due to fear of being stigmatized (Geng, et.al., 2016; Nabukeera-Barungi, et al., 2015). Contrary to the reported findings, an analysis was conducted to assess the association between self-reported stigma and LTFU. The results of the analysis revealed that there was no association between LTFU and stigma, they did not reach statistical significance, and there was no evidence of a linear trend (Evangeli, Newell, Richter, & McGrath, 2014).

Though fear of disclosure was revealed as one of the major barriers in the current study, contradictory results in a Caribbean study discovered that nearly all women had disclosed thier information to at least one person but did not receive expected support. Reactions to disclosure were causes of stress, with some experiencing stigma and discrimination. However, despite the unpleasant experiences with disclosure, no strong theme emerged related to disclosure and adherence. In the same study, conversely, health workers reported that that non-disclosure contributed to patients' non-adherence (Vitalis & Hill, 2017).

The current study found that patients fear to disclose their HIV status due to fear of rejection and stigmatization. In fact, there is evidence that patients can experience stigma and discrimination following the disclosure (Vitalis & Hill 2017). There are studies, however, that reported disclosure as helpful in getting the social support one needs to adhere to medication. For example, patients were not stigmatized following their disclosure in a Beijing study in which participants reported that they received emotional support after they disclosed their HIV status to their family members (Wang, Chen, Lin, Bao, Zhao, & Lu, 2016).

5.1.3. Fear of lack of confidentiality

Patients said that their confidentiality was compromised by nurses and home based carers. They shared with certainty that the clinic staff disclosed their HIV status and the fact that they were on HIV medication to the other community members in the village. Patients pointed out that it is easier for home based carers and nurses to share their confidential information with other people in the village because they reside in the same village as their patients. Patients are also afraid that if other people find out that they are on ARVs, they will be stigmatized by community members. However, nurses denied that this was true. They stated that patients' speculation that clinic staff disclose patients' HIV status and the fact that they are on HIV treatment is incorrect. The nurses mentioned that patients may assume that since they live in the same village with them, their health issues will be shared with other community members.

There are consistent results in various studies. As in a study conducted in Kenya, lack of confidentiality by healthcare providers was raised as a concern by patients. Patients highlighted that they were afraid that health providers would disclose the HIV status especially of patients known to them. This relates to what one of the patients in the current study said that they prefer travel to a far distant clinic for their HIV medication to avoid confidentiality issues. These results regarding lack of confidentiality are further supported by other Ethiopian studies. A study conducted by Tiruneh, et al., (2016) found that patients reported fear of confidentiality as a reason for non-retention in care. In the current study, patients stated that they were not satisfied with the procedures in the clinic. They mentioned that the procedures compromised their privacy and confidentiality, and therefore dropping out of care solves this problem. Related results in another Ethiopian study also stated that patients articulated their concern about lack of confidentiality by clinic staff, including counselors and clinicians. Patients assumed that their health issues might not be kept confidential and therefore became hesitant to remain in care (Lifson, et al., 2012).

5.1.4. ART negative side effects

The current study discovered that patients stopped treatment because they felt that the medication made them feel sick (e.g., dizziness and nausea). Patients were not aware that the medication may have side-effects; therefore, they thought the medication made them more sick and so they stopped taking their medication. These results are consistent with the results of a study in Ghana by Ankomah, et al. (2016), which revealed fear of side effects as the main barrier that prevents patients remaining in care. Feeling sick was also a commonly reported reason for skipping appointments in a study conducted in Philadelphia, United States. Participants related their symptoms to a range of factors including compromised immune systems that made common colds and the flu more potent, and feeling emotionally low (Yehia, Steward, Momplaisir, Mody, Holtzman, et.al., 2015).

Medication side effects were one of the main reasons reported by women who stopped treatment. Female participants indicated that unbearable side effects such as drowsiness, headache, diarrhea were reasons for non-retention (Vitalis & Hill 2017). Similar results were uncovered in a study conducted by Adamian, Golin, Shain, and Devellis, (2004), where experiencing side effects was reported as a reason for non-adherence. Likewise, in a Malawian study by Kim, Zhou, Mazenga, Ahmed, Markham, et al. (2016), side effects were also the most commonly reported barrier to ART non-adherence. Half of the respondents who stopped ART did so because of side effects, which included dizziness, nausea or vomiting, nightmares and hallucinations. A similar study to the current study among HIV positive people who were lost to follow-up and healthcare workers (HCWs) in Kenya, Uganda, Tanzania, Malawi, Zimbabwe and South Africa study found that experience of these ART side effects were severe enough to prevent them visiting the clinic and caring for themselves and prevented them from retaining in care (Renju, Moshabela, McLean, Ddaaki, Skovdal, et.al., 2017).

5.1.5. Unsatisfactory treatment by nurses

The study established that patients dropped out of care due to negative treatment by nurses. Patients highlighted that nurses are impolite and disrespectful towards them during their regular visits. Therefore, to avoid the hostile treatment, patients left care.

This finding is similar to the results of a South African study that was conducted in Durban by Bassett, Coleman, Giddy, Bogart, Chaisson, et al. (2017), which found that the second most highly reported perceived barrier was poor service delivery in the health facilities. A consistent study by Croome, Ahluwalia, Hughes, and Abas (2017) conducted in 24 countries in Sub-Saharan Africa also revealed that the majority of the patient participants experienced negative treatment from clinic staff. This was a primary barrier that discouraged them from remaining in HIV care. Likewise, undesirable experiences received in HIV care were felt to negatively affect retention by patients in Ethiopia. Patients expressed that doctors or nurses did not have patience and did not express a welcoming attitude towards them, and this was related to their leaving care (Lifson, et al., 2012).

Another finding related to the current results found that patients revealed that problems with their health provider and other interpersonal relationships with the providers led to their non-retention in care (Croome, et.al., 2017). Consistent findings showed that patients reported that some of the nurses in the clinic were rude and disrespectful to the patients, and this discouraged them to return back to the health facility (Buchberg, Fletcher, Vidrine, Levison, Peters, et al., 2015).

Negative attitudes by health care providers is not only a barrier in Africa, but also worldwide. Likewise, in a study conducted in Russia, negative attitudes by health providers was also cited as a barrier to retention in care (Pecoraro, Mimiaga, O`Cleirigh, Safren, Blokhina, et al., 2014; Kuznetsova, Meylakhs, Amirkhanian, Kelly, Yakovlev, et al., 2016). Similar results in another study conducted by Sangaramoorthy, Jamison, and Typhanye (2017) in the United States among older women (40-71), participants described experiences of rejection from health care professionals as the main barrier for non-retention in care.

Surprisingly, health workers also reported that other health workers treated patients impolitely.

Nearly all (97.7%) of Nigerian health workers reported observing discrimination against PLWHA by other health workers in their facilities that may have resulted in patients' non-adherence or LTFU (Sekoni, & Owoaje, 2013). However, in the current study, none of the nurses agreed with the patients' allegations regarding rude and unwelcoming behaviour from nurses.

5.1.6. Traditional/ religious beliefs and denial

In contrast, fewer patients in the study dropped out of care due to use of traditional medication. However, patients did substitute traditional medication for ART. They believed that they could be cured by a traditional healer through use of traditional medication. Patients further said that HIV is dirty blood that can be easily cleaned by use of traditional medication. They believed that traditional medication will clean the HIV blood and then they will be HIV free. Nurses also think that patients have strong traditional beliefs that cause them to deny that they have HIV. As a result, they drop out of care to seek healing from traditional and faith healers. In contrast, none of the patients confirmed use of faith water as an alternative treatment. Nurses also believe that some patients are secretive about the fact that they use traditional medication or faith water because they are aware that substituting ART with traditional medicine or holy water is not approved of by the nurses. It is possible that few patients admitted to using traditional medication/faith water instead of ART because they feared disapproval.

Twenty nine patients declared that they were not using any alternative treatments (traditional/ faith healing). Only one patient in the study confirmed that she opted for traditional medication as an alternative therapy because she strongly believed that she would be healed. This relates to the results of a study conducted in Malawi, to identify patients` reasons for interrupting ART. Of the 147 patients, only one patient stated traditional medication as the reason for ART interruption (Tabatabai, Namakhoma, Tweya, Phiri, Schnitzler, & Neuhann, 2014). Also, some of the nurses reckon that fewer patients might be using both ART and traditional medicine. They emphasized that patients always deny when they are confronted about it, but their health outcomes are poor (such as high viral load). Indeed, none of the patients interviewed confirmed combining traditional/faith healing with ART.

On one hand, an Ethiopian study by Tiruneh, et.al. (2016) found that use of religious healing (holy water) was one of the barriers to remaining in care, study participants believed that holy water cures HIV. In another study by Vitalis, and Hill, (2017) in the Caribbean, results showed that some postpartum women believed that God would cure them; as a result, they defaulted from their medication and put their trust in the pastor for remedy. These participants hoped to be healed by God because they attended churches where pastors bragged that they could heal those who had the HIV virus. On another hand, in an Ethiopian study, patients believed in holy water or other spiritual interventions as ‘‘cures’’ for HIV; hence, they assumed that they did not need ART and other HIV clinic-based care. They had strong beliefs that holy water could cure HIV. (Lifson, et al., 2012). Similarly, a Congolese study also found religious beliefs to also be a barrier for ART adherence. The belief that HIV virus was caused by witchcraft led a few participants from adhering to ARV treatment and ended up being lost to follow-up in search for a potential cure (Musumari, et.al., 2013). In a further supporting study, patients believed that holy water cures HIV; they are convinced that HIV is God’s punishment not a virus. Hence, according to them, only God can heal the virus so that they are HIV free. This perception led patients to discontinue treatment (Tiruneh, et al., 2016). Therefore, this may mean that religious treatment challenges retention for people who believe in traditional or religious healing.

Interestingly, adults also impose their spiritual belief that HIV can heal their children. Consequently, this played a huge role on non-adherence among adolescents. Some adolescent patients stopped taking ART for six months after being declared healed by adults at a healing prayer school in South Africa. In this prayer school, the pastor claimed that all those on ART have been healed following a short prayer in church (Denison, Banda, Dennis, Packer, Nyambe, et.al., 2015).

Contrary to all the above results that have been reported that religious beliefs are barriers to retention in care among HIV positive individuals, findings in one of the studies conducted in Congo discovered religious beliefs as a facilitator to remaining in care. Many participants sustained the belief that God provided the knowledge to make ARVs; thus, the ARVs would help them feel better and live a longer healthy life. This mindset motivated them to keep adhering to the treatment (Musumari, et.al., 2013).

5.1.7. Difficulty taking time off from work/medication shortage

In the current study, some patients indicated that they unwillingly dropped out of care due to difficulty getting time off from work. Also, they said that the clinic is not making it any better by refusing to give them medication in advance to last them for longer periods. However, the nurses confirmed that they would provide patients with medication that would last them for two to three months, but only to selected patients who have a satisfactory clinical outcomes such as suppressed/low viral load and higher cd4 count. Subsequently, other patients who have poor health outcomes (High viral load, low cd4 count) do not qualify for getting medication in advance. These results are supported by an Ugandan study that sought to identify barriers to sustained HIV care. One of the barriers mentioned was not being able to get enough medication to last patients for months at a time when they were traveling (Bogard, et.al., 2016). Another consistent study found that difficulty taking time from work regularly is a primary barrier to remaining in HIV care (Ankomah, et.al., 2016).

Similarly, patients reported that competing priorities for work, child care, and other domestic responsibilities were also barriers to clinic attendance. Many families supported themselves by farming or day labor, and many women had child care and other household responsibilities. They reported that being in the clinic for an entire day could impose hardships on the entire family and clinic attendance was compromised (Lifson, et.al, 2012). An additional study discovered the same findings, patients mentioned that work or child care responsibilities interfered with coming to the clinic. They had difficulties leaving work to visit the clinic or they had child care responsibilities; hence, they stopped visiting the clinic (Geng, et.al., 2016).

5.1.8. Financial constraints

Lack of finances for transportation/nutritional food was rarely mentioned as a barrier for retention in care in the current study. Nonetheless, there are many studies that reported financial constraints (lack of funds for transportation/nutritional food) as one major barrier to non-retention in care. For instance, a study conducted in Ghana by Ankomah, et al. (2016) among health care providers confirmed that financial constraints were a major barrier that prevented patients from accessing treatment. Patients mentioned that they couldn’t afford transportation costs as well as administrative monthly costs that they are required to pay at the health facilities.

Consistent results were revealed in an Ethiopian study that distance to the HIV clinic is a barrier to retention, with the requirement for transportation, lodging, and other travel-related expenses; this was a particular problem for rural patients who might have to spend the night in town near the clinic before returning to their home village. So, they could not afford to spend on transport and lodging every time they had to visit the clinic (Lifson, et al., 2012). Relatedly, findings in a Cameroonian study reported that some of the clinics are located further away from patients` homes, and this poses a challenge for patients to reach the facility. Hence, it was found that one of the major factors associated with high LTFU rate was the long distance to the clinic; patients had to travel for over 5 km to the facility (Bekolo, Webster, Batenganya, Sume, & Kollo, 2013).

Transportation cost is not only a barrier in developing countries but also in developed countries. A systematic review of empirical studies concerning barriers to care among patients with HIV in rural areas of the United States found that transportation was a major barrier to care. Between 19% to 45% of participants reported that transportation was a significant barrier to attending medical appointments and receiving HIV-related care (Pellowski, 2013). Financial constraints were again acknowledged as a barrier to retention in another US study where participants stated financial constraints were a key challenge that prevented them from obtaining consistent HIV care. Participants reported that they could not get to the health care facility for the medication due to the high cost of public transportation (Sangaramoorthy, et.al., 2017).

All the above mentioned findings are not surprising given that many individuals who live in rural areas with clinics situated in far distances must travel for long distances in order to receive HIV care. This usually means that primary care is not conveniently located and requires substantially longer travel times for persons living further away from the clinics (Schechter, et al., 2014). In addition, many rural people must oftentimes rely on unreliable forms of transportation such as public transportation or dependence on others for rides. Similarly, in one study, 45.3% of the sample had difficulty traveling to appointments due to transportation costs (Sarnquist, Soni, Hwang, Topol, Mutima, & Maldonado, 2011).

Although lack of finances for transportation was infrequently mentioned as a barrier in the current study, some of the patients preferred to attend clinic further away from their homes due to fear of stigma. This compromised their retention in care because they can’t always afford to travel to further away clinics. These results are similar to the results of a study conducted in Ethiopia by Tiruneh, et.a., (2016) which revealed that some patients preferred to enroll in care facilities located relatively far from their neighborhoods, incurring additional costs in time and transportation.

Another financial related problem is lack of money for good nutritional food related to non-retention in care. For instance, Tiruneh, et.al. (2016), found that lack of money for good nutritional food is a reason for poor retention, and participants reported that to take their medications they are required good nutrition, which they could not access because of poverty. Additionally, in a study conducted in the Caribbean region, both clinic patients and health care staff indicated that inadequate food and lack of finances were deterrents to adherence. About half of the pregnant women who were non-adherent cited lack of food as the reason for non-adherence. These women stated that taking ART on an empty stomach would make them feel sick (Vitalis &Hill, 2017). A supporting study conducted in 24 Sub-Saharan African countries found that not having access to adequate food is a barrier to retention in care (Croome, et.al., 2017). Moreover, in another African conducted study by Lifson, et.al (2012) in Ethiopia, food insecurity was similarly a barrier to retention in HIV care. It was believed that taking ART on an empty stomach could aggravate certain abdominal side effects, hence patients defaulted from care. Surprisingly, few patients in the current study mentioned economic constraints (for transportation costs nor nutritious food) as a barrier to retention in care, even though

Sekhukhune is a rural setting with more than 50% of the population employed .

5.1.9. Patients self-transfer

In the current study, nurses frequently reported patients' self-transfer as a barrier to retention in care. They mentioned that patients are labeled as LTFU in their records due to self-transfer, but patients did not report this. However, there was limited literature on patients' self-transfer as a barrier to retention in care. A study conducted in three Eastern African countries (Uganda, Kenya and Tanzania) to assess reasons for non-return in care revealed that of 18,081 patients 10% of the patients self-transferred themselves without obtaining an official letter from the previous clinic (Geng, et al. 2016).

5.1.10. Disability grant

Disability grant was only mentioned by nurse participants as a barrier that may cause patients to default from treatment. They assumed that some of the patients default from treatment intentionally so that they get weak, sicker in order to quality for a disability grant. This is supported by the results of a study conducted by (Croome, et.al. 2017) where a patient participant confirmed that he dropped out of care due to fear of losing disability grant.

In this study, however, none of the patients confirmed that receiving a disability grant encouraged them to drop out of care. Moreover, none of the patients in this study reported that they received a disability grant.

5.2. Theme 2: Nurses' and patients' perspective on the strategies that would help to address barriers to help patients remain in care and take ART consistently

Patients and nurses reported on strategies that could assist in re-engaging and retaining patients in care. The strategies explained included team work, heath education, social support, satisfactory treatment by staff, extended working days, and patients' confidentiality. The two commonly mentioned strategies were health education and patients' confidentiality. Patients felt that they were not well informed on the importance of ART and how it works. Moreover, a majority of the patients were concerned about the confidentiality of their HIV status and the fact that they were on ART. Consequently, they said that they would be re-engaged and stay in care only if they were assured confidentiality by clinic staff.

Nurses reported that the strategies that helped to retain patients in care included team work, heath education, social support, extended working days, and patients' confidentiality. The most commonly reported strategy was health education and team work. They believe that if patients are equipped with detailed knowledge on HIV and ART, they will remain in care and those that have dropped out of care may re-engage back into care and be retained. They also reported that working as a team has helped them to retain more patients in care. The following section describes strategies that help retain patients in care.

5.2.1. Health education

Health education has been highlighted as a major strategy that could retain patients in care. Nurses recognized that health education is vital and should be strengthened in the clinics. Patients also thought that they would appreciate more in-depth education from the nurses on HIV and ART. They are certain that if they are well equipped with knowledge they would remain in care because they would understand how HIV and ART worked. There are a variety of studies that have found that education is the main intervention that helps HIV –positive patients to remain in care.

Patients in a study conducted by Lifson, et al., (2012), recommended that education and awareness-raising programs be strengthened to avoid misconceptions about HIV and to decrease stigma toward people living with HIV. Patients said that they appreciate receiving information about HIV, ART, and other health promoting measures such as nutrition. They are convinced that knowledge about ART and HIV will help them remain in care.

A US study found that patients' knowledge about what ART does for their health and what could happen when they stop treatment gave them courage to remain in care. Showing that in-depth education on ART and HIV is fundamental to retaining patients in care (Buchberg, et al., 2015). Consistent results also revealed that the most commonly mentioned facilitator to remain in care was the quality of staff advice. This involves advice provided by health facility staff and community counsellors. Participants stated that they got encouragement to remain in care through the good advice they got from the health workers (Schechter, et al., 2014).

in a South African study conducted among CHWs, community awareness and education campaigns were suggested as a way to distribute knowledge to uninfected family members about signs and symptoms of HIV, how ART works and how to use it, and what to do if a family member tests HIV-positive. This can minimize stigma and discrimination by the community and family members. This educational approach can help community members to appreciate HIV as a medical illness and to become more supportive of patients taking ART. In return, patients will feel accepted, supported as a result engage and remain in care (Loeliger et al., 2016).

Furthermore, in a study where nurses use motivational interviewing to engage with patients, patients mentioned the possibility of becoming sicker or developing AIDS as a motivation for them to be adherent. This showed that an engaging approach to education resulted in an understanding of how ART and HIV worked. Hence patients were clear that if one stop their medication, their health will eventually deteriorate, they may develop AIDS and possibly die. This demonstrates that motivational interviewing can successfully equip patients with the knowledge they need to make informed and beneficial decisions (Adamian, et.al., 2004). patients suggested it may be beneficial for nurses to receive training on counseling and education skills, including delivering health messages in ways that are culturally and educationally appropriate to the client's background (Lifson, et al., 2012).

5.2.3. Social Support

Nurses reported that social support by either health workers or family members is an important factor of adherence and retention in care. They emphasized that social support especially from family members is beneficial to patients because they can have someone to rely on when they need any kind of support such as emotional support. They can also remind the patient to take their medication. The stated that any support system person is allowed to collect medication on the patient's behalf if they are unable to.

There are various studies which concur with this. For instance, in a review conducted by (Hall, et al., 2017), provision of emotional support offered by lay health workers and peer counselors encouraged hope and a positive outlook among patients, which increased retention in care.

Likewise, in a Ugandan study, partner/family support, peer support was one of the most important factors for retaining patients in care. Family support for the women, particularly from their partners for those who had disclosed was reported to facilitate good adherence. This support ranged from being reminded to take treatment, counselling, providing them with transport fare to visit the health facility (Buregyeya, et al., 2017). A further concurrent study also indicated that support from family and/or friends was a frequently reported facilitator of ART-adherence in a study conducted in Lesotho. Patients mentioned that the members of the family usually remind them when it it time to take their medication (Axelsson, Hallager, & Barfod, 2015). More consistent results were revealed in a study conducted by Holtzman, et.al., (2015). Supportive family members, friends, and neighbours were considered influential in helping patients maintain appointments and adhere to therapy. These individuals would remind patients of their appointments, offer transportation, and on occasion accompany them to medical visits. Furthermore, they motivated patients to take their medications, with some daily enquiry about their adherence.

Additionally, participants in a study conducted in Ethiopia said lack of personal or social support from family, friends, and the community was a barrier to remaining in care and adhering to ART, while strong and consistent support made retention easier. Several participants reported that disclosure of HIV status to family or friends, although initially difficult, typically resulted in greater social support. (Lifson, et al., 2012). In the same study, patients recognized the limitations of clinic staff (both number of personnel and available time). As a result, they recommended that social support also be offered at the community level, including assistance interacting with the HIV clinic concerning registration at the clinic for medical appointments, drug side effects, and other medical concerns.

Social support from peers in a form of support groups (people who are also HIV-positive) was cited by HIV-positive patients as essential. Patients shared that there were monthly group meetings facilitated by community counsellors at health facilities. In this meetings, all PMTCT participants have an opportunity to share their experiences and discuss relevant health issues. Some women described the role support groups played after being previously LTFU, they indicated that support groups have assisted them to remain in care (Schechter, et.al., 2014). Receiving peer support from HIV-infected women who have overcome their personal barriers to receiving HIV care, who are medication adherent, and have achieved viral suppression served as role models and provide invaluable social support (Reback, Ferlito, Kisler, & Fletcher, 2015)

This kind of support encourages the HIV-positive patients who are struggling with adherence to see that they are not alone and adhere in treatment.

Not only adults, but also adolescents recognized peer support as an important tool for adherence, they spoke of the clinic-sponsored groups for ALHIV as a valuable opportunity to make friends, encourage their peers and help each other remember to take their medications and hear about the experiences of other PLHIV. This platform allows them to see the importance of adherence and remain in care (Denison, Banda, Dennis, Packer, Nyambe, et.al., 2015).

5.2.4. Satisfactory treatment by staff/proactivity by staff

Nurses in the study cited that good interpersonal relationships with the patients helps patients to feel homely in the health facility. In this way patients will not hesitate to re-visit the clinic due to the warm welcome and service they receive every time they visit the clinic.

Concurring findings on satisfactory treatment by staff as an important intervention was further reported in a study conducted in the United States. Health providers indicated that connecting with patients on a personal level to foster respect and trust, where they show empathy and interest in patients beyond their HIV care needs has helped them to retain patients in care. Health Providers further mentioned that they create a supportive and caring medical environment for patients by offering a medical home (Gelaude, et al., 2017). Another supporting study showed that good relationship with the health providers is a facilitator to medication adherence (Adamian, et.al., 2004). Similarly, in a study conducted by Bam, et.al. (2015). It was discovered that the conducive environment at ART clinics (P = 0.004) were significantly associated with ART adherence. Conducive environment includes clinic staff being welcoming, helpful and polite.

Consistent results in a study by Buchberg, et al., (2015), cited that strong relationships with healthcare providers has been identified as a strong facilitator to retain patients in care. Patients mentioned that they felt good about the support they received throughout the one on one with the health providers during their clinic visits and this makes them to feel good about themselves. This in turn gave them courage to come to the next visit.

More reliable results indicated that supportive clinic staff that expressed genuine concern for patients promoted engagement and remaining in care. Patients endorsed trust, compassion, delivery of individualized care, and responsiveness as the most vital factors that encouraged them to remain in care and not be afraid to make their return visit (Holtzman, et.al., 2015). In the same study, patients further elaborated that health providers displayed these characteristics when they treated patients as equals, considered their uniqueness, gave them the opportunity to talk about their personal lives, followed-up with them outside the office visit, and returned their phone calls. These qualities and actions created a relationship of trust, enabling patients to follow through with their providers’ advice and recommendations. Many felt that their providers cared about them as individuals when they took time to listen to their problems. Patients admitted that poor relationships with providers deterred them from attending appointments, while positive relationships supported adherence to treatment plans (Holtzman, et.al., 2015).

Besides satisfactory treatment by clinic staff as a way to encourage patients to remain in care, nurses also highlighted that nurses’ proactivity might also help to retain patients in care before they are actually LTFU. Nurses in the study acknowledged that tracing the patients as soon as they miss their first or second appointment helps to retain patients in care. Unfortunately, it is said to be difficult to trace patients in some instances. For instance, nurses stated that they have difficulty tracing those patients who work on the farms and mines as well as students because they usually give incorrect contact details. As a result, when they call, it never goes through, and those patients are found to have relocated from their initial address. Therefore, it is hard to tell if they are self-transfers or LTFU, so automatically they are recorded as LTFU when the miss their clinic appointments for 90 days or more. This is supported by the results of a study conducted by Gelaude, et al. (2017), it was revealed that lack of reliable contact information by patients makes it harder to following up with patients at risk of dropping out of care.

5.2.5. M-Health

M-Health has not been reported by any of the study participants in the current study as a possible intervention strategy. However, it is important to briefly discuss it as it has been widely researched and proven to help retain HIV-positive patients in care.

According to few studies in the review, M-health (using mobile phone applications) was useful in increasing retention in care. This included passive ARV medication reminders on cellphones and active enquiring and addressing barriers to retention through text messaging (Hall, et al., 2017).

5.2.6. Good nutritional food

Nutritional food was never suggested by any of my study participants as a strategy that may assist with the re-engagement and retention of patients in care. This is simply because lack of nutritional food was never identified as a barrier for retention. Patients in studies, however, which cited lack of money to buy nutritional food as a barrier to retention in care reported the important role of good nutritional food. They suggested that there should be facilitation of linkages to such community-based groups to assist with their nutritional needs. With good nutritional food, PLWH could be retained in care (Lifson, et al., 2012).

5.3. Conclusion

For a long time, the Sekhukhune district has experienced high rates of LTFU compared to the other districts of Limpopo Province. We did not know the reasons that contributed to these high rates. Therefore, this current study was conducted to discover what contributes to LTFU from patients' and nurses' perspective. The information provided by participants has been found in the current study and has been supported by literature world-wide, but there was seldom information discovered in the literature about the disability grant as one of the motivators for HIV-positive patients to default in care. Also, literature on factors contributing to loss to follow up of patients was mostly articulated by patients and hardly ever nurses. This demonstrates that this current study is innovative because it did not only explore patients' perspectives on LTFU but also explored nurses' perspectives on factors contributing to loss to follow up. The next chapter explores the intervention models in HIV care that might be relevant to guide the strategy development to retain patients in HIV care.

CHAPTER 6*:* PROPOSED STRATEGY

6. Introduction

The proposed strategy was developed with the aim to improve medication adherence in HIV care. As a result, I applied the analysed findings of the study, suitable psychological models and literature to contribute to the design of a more effective strategy to promote adherence to HIV medication. Literature was also provided regarding the efficacy of all specific models in improving ART adherence in HIV care. Each model was reviewed to determine whether it was appropriate to tackle certain barriers and improve ART adherence and retention in care.

Adherence to treatments is a main determinant of HIV clinical outcomes including suppression of viral load, avoidance of illness, and longevity (Heestermans, Browne, Aiken, Vervoort, & Klipstein-Grobusch, 2016). Despite this, antiretroviral therapy non-adherence is a global common problem (Melaki, Mothiba, & Mbambo-Kekana, 2016). Strategies are needed to improve adherence. There are numerous psychological theories of behaviour change that increase medication adherence. The purpose of this chapter is to explore the intervention models in HIV care that might be relevant to guide strategy development to retain patients in HIV care and to develop recommendations that may be useful to reduce the rate of non-adherence and loss to follow up in patients with HIV in the Sekhukhune district of Limpopo Province.

6.1. Brief review of the study aims and findings

The current study identified the factors contributing to LTFU from the perspectives of HIV-positive patients and their nurses, and elicited their perspectives on the strategies that would help them to address barriers to remaining in care and taking ART consistently. Data revealed various factors that contribute to HIV-positive patients' loss to follow up. While factors vary due to every individuals' unique experience, several reasons emerged consistently that contributed to discontinuation of HIV treatment. Patients' reasons included lack of understanding of ART, feeling well physically, and experiencing negative side effects, along with having negative feelings about lack of confidentiality and fear of disclosure. Additional patient reasons were conflicting beliefs such as traditional/ religious beliefs; experiencing system problems such as lack of enough medication at the clinic, and financial barriers such as difficulty taking time off from work and lack of funds to travel to the clinic. Nurses' explanation of LTFU included patient traditional/religious beliefs, nurses' and clinics' breaches of confidentiality, and observing patients dropout due to their feeling better physically. Additionally, nurses listed a few barriers to retention in care that were not outlined by patients.

These include self-transfer, lack of understanding of ART, and receipt of a disability grant. While feeling well physically, fear of disclosure, lack of confidentiality, traditional/ religious beliefs, and poor understanding of ART were consistent between patient and nurse explanations for LTFU, a barrier that was only identified by nurses was receipt of a disability grant. Barriers identified only by patients were difficulty taking time off from work during weekdays for clinic visits, lack of funds to travel to the clinic and experience of negative side-effects. The disagreement about reasons for LTFU between nurses and patients may be a factor itself that merits intervention.

In addition to identifying those factors that contribute to patients' loss to follow up, an additional contribution of this study is its investigation of the nurses whose clinics have zero/ low rate of LTFU, and who shared the strategies that they use to retain their patients in care. Those successful at retention in care outlined their strategies including team work, health education, social support, and in-service education on ethics and ethos. Patients also suggested health education and confidentiality assurance about their HIV status as possible strategies that can encourage them to re-engage and stay in care. In contrast, nurses whose clinics have high rates of LTFU also proposed strategies that may work for them to keep patients in care, but these differed significantly from those of nurses whose clinics are already successful. Specifically, suggested strategies of nurses in clinics with high LTFU included development of social support groups, health education and providing "compliant" patients enough medication to last them for a few months. Significantly, health education has been a frequently mentioned strategy by both patients and nurses. Centers for Disease Control and Prevention (CDC) South Africa developed a comprehensive HIV care in 2009 to educate and provide support services to PLWH which has since been implemented in most clinics in South Africa. This support service included intervention components to help people accept ones HIV status, engage in disclosure of their HIV status to partners, engage in partner counseling, get psychosocial support, experience outreach services, and receive treatment adherence counseling (CDC, 2011). However, it is apparent, given patients` and nurses` responses to this study, that not all of these services are being adequately provided across district clinics. Hence, the development of further strategies to reduce LTFU is vital in this regard.

6.2. Standard intervention models in HIV care

Non-adherence to treatment for HIV diseases has severe consequences. Interrupted treatment may reduce the effectiveness of the treatment and cause drug resistance, which may result in more infections (Azia, Mukumbang, & Van Wyk, 2016). Intervention strategies to improve adherence rates in developing countries such as South Africa are urgently needed

(Azia, et.al. 2016). Below, we will consider which intervention models are appropriate to explore and utilize to improve adherence, both by examining existing literature, and by analyzing whether various models hold promise to improve LTFU in the district through the lens of the study data and findings.

Currently, there are more than 30 psychological theories of behaviour change (Munro, Lewin, Swart, & Volmink, 2007). However, for the purpose of this chapter, the most relevant four theories (IMB, HBM, SAT, SCT) will be used to guide the intervention strategy I will propose to help HIV-positive patients to remain in care and adhere to their HIV medication in the Sekhukhune district. Noteworthy, this study will be the first in this province to utilize existing intervention models to guide strategy selection to help HIV-positive people to remain in care.

These four theories were chosen because each of these models have been tested in practice with positive health benefits (Chang, Choi, Kim, and Song, 2014). These models have been extensively and effectively used in various health behaviour change programmes worldwide. Regardless of their relative efficacy, programmes guided by these models appear to have contributed to achieving permanent positive health outcomes such as remaining in HIV/TB care (Prochaska, & Prochaska, 1999). Particularly, the models outlined below have the potential to both improve our understanding of medication adherence and contribute to the design of more effective interventions to promote adherence to HIV medication in the rural context of Sekhukhune district.

Furthermore, theories such as the health belief model (HBM) and social-cognitive theory (SCT) were chosen because they include a focus on cognitive variables as part of behaviour change (Stroebe, 2000). They further share the assumption that attitudes, beliefs and expectations of future events and outcomes are major determinants of health related behaviour (Gebhard & Maes, 2001). These theories propose that individuals will choose the actions that are likely to lead to positive outcomes. Moreover, IMB was specifically chosen because of its empirical literature showing its effectiveness for behaviour change. For instance, Simoni , Pearson, Pantalone, Marks and Crepaz, (2006) found that giving basic information to patients, and engaging them in discussion about helping them to overcome cognitive barriers were effective in improving adherence.

The specific intervention theories considered as potential contributors to a new strategy to promote ART adherence in the district are: Information Motivation Behaviour Skills Model (IMB); Health Belief Model (HBM); Social Action Theory (SAT), and Social Cognitive Theory (SCT). In the next section, I will demonstrate how each of the selected theories is appropriate in the design of a strategy that will be more effective for tackling specific barriers and promoting treatment adherence and retention in care in a unique cultural setting, Sekhukhune district of the Limpopo Province. The long term goal is to use the data collected during this study to inform a strategy that facilitates ART adherence and reduces LTFU in the district.

6.2.1. Information Motivation Behavioural Skills Model (IMB) to address patient barriers: (difficulty taking time off from work; lack of understanding of ART; denial; feeling well physically; experience of negative side-effects; traditional/religious beliefs).

IMB was developed to promote contraceptive use and prevent HIV transmission. It has since been adapted for designing interventions to promote adherence to ART. This model as proposed by Fisher and Fisher (1992) recognizes three vital constructs, which are information, behavioural skill, and motivation.

Information refers to the basic knowledge about a medical condition such as HIV, and is an essential requirement for behaviour change, but not adequate in isolation. The second component is motivation, including personal attitudes towards adherence; perceived social support for the behaviour; and the patients' perception of how others with the condition might behave. Finally, behavioural skills includes components such as ensuring that the patient has the skills, tools, and strategies to perform the behaviour as well as a sense of self-efficacy, or the belief that they can achieve the behaviour. All these components need to be directly relevant for the desired behaviour to be effective. The next figure highlights the IMB model by (Fisher et al., 2008).

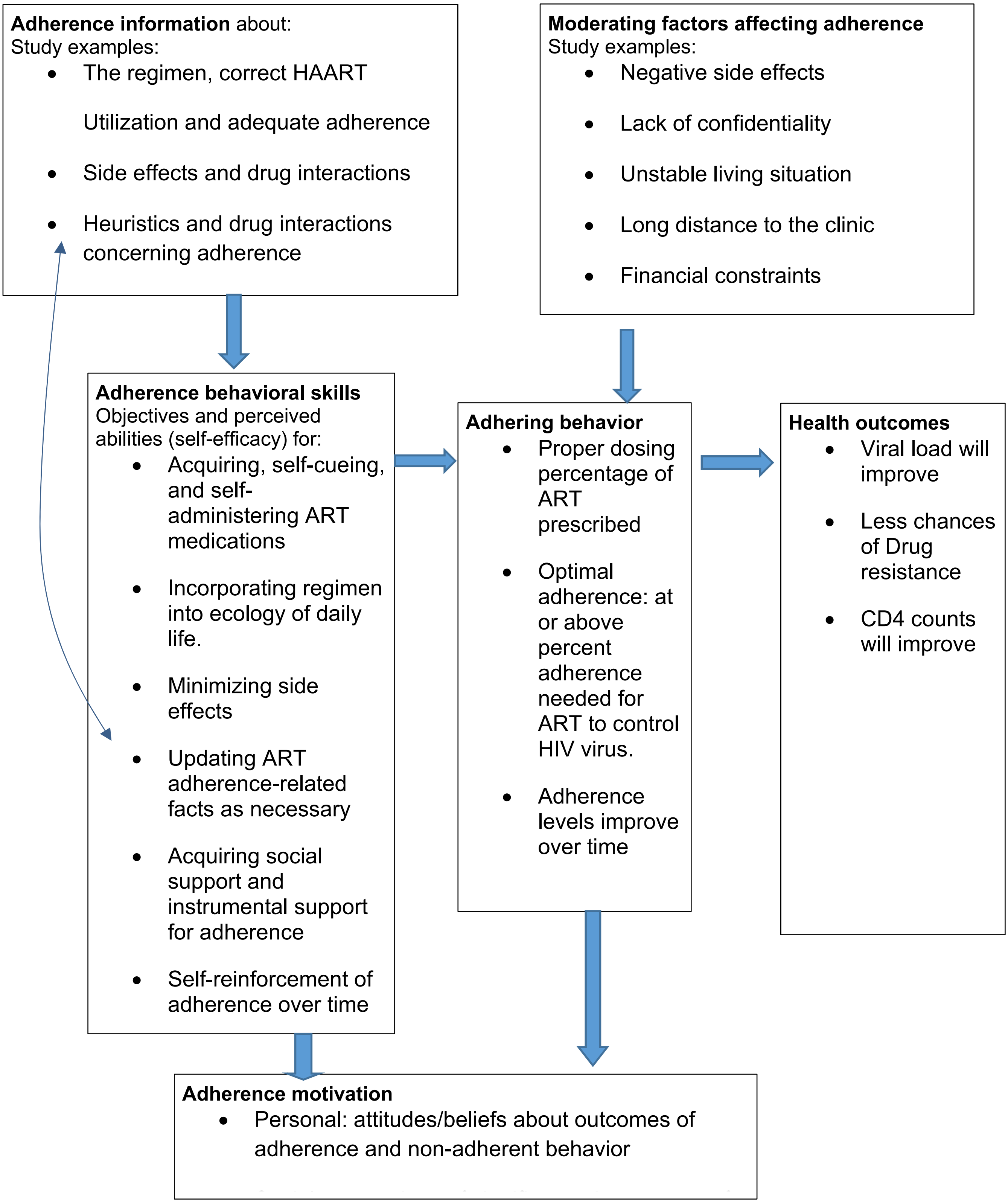


Figure 6. Adapted Information Motivation Behaviour Skills (IMB) Model, (Fisher et al., 2008)

Information, motivation, and behaviour skills are vital in the improvement of ART adherence and retention in care. Interventions using these constructs can address the patient barriers experienced by the patients and help them remain in care. Unfortunately, all the constructs outlined by IMB were shown in this study to be inadequate among patients; hence the IMB model is appropriate for this context. Specifically, there are substantial gaps in information among patients living with HIV. In the current study, concerned patients stated that they did not have sufficient information on either ART or HIV. They reported that they were not provided with most of the information, and as a result they made assumptions about ART and HIV. For instance, one patient assumed that since she was using condoms with her partner, she did not need to take medication anymore. Another patient presumed that ART was for the protection of her unborn baby when she was pregnant and now that she has given birth, she no longer needs medication. Due to lack of correct information and facts, patients further believe myths about HIV or ART. Some patients held the belief that HIV is a result of witchcraft ,and thus they think it can be cured by traditional healers. They confidently reported that HIV medication would be their last resort should the traditional healer fail to cure the HIV virus. These assumptions and myths result in patients' LTFU from HIV care. Patients in the present study further indicated that the reasons they left care is because they had no preparation for the experience of negative side effects in the early stages of taking medication. Without information about the likelihood of and the nature of side effects, they felt that the medication was making them sick, not better, and they stopped taking the medication They further reported that they believed that the side-effects would last as long as they were on the medication. They failed to understand that most ART side effects are predictable, manageable, and short-term.

Some of the nurses verified that due to long queues at the clinics and the fact that they are under-staffed, they do not spend enough time with the patients during consultation, leading to a gap in patient knowledge about most of the facts relating to HIV/ART. Frustrated nurses reported that should they spend time on health education about ART or HIV care generally, they will spend too much time with patients with HIV, leaving others not attended to. They report that providing medication to patients with HIV is more important that educating them about health issues. In sum, this information gap was reported by both patients and nurses, and shows that patients are not well informed about 1) the importance of ART, 2) disadvantages of defaulting, 3) predictability and manageability of possible side effects, 4) how HIV/ART works, and 5) the difference between facts and myths about HIV and ART. This knowledge gap contributes to low motivation among patients to stay in care, certainly in part caused by their lack of appropriate knowledge on ART and HIV. Nurses whose clinics have achieved low rates of LTFU further pointed out that providing patients with all the relevant information has been the key to retaining their patients in care. These nurses highlighted health education both at the waiting area and consultation rooms as strategies that help them to achieve low LTFU. Successful nurses reported that patients' health education should be more comprehensive and conducted in the consultation rooms because patients need privacy to feel comfortable to ask questions when they do not understand. They mentioned that in the waiting room, patients are shy to ask questions in the presence of everyone hence they prefer health education to be emphasized in the consultation rooms. Therefore, it is clear that there is an urgent need for nurses to provide correct ART adherence and HIV information at the clinics to enable patients to be well informed about correct intake of ART, the importance of adherence, possible side effects, as well as myths and facts on ART and HIV. Since nurses whose clinics have the highest LTFU rate reported that they are understaffed and cannot spend time on health education during consultation, they can provide general health education on HIV/ART in the waiting area rather than individually, and could provide private health education on days when the clinic is not busy. This will give patients the opportunity to ask questions, which could prevent patients from dropping out of care due to lack of adequate information. However, optimally, even these nurses should be encouraged and incentivized to provide the same kind of private education in consultation rooms as is done by nurses with low LTFU.

The study also identified gaps in motivation. Patients stated that they did not feel motivated to stay in care. They reported that they did not have adequate social support from either nurses, intimate partners or family members. They specifically reported that nurses were not welcoming and did not give them time during consultation to ask any questions. Some also stated that if family members/intimate partners could show them support such as assisting with transport fare, they would feel supported and therefore motivated to adhere. Patients wished that the nurses could be welcoming and provide them with necessary information, so that they would be able to ask questions and be motivated to return to the clinic for their next visit. Patients clearly recognised motivation as the key construct needing to improve to encourage them to remain in care. Patients also mentioned that peer/partner support could motivate them to be adherent. Some of the clinics did not have peer support groups, and patients clearly stated the need for support from other HIV-positive people. They passionately discussed how this would help them not to feel alone in this journey and therefore motivated to stay in care. Patients also reported that they prefered encouragement to remain in care from nurses during home visits. Patients emphasized that this would make them feel cared for.

The nurses whose clinics have low LTFU rate illustrated that providing social support to their patients increased retention in HIV care over the years. Social support provided to patients motivated them to stay in care. Nurses stated that, as clinic managers, they oversee the functioning of the clinic, but if patient needs must be addressed, they put their responsibilities as managers on hold. Instead of completing administrative work, they go in the village to trace the patients who have missed their appointment (two or more) before they become LTFU. During these home visits, they encourage and motivate the patients to return to the clinic. Nurses reported that in all cases, all the visited patients returned to care and are now adherent but not if the home based carers traced the patients without success. Nurses take responsibility to trace the patients because patients report they have no trust in the home based carers and do not welcome them in their homes. The nurses explained that peer support groups also help their patients to feel motivated to stay in care. This helps patients realise that they are not alone in this journey and that they have support from peers who are also HIV–positive. The nurses explained that patients who have family support are able to send their family members to collect medication on their behalf if they are for any reason unable to. Nurses believed that this type of social support helps to retain patients in care and take ART consistently.

However, even if patients have the information and motivation they need, patients will not necessarily develop the relevant behavioural skills to overcome barriers experienced on their own. One could hope that patients would develop the confidence to remain in care regardless of the challenges experienced. The needed skills include: 1) those related to medication adherence, such as forecasting when medications will run out, taking medications on a routine schedule and keeping track of doses taken, proactively seeking clinic visits to refill medications and to assess clinical progress, and 2) those skills needed to help them get appropriate social support, whether from peers with HIV, family, or community members, or clinic care providers. Currently, skills building in these 2 areas is not provided. If skills building in these areas were provided, patient adherence to HIV care and retention in care would be maximized, which will result in positive health outcomes such as suppressed viral load and high CD4 count, and in turn, to live long healthy lives.

The following quotations illustrate the need to equip the patients with correct information on ART (side-effects, advantages of ART) and HIV/ART facts as the IMB demonstrates Patients reported how they dropped out of care due to experience of side-effects. They said:

“After taking the medication I felt nauseous, therefore I discontinued taking the medication because it made me feel sick”.

“The medication made me feel dizzy, it was too much to bear so I stopped taking the medication”.

This implies that nurses should provide patients with adequate information on expecting and coping with transient side-effects ahead of time during initiation of ART. In this way, patients will not be surprised when they experience these side-effects. They will be conscious and know how to minimize the side-effects and make them bearable.

Another vital reason to furnish patients with relevant information is because patients believed that HIV can be cured by either traditional healers or pastors from church. Here is what one of the patients said:

“I am using traditional medication to fight what I have in my body; the traditional medicine will clean my blood then I will be HIV free”.

Nurses said:

“Some of the patients are ensured by their pastors at church that God will heal their HIV”.

“Patients tell us that they were instructed by a traditional healer to stop taking their HIV medication and focus only on the traditional medication”.

This implies that patients should be educated on the importance of ART with emphasis that HIV cannot be cured, but can be managed with ART. Community outreach programs to educate community traditional healers and pastors on HIV symptoms and the importance of ART may help them to be more knowledgeable on HIV and ART. They can therefore refer patients with HIV to the clinics. Above all, it is clear that all the IMB model constructs are vital for ART adherence and if taken into careful consideration during the intervention. There is a clear need to utilize this evidence based model to facilitate possible behavioural change for HIV-positive patients who have defaulted from care in the Sekhukhune district.

6.2.1.1. Literature review on efficacy of interventions based on IMB model

The effectiveness of IMB-based interventions to promote various health behaviour changes has been widely researched. There is sufficient literature which demonstrates the impact of IMB-informed interventions on health behaviour change in the specific area of ART adherence. The following section outlines selected research studies that proves the efficacy of IMB-based interventions in promoting ART adherence among HIV-positive patients.

A South African study was conducted by Peltzer, Ramlagan, Jones, Weis, Fomundam, and Chanetsa (2012) to assess the effectiveness of lay health workers who lead structured group intervention to improve adherence to ART at a district hospital in KwaZulu-Natal. The results showed that lay health workers enhanced the adherence information component of the medication adherence. Adherence knowledge increased significantly, and there was a significant improvement in ART adherence. Adherence information led to ART adherence. Another South African study conducted at 57 public health care facilities evaluated the effect of a community-based adherence support programs on ART outcomes (Fatti, Meintjies, Shea, Eley, & Grimwood, 2012). The community-based adherence support programs involved lay community health workers doing weekly home visits, supervised the taking of pills, and provided individual counseling with patients regarding adherence. The study revealed that LTFU was lower in groups that received community based adherence support and that these patients had better ART outcomes.

Unfortunately, it is unclear if the use of lay health workers to provide adherence education and counseling could work in this district considering the lack of trust patients have in lay heath workers (regarded as home based care workers in the Sekhukhune district). Patients indicated that home based care workers do not keep their health issues confidential, and therefore they do not wish to interact with them in any manner. However, if home based care workers could be better trained and continuously receive in-service training on ethics, especially confidentiality, patients might become open to interact with them. Another alternative would be for nurses to facilitate the delivery of adherence information as well as adherence counseling. This may work more effectively because patients trust nurses more than home based care workers in the Sekhukhune district.

A Nigerian study investigated the effect of adherence counseling on patients` adherence to ART. At post-intervention, 76.9% of the intervention group and 55% of the control group achieved adherence. Adherence counseling was facilitated by nurses. The study found that patients trusted the nurses and believed that adherence could be achieved if they receive adherence counseling provided by nurses during their clinic visits (Maduka, & Tobin-West, 2013).

A related systematic review was conducted in Korea by Chang, et.al. (2014) on the information-motivation-behavioral skills (IMB) model. The main aim was to investigate specific intervention strategies that focus on information, motivation, and behavioral skills and to evaluate their effectiveness for people with chronic diseases. The most frequently used intervention strategies were instructional pamphlets for the information construct, motivational interviewing techniques for the motivation construct, and instruction or role playing for the behavioral skills construct. The results showed that most studies reported significant behavioral changes at the first post-intervention assessment. Therefore, the results of the review revealed that IMB model has the potential to yield efficacious behavioural interventions.

The IMB model seems to apply to many of the barriers found in my study. Both information and motivation strategies from IMB model should be considered for this district because many study participants had low levels of education and some of them cannot read nor write. Therefore, for the information construct, instructional pamphlets alone are not appropriate for use in this study setting. For example, most patients will be unable to comprehend the message on the pamphlets on their own. Therefore, informational pamphlets should be used only as a visual tool to engage patients in a helpful conversation with nurses. During information provision, nurses should motivate patients to stay in care using a non-judgmental and respectful conversational approach. During this conversation, the nurse should use the elicit-provide-elicit approach which involves first finding out what the patient already knows, correcting any misunderstandings, filling in gaps in knowledge, and last checking how the information shared is being received and interpreted by the patients (Miller and Rollnick, 2012).Throughout this process, nurses should also engage patients in the process of motivating them to stay in care. For example, if patients have a perception that HIV can be cured by traditional medication, nurses can provide them with accurate information in a respectful manner. The information provided may include the fact that HIV cannot be cured by any medication(traditional/western) and to explain the need for lifelong adherence to ART. If nurses use such a motivational interviewing approach, patients will be free to express their concerns and to ask the nurse for the information they need. For the behavioral construct of the IMB, role playing may also be feasible, especially for those clinics that have peer supporters. Patients can role play with the peer supporters to practice and improve their behavioural skills such as planning doses, creating reminders about medication pickups, and recording medication taking daily. HIV-positive patients also feel more comfortable when talking with other HIV-positive people who can help them to feel supported and less lonely. This could address the lack of social support that was noted as a patient need by nurses.

A number of IMB studies have shown the model to be useful in promoting better HIV care. Specific to ART adherence, a U.S. study assessed the determinants of ART adherence in a sample of 149 HIV-positive patients. The results indicated that accurate knowledge about ART was correlated with personal and social motivation. The results also demonstrated that being better informed, socially supported, and perceiving fewer negative consequences of adherence were independently related to stronger behavioral skills for taking medications, which in turn was associated with self-reported adherence (Amico, et.al., 2009)

Similarly, in a study of 109 HIV-positive patients testing the IMB model for ART adherence theory (Horvath, Smolenski, & Amico, 2014), the relationships proposed by the IMB Model of ART Adherence were partially confirmed. Information did not demonstrate significant relations to either motivation or behavioral skills, nor did it directly associate with adherence. As predicted by the model, however, behavioral skills had a direct association with all measures of self-reported adherence, and motivation was associated with behavioral skills (Torija, Va´zquez, Montijo, & Romo, 2015). Similarly, Horvath and colleagues investigated whether the IMB model is a useful predictive model of ART adherence among PLWH who were primarily recruited in out-of-HIV-care settings. Path models were used to assess the fit of a saturated versus fully mediated IMB model of adherence. All IMB constructs were associated with adherence as predicted by the theory (Horvath, Smolenski, & Amico, 2014).

Kalichman, Cherry, and Cain, (2005) pilot tested a brief HIV treatment adherence improvement counseling intervention for people with lower health literacy. Guided by the IMB, the investigators designed an intervention based on health education principles for lower literacy populations, and formative research. The intervention was a nurse-delivered HIV treatment adherence intervention. Results from a pilot test with 30 HIV-positive men and women with lower health literacy showed that the intervention increased HIV/AIDS knowledge, intentions to improve adherence, and self-efficacy for adhering to medications. Participants exposed to the intervention also showed improvement in medication adherence. These participants' literacy characteristics may be similar to the literacy of the patients in this study, who also have lower literacy levels. This study demonstrated that a nurse-delivered intervention can improve adherence even among patients with low level of education.

The above outlined literature demonstrates that these three constructs (information, motivation and behavioral skills) work well together and not independently from one another to promote ART adherence. The IMB model is the basis of the strategy I will propose to improve ART adherence and retention in care. Patients will be provided with information and motivation they need by the nurses and peer supporters to help them develop behavioural skills they need to adhere to ART and remain in HIV care. This strategy will require nurses and peer supporters to provide patients with necessary information in a more engaging way and motivate them to take action on behaviour change. This is feasible for the current study population considering that many patients reported that they are more comfortable engaging with the nurses and peer supporters than with community home based carers. The nurse should ensure privacy so that patients will engage and ask questions as needed. Though a majority of patients in the study emphasized their preference for privacy, helpful information can also be delivered in the patients` waiting rooms. A combination of engaging private consultation and more general education and information provision could promote information, motivation and behavioural skills development.

6.2.2. Social Action Theory (SAT) to address structural barriers

(long distance to the clinic; lack of funds to travel to the clinic; disability grants). Social action theory has been indicated by various scholars to be effective in improving ART adherence hence I chose it to guide me on how address stipulated structural barriers to improve ART adherence in the district of Sekhukhune.

Social action theory focuses on behaviour change and social support that can assist in fostering and maintaining that change (Mukumbang, Van Belle, Marchal, & van Wyk, 2017). Social action theory is appropriate to minimize structural barriers experienced by HIV-positive patients. This theory is also relevant to improving ART adherence in this study setting because of its ability to identify and eliminate factors that contribute to negative health behaviours, which are detrimental to good health and introduce positive health behaviours, which, in turn, will enhance good health (Reynolds, et al., 2010, Ewart, 2009). Social Action Theory (SAT) further suggests the need to expand individually-focused concepts by including inter-dependence with others as a determinant of continued behaviour change. Below is a figure demonstrating Social Action Theory (SAT).

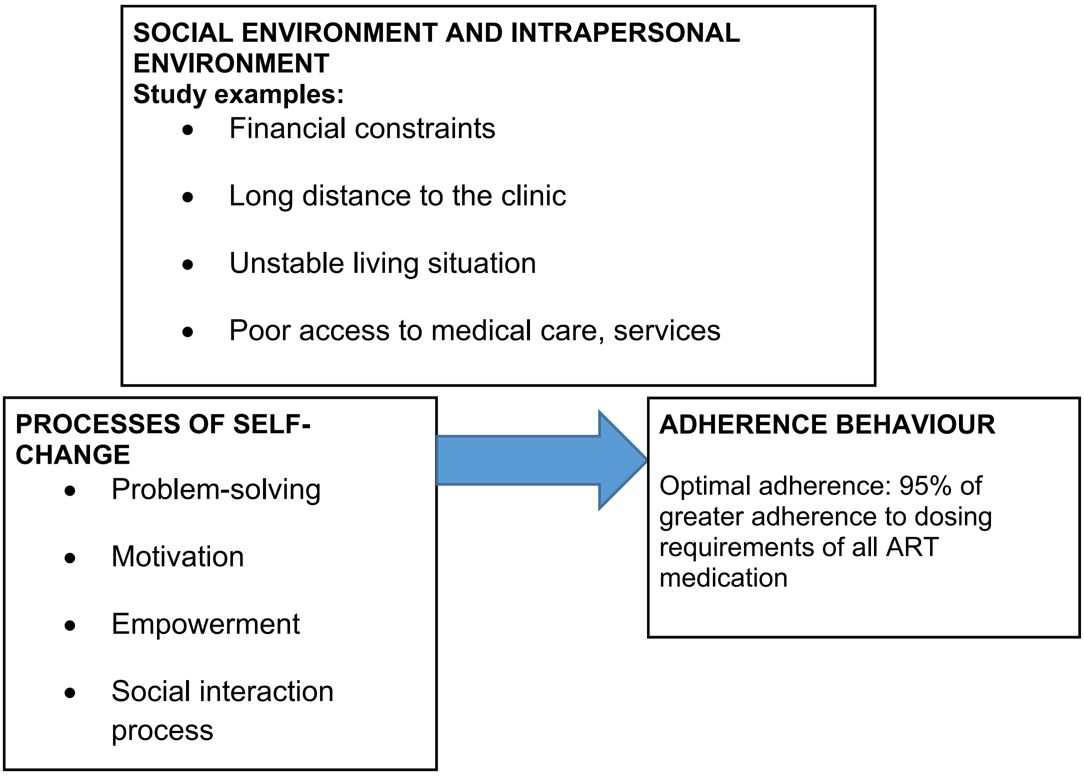


Figure 7: Adapted Conceptualization of the Social Action Theory for ART adherence. Obtained from Ewart (2009).

Unfortunately, in the present study, both social support and inter-dependence with others are challenges for the study respondents. Patients stated that they do not have sufficient social support to encourage them to adhere to their medication, and interdependence with others is non-existent. Patients reported that due to their unemployment status, they sometimes don’t have money to travel to the clinic and would appreciate financial support from their families such as transport fare to enable them to travel to the clinic for their medication refills.

Some of the patients prefer attending clinics further from their village to due to lack of support from the nurses in clinics nearer to them. Patients explained that they do not get the support they need from the nurses at the local clinic. Consequently, they opt for far distant clinics with the hope to receive better support. Therefore, less optimal nurse attitudes lead them to experience barriers such as long distance to the clinic and lack of enough funds to travel to the clinic. Patients further stated that they would be grateful to receive emotional support from nurses and family members. They stated that this support would encourage them to stay in care. Moreover, nurses reported their observations that sometimes, patients` unemployment status and non-existent social support (financial support) from their family and friends, leads them to dropping out of care so that they will get weak and sicker in order to qualify for a disability grant. Nurses think that some patients see this as a solution to their financial problems.

According to SAT, several elements of a strategy for the district are suggested. For instance, in the area of instrumental support, patients can reduce their financial barrier by replacing taking a taxi to the clinic with taking a bus to reduce transport costs. The family member may also offer support by assisting the patient to find a job to avoid depending on a disability grant for survival. In the area of social support, patient could get a ride from neighbours, family member or friends if they are willing to offer such support. A more efficient way to eliminate long distant travel to the clinic would be to educate nurses at local clinics to offer the necessary social support to encourage patients to remain in care. In fact nurses from clinics with low rates of LTFU reported that providing sufficient social support to their patients has encouraged their patients to stay in care for decades. Nurses also reported family support as an important element to retention in care.

One intervention guided by the SAT to improve adherence to ART was a brief intervention and aimed at improving patients' adherence by addressing their self-regulation capabilities and the larger social environmental context. This intervention fostered support for adherence from a relationship partner to tackle structural barriers and improve adherence by encouraging social support from the partner (Remien, et.al., 2005). This intervention can be applicable to those who have a partner. Patients believed that partner support is essential to help them adhere to their medication, and they wished they had the courage to disclose to their partners without fear of being rejected. However, some patients in the current study did not have intimate partner support. Many patients did not disclose to their partners due to fear of rejection. This might be the reason their partners could not offer support. Therefore, one part of the strategy might be for nurses to encourage appropriate disclosure during health education sessions. This may help patients to secure social support from their partners to overcome barriers and improve adherence. Social interaction processes between the patient and health care providers and with significant others are important elements in the self-change processes. The statements below demonstrate the need for social support and financial support to enhance retention in care as per SAT. One of the patients said:

"I stay far away from the clinic and at times I cannot afford to transport fare to the clinic, that is the main reason I stopped going for my medication refills".

The following statement shows that in-service training on ethics is essential to avoid LTFU in the clinics. Some patients opt to go for medication refills at other clinics, which are mostly far from their homes due to lack of support and confidentiality from the nurses in their local clinics. The patient said:

"I will never go for my medication refills in the clinic nearer to my village, the nurses and the HBCs there gossip about our HIV status instead of giving us support, so I will rather go to a faraway clinic where I will receive the support I need" .

This suggests that nurses and home based carers need continuous in-service training on ethics especially confidentiality and respect for patients to ensure that they are constantly reminded that patients information should remain confidential at all times. Confidentiality and respect will give patients courage to stay in care since they would be assured that no one will know their health related issues.

The following statements demonstrate that patients acknowledges that partner support will encourage them to adhere to their medication; hence, it is vital for nurses to educate patients on the importance of disclosing to people they trust. The patients said:

"I wish my husband can support me emotionally, then I would not have to hide my medication all the time"
"After disclosing my HIV status I would like him to support me so that I take my medication even in his presence, perhaps he can remind me to take the medication if I forget".

This implies that patients do not get the necessary support they need from their partners. They are afraid that after disclosing they will be stigmatized and experience more discrimination. They do not have the confidence to continue treatment if they were to experience discrimination following disclosure. They are also not encouraged to disclose by nurses. Nurses should encourage the patients during health education and clearly outline the advantages and disadvantages of disclosing. One advantage might be that there is a great possibility to receive support from your loved ones after disclosing to them. Nurses could teach patient conversational skills for disclosure through role modeling. Nurses whose clinics have low rate of LTFU highlighted how they support their patients to achieve low rates of LTFU:

"Regardless of the long queue in the clinic, we do not rush our patients, we give them enough time during consultation to listen to our health talk and ask questions".

'We offer sufficient emotional support for our patients hence they never miss their appointment".

This shows that emotional support is essential to retain patients in care. Nurses who have low rates of LTFU in their clinics take time engaging with the patients in respectful ways. This encourages patients to remain in care and to be adherent to their medication. The patients are able to stay in care because they feel encouraged and respected by the nurses during health talk in the consultation room when they come to collect their medication.

6.2.2.1. Literature review on the efficacy of SAT in health behaviour change

Evidence for this recommendation was provided by a randomized controlled trial of a couple intervention that improved medication adherence among ethnically diverse, relatively poor patients in an inner-city (New York City) clinic setting by including their uninfected primary partners in adherence counseling and support sessions (Remien, et.al., 2005).This strategy could be adapted in the Sekhukhune district because South Africa already has a policy of involving treatment support partners, often referred to as “treatment buddies” in the initiation of ART for eligible patients. This approach is already recommended for adaptation in the South African context. (Mukumbang, Van Belle, Marchal, & van Wyk, 2017). Relatedly, a South African study found that disclosure has a positive impact on adherence. The study found that those participants who have disclosed were supported by family members and adhered to their medication (Skhosana, Struthers, Gray, & McIntyre, 2009). By encouraging appropriate disclosure, this positive outcome can also materialize among patients in the Sekhukhune district. A similar South African study found that partner support has a positive influence on adherence, the support provided by partners included emotional, informational support, along with intimacy and commitment. These results show that primary partners are important pillars of support for ART adherence especially in the context of high unemployment and poverty (Conroy, Leddy, Johnson, Ngubane, Van Rooyen, & Darbes, 2017).

A Malawian study also found that one of the primary facilitators for retention in HIV care was the existence of a strong support system, including treatment supporters who offered treatment-related encouragement and assisted with medication pickups. Most had disclosed to more than one person, in order to ensure help would be available when needed. For women who were in relationships, an important aspect of their support system was having a supportive husband or partner. Partners supported women’s retention and adherence by motivating them to start taking the prescribed ARVs, reminding them to take their drugs daily, and assisting them financially to remain in care including providing transport money (Gugsa, Potter, Tweya, & Phiri, 2017).

Additionally, a Ugandan study found that instrumental support in the form of goods or services facilitated adherence by helping patients take or pick up their medications, as well as by alleviating daily tasks to allow patients to attend the clinic (Rouhani, O'Laughlin, Faustin, & Ware, 2017). Lastly, a South African study investigated the relationship between social support and ART adherence. The results showed that social support had both direct and indirect relationships with ART adherence (Kekwaletswe, Jordaan, Nkosi, & Morojele, 2017).

Thus, all the above studies found that inter-dependence with others and social support (emotional/ financial) played a vital role in medication adherence and remaining in care. If these are present, patients are more able to eliminate barriers and access the clinic for medication refills. As a result, they remain in care and adhere to their medication, improving health outcomes such as viral load suppression and achieving overall good health while living with HIV (the overall goal). Taking into consideration that all participants in the current study were unemployed, financial support from family members or intimate partner especially for transport fare seems important. In a situation where family members/intimate partner are unemployed, the best they can offer is emotional support (reminding patients to take medication, medication pick up, or cheering them up). So, SAT recommends that patients receive social support , whether instrumental or emotional support, to be able to stay in care and adhere to their ART.

6.2.3. Health Belief Model (HBM) to address the Psychosocial barriers (fear to disclose ones HIV status to partners; fear of HIV stigma and discrimination). These psychosocial barriers were described by patients as obstacles that continue to discourage them to stay in care. As a result, a solution to these obstructions should be outlined. Therefore, below is detailed information on how HBM will be effective in addressing the stipulated psychosocial barriers to promote ART adherence, and shows support from the literature that entails HBM's efficacy to improve ART adherence.

The HBM is a cognitive interpersonal approach that views humans as rational beings who behave in certain ways to minimize what they perceive as threats (e.g., non-adherence to medication) and enhance what are perceived as benefits (e.g., adherence to ART). This model is composed of several interactive states of belief, which collectively affect ART adherence. This model has core assumptions indicating what should be addressed:

- **Perceived susceptibility**, which refers to one's opinion of chances of getting a condition. Patients in the present study did not understand that non-adherence makes them vulnerable to opportunistic infections which might lead to death. They were also not knowledgeable that unprotected sexual intercourse may cause re-infections, which put their health at risk. Instead, they defaulted from care and continued having unprotected sex. They were generally not well informed about the disadvantages/dangers of dropping out of care.

According to HBM, in this study, if HIV-positive defaulters for example, perceive themselves as being at high risk of getting opportunistic infections and possibly dying from those infections, they are more likely to be adherent to their medication and remain in care. As a result, it is important for patients to have a clear understanding of the chances of getting sick if they are not adherent to their medication. It is also important for patients in the study to know the dangers of engaging in unprotected sex.

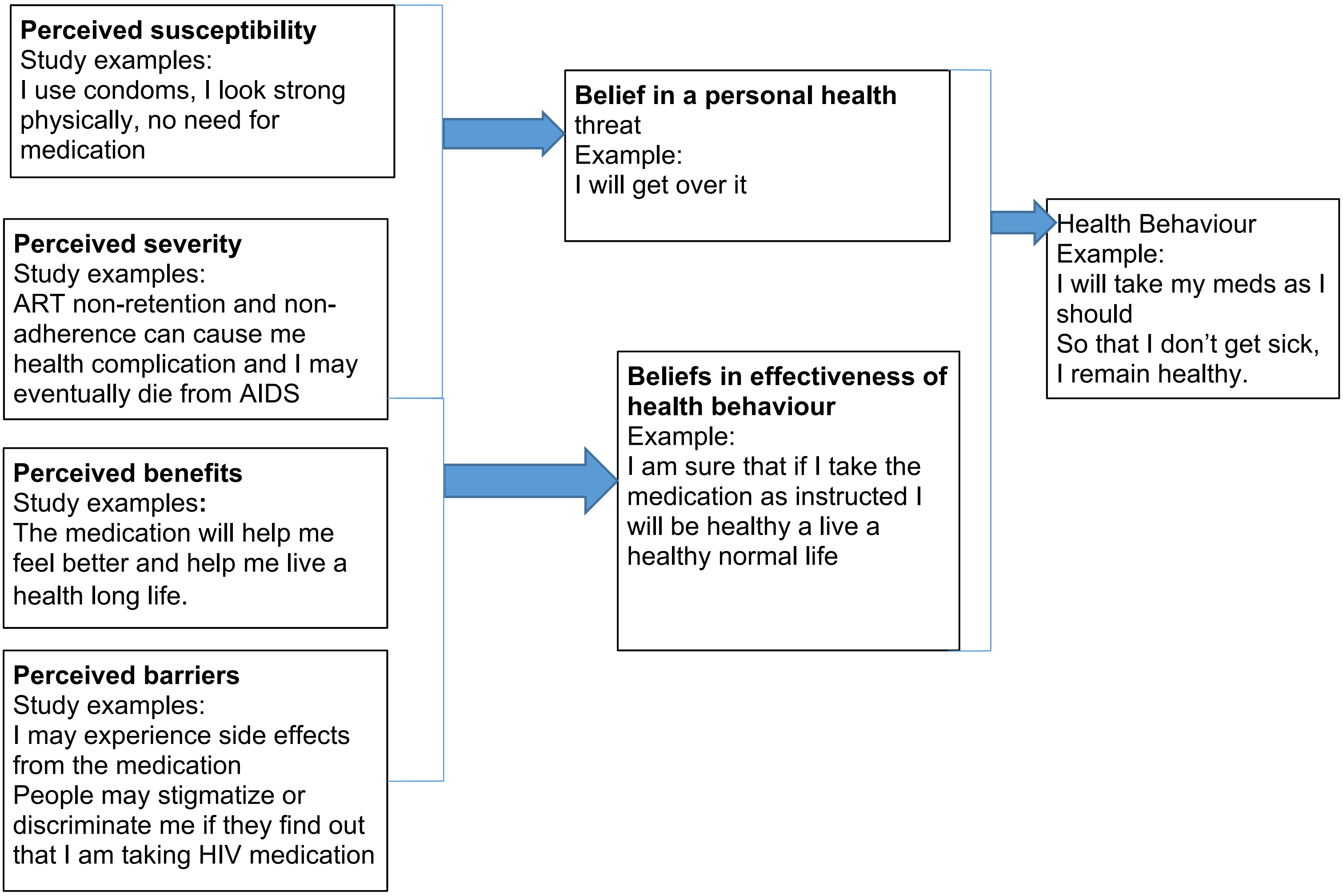
- **Perceived severity,** this means one's opinion of how serious a condition and its consequences are. Sadly, most of the patients in the study do not understand the seriousness and consequences of non- retention in care. Patients are clueless about the consequences of not taking their medication consistently. They do not understand that defaulting from care puts their health at risk. In this study context, this implies that if patients have the opinion that non-adherence and defaulting from care can result in serious health complications (such as virological failure, TB, AIDS); they will take responsible health actions (remaining in care and consistently take HIV medication). With this knowledge patients may also refrain from engaging in unprotected sex to avoid re-infections or infecting others.
- **Perceived benefits**, refers to one's belief in the efficacy of the advised action to reduce risk or seriousness of the impact. In this study, majority of the patients are unaware of the positive advantages of staying in care, hence they defaulted. They have no idea that ART can save their lives. Here, as per HBM, patients have a positive expectation that by taking a recommended action, they will have positive health outcomes. Patients also have an understanding that HIV medication adherence can help them avoid health complications. At this stage, they further recognise that retaining in care and adhering to the medication, as recommended by health providers, results in positive benefits such as living healthy long lives like everyone.

Some of the patients demonstrated an understanding of the benefits of adherence and staying in care. They pointed out that they were aware of the positive health benefits of staying in HIV care. They said that they stopped taking their medication because of fear of being stigmatized and discriminated in the community and not because of lack of knowledge on HIV and ART. So this shows that knowledge alone about benefits of medication adherence is not enough to keep patients in care. In addition to knowledge on benefits of ART, patients should have the self-efficacy to remain in care and adhere to their medication.

Perceived barriers, indicates ones opinion of the tangible and psychological costs (stigma, transportation costs, etc.) of advised action. In the present study, patients are aware of barriers that hinders their non-retention in care. However, I presume that patients at this stage are already aware of adherence benefits, and this will help them to take informed, responsible health related actions that will benefit them regardless of the experienced or perceived barriers. For example, patients may choose to ignore people stigmatizing/discriminating them and focus on living a long healthy life through excellent medication adherence.

- **Self-efficacy.** This component has been added to the HBM on many occasions since the late 1970s, when Bandura first introduced this concept of act or task specific self-confidence. It means the belief in one's ability to execute a given behaviour (Bandura, 1977). This is the most vital assumption to resolve the psychological barriers in this study. There is no one who can assure that HIV-positive people can never be stigmatized and discriminated, hence self-efficacy is of utmost importance . At this point, patients have the confidence that regardless of the perceived barriers such as stigma and discrimination, they will adhere to the medication so that they can experience positive health outcomes (perceived benefits). Most patients in my study did not have the self-efficacy needed to remain in care and to be adherent to their medication, hence they were LTFU due to fear of stigma and discrimination.

All these core elements of HBM work together. For instance, patients need to be educated and well informed on all these assumptions in order for them to understand the dangers of non-adherence, the benefits of adherence, and to have the self confidence that they can adhere to their medication regardless of all these psychological barriers they come across. The figure below summarizes the Health Belief Model:



Perceived susceptibility
Study examples:
I use condoms, I look strong physically, no need for medication

Perceived severity
Study examples:
ART non-retention and non-adherence can cause me health complication and I may eventually die from AIDS

Perceived benefits
Study examples**:**
The medication will help me feel better and help me live a health long life.

Perceived barriers
Study examples:
I may experience side effects from the medication
People may stigmatize or discriminate me if they find out that I am taking HIV medication

Belief in a personal health threat
Example:
I will get over it

Beliefs in effectiveness of health behaviour
Example:
I am sure that if I take the medication as instructed I will be healthy a live a healthy normal life

Health Behaviour
Example:
I will take my meds as I should
So that I don't get sick, I remain healthy.

Figure 8: Adapted Health Belief Model adapted from Hochbaum, Rosenstock and Kegels (1950)

Furthermore, the statements below show that there is a need for a strategy to address all constructs of the **HBM**. For example, if patients perceive dropping out of care as risky, they are more likely to stay in care and be adherent to ART. Below are statements that show that patients in the current study do not see their actions (defaulting from care) as risky, hence they are LTFU.

"I stopped taking my medication because I don't feel sick, I feel healthy".

"I don't use condoms with my boyfriend because, if I demand to use a condom he will be suspicious that I am HIV positive".

"I see no need to continue taking medication because I am practicing safe sex".

"I see no use of taking medication if I am not bed ridden, I am still healthy".

"I don't feel any pains in my body, I don't need medication".

Patients are unaware of the negative consequences of non-adherence and how HIV and ART work. They are not well informed of the benefits of staying in care; hence, they also believe that when one is not bedridden it means they do not need HIV medication. Therefore, nurses should be encouraged to use a motivational interviewing approach to engage with the patients. Nurses should patiently educate the patients about HIV and ART.

Below is what the nurses whose clinics have low LTFU rate said about their patients' understanding of ART benefits:

"My patients are aware that ART is their life. That is why they are still in care".

"The patients in the clinic know that without ART their lives may be shortened hence they never make a mistake of missing their refill appointments".

These shows that if patients are educated their knowledge of HIV and ART will be enhanced. These patients stayed in care and adhered to their treatment because they were well informed and motivated to stat in care.

6.2.3.1. Literature review on the efficiency of HBM in health behaviour change

This model has been recognised as an effective model for promoting numerous positive health behaviours such as adherence to HIV medication. There are several studies on the efficacy of HBM on health behaviour change, especially ART adherence. For instance, a Canadian study found that patients with high mean belief scores reflecting perceived necessity of antiretroviral therapy did better on ART adherence (Gunther, Foisy, Houston, & Hughes, 2014). Similarly, an American study by Kemppainen, Kim-Godwin, Reynolds, and Spencer (2008) found that the majority of the respondents acknowledged the importance of HIV therapies in the management of HIV; 91% of participants agreed that HIV therapies would help control the HIV virus, and 85% agreed that HIV medications would be effective in the management of HIV and were also adherent. In an American qualitative study, beliefs in the effectiveness of medication predicted the best levels of ART adherence. In the absence of beliefs about the benefits of treatment, individuals were unlikely to adhere to treatment (Sayegh, Thaler, Arentoft, et.al., 2016). Aligned with the HBM, the results showed that higher perceived efficacy of treatment levels directly predicted better ART adherence.

Gonzalez, et al. (2007), also showed that necessity beliefs about ART predicted better adherence. Similarly, results of an American study on the relationships between beliefs about medications, health literacy, and self-reported medication adherence found that patients who had negative beliefs about medications, who were <65 years of age, or who had low medication self-efficacy reported low medication adherence (Gatti, Kara, Jacobson, Gazmararian, & Kripalani, 2009). Finally, a systematic review showed that adherence is significantly positively correlated with patients' beliefs in the severity of the disease to be prevented or treated ("disease threat"). This suggest that the objective severity of patients' disease conditions, and their awareness of this severity, could predict their adherence (Dimatteo, Haskard, & Williams, 2007).

The results of the current study show that due to their lack of education on benefits of ART, patients do not understand how ART can help them live healthy, long lives. They also lack understanding of the negative consequences of medication non-adherence and dropping out of care. However, the responses in my study also show that belief/knowledge alone is not enough. Rather, patients should also have the confidence to be adherent regardless of barriers experienced. For instance, there were patients who showed understanding of ART benefits and also believe in the positive health outcome of the medication but were non-adherent because of fear of being stigmatized and discriminated. While studies demonstrated that beliefs about benefits/effectiveness of ART medication predicted high adherence and absence of beliefs predicted non-adherence, it is important to instill more than knowledge about the benefits of ART adherence; patients also need help building their confidence to manage HIV and remain in care.

6.2.4. Social Cognitive Theory (SCT) to address system barriers (unwelcoming and rude behaviour by nurses; lack of confidentiality by nurses and HBCs; patients self-transfer; lack of enough medication). Most of these barriers are out of the patient's control, but, these barriers can be resolved through the guidance of SCT for better ART adherence. Thus, a detailed discussion follows on why SCT is of relevance to address some of the system barriers described by patients in the Sekhukhune district. Literature on the efficacy of SCT in promoting ART adherence among HIV-positive patients worldwide will follow, culminating in recommendations for the district.

SCT was chosen to address the system barriers stipulated in this study. Based on evidence in the literature, SCT is appropriate to tackle the specified obstacles. Consequently, this section will discuss why SCT is the appropriate theory for addressing system barriers in the study context as follows. The next figure outlines the SCT:

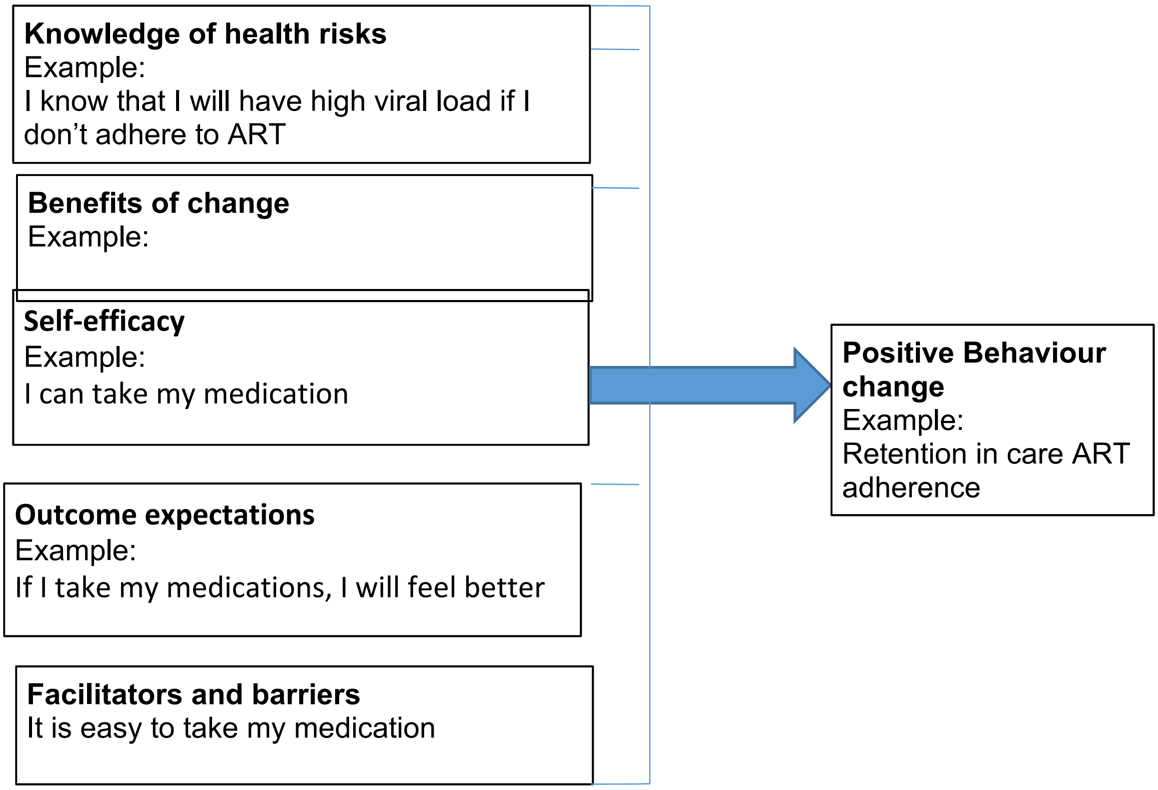


Figure 9: Adapted Social cognitive theory obtained from Bandura (1977)

According to Bandura, although SCT acknowledges that knowledge of health risks and the benefits of treatment are necessary to perform health behaviours, this in itself is not enough. Additional self-influences are necessary to achieve changes that will result in the desired health behaviour; and this concept is called self-efficacy. So, the two cognitive processes that influence behaviour in SCT are called self-efficacy and outcome expectation.

Self-efficacy is a known predictor of health behaviour in patients with chronic medical conditions, and influences adherence to ART. Antiretroviral adherence self-efficacy is an individual's belief in the ability to continue taking antiretroviral therapy (ART) despite the various challenges they may encounter in doing so. It also proposes that positive behaviour change occurs as a result of the person's belief about how capable they are in performing those behaviours that would lead to the desired outcome. As expected, patients in my study did not have the self-efficacy to remain in care and adhere to their medication. Once they received hostile treatment in the clinics, they discontinued care, showing their need to bolster skills of staying in care due to the challenges experienced. In this case, according to SCT, HIV-infected patients on ART with self-efficacy will choose to adhere to their medication if they believe that doing so will result in increased quality of life, regardless of the hostile treatment by nurses. This means that if patients expect that adherence can help them live a healthy, long life, they have a higher possibility of adhering to their treatment (outcome expectation).

This theory further shows that human behaviour is learned. HIV-positive peers also play a crucial role in adherence. It is important to note that HIV is still thought a taboo in the rural Sekhukhune district, so it becomes difficult to witness anything from other HIV-positive patients because they are discreet about their HIV status. Most HIV-positive patients do not want anyone to know that they are HIV-positive, let alone to be ambassadors. However, nurses from clinics with low rate of LTFU have indicated that having peer supporters in their clinics has helped them to retain patients in care. They stated that peer supporters encourage and support other HIV-positive patients to stay in care. Through peer supporters, HIV-positive patients get encouraged as they witness other HIV-positive patients (peer supporters) in care and living healthy lives. Witnessing those peers looking healthy and living normal lives have encouraged many HIV-positive patients to stay in care and to take their medication consistently regardless of all the challenges experienced. Moreover, the peer supporters could also use cognitive and behavioural strategies to empower patients to negotiate problems around ART adherence and to establish supportive relationships, which strengthen patients' ability to adhere; all these would subsequently lead to better adherence and good clinical outcomes.

Moreover, Bandura describes four sources of information that influence self-efficacy; these are performance mastery, vicarious experience, verbal persuasion, and physiological symptoms. Integration of information from one or more different sources is important for the effectiveness of self-efficacy. All of these sources are equally applicable for ART adherence among HIV-positive patients who are on antiretroviral therapy for a prolonged time. All these sources of information are outlined below:

- **Performance mastery**

This refers to knowledge and skill gained through experience and perseverance. This implies that a strategy of teaching patients how to avoid negative self-talk, as well as how to monitor self-defeating thoughts and how to replace them with task-focused ones, will help them avoid hopelessness associated with non-adherence to antiretroviral therapy. Patients in the current study stated that they default from treatment due to impolite behaviour by nurses, this makes them lose interest in visiting the clinic again. Therefore, in this context, patients will learn how to avoid negative self-talk in response to unwelcoming behaviour or lack of confidentiality. They could learn to replace self-defeating thoughts with task-focused thoughts. It is possible that these skills could be instilled by peer supporters. Following this, patients will have the confidence to stay in care and adhere to their medication regardless of the negative treatment at the clinic. None of the clinics that have low rate of LTFU mentioned teaching patients to avoid negative self-talk. This means that this will be something new for all clinics in the district, but it can be successfully carried out by nurses and peer supporters, if they are trained to do so.

- **Vicarious experience**

Vicarious experience occurs when a person observes other people completing a task successfully. This serves as a way of modeling self-efficacy for the observer. This will also be in the form of vicarious reinforcement where ART adherence is being reinforced by seeing another HIV-positive patient being rewarded for it. The only people that HIV-positive patients can observe are peer supporters because they are easily accessible in the clinics. Nurses whose clinics have low rate of LTFU have advocated that their HIV-positive patients witness peer supporters advocating their medication adherence and witness their healthy lives with no or limited opportunistic infections (reward). This helps patients be encouraged and re-enforces their health behaviour (adherence) given the positive health reward (healthy life). Thus , it is safe to assume that even defaulters are more likely to re-engage in care and take their ART consistently if they observe healthy positive outcomes from peer supporters in the community since they no longer visit the clinic. It is notable that not all the clinics in the district have peer supporters. I will encourage the clinic managers to recruit peer supporters as part of their overall intervention strategy.

- **Verbal persuasion**

This strategy usually takes the form of encouragement or discouragement from another person and is the most commonly used self-efficacy approach used by healthcare professionals. It is used to attempt to convince someone that they can succeed at a particular task. Verbal or social persuasion serves to reinforce feelings of self-efficacy when facing the minor failures associated with adherence to ART. This form of support has been shown to result in patients learning new skills and exploring more self-care behaviours. Unfortunately, patients said that nurses do not encourage them in any way, hence they default the moment they see a challenge. They are not convinced that they can successfully adhere to their medication. Furthermore, this will be a difficult task to be administered by nurses since they are said to be rude and impatient. This could, however, be successfully carried out by health professionals with some additional training. So, for this to be a success in the study context where nurses are hostile, nurses may need to receive in-service training on ethics with emphasis on how they communicate respectfully with patients. Then, they can encourage patients to be confident about adhering to their medication even when facing minor challenges and failures. Patients will get verbal persuasion from nurses especially during consultation. Nurses will persuade the patients that they are capable of adhering to the medication and implant confidence in their mind that, regardless of any challenges faced, they can remain in care and adhere to their medication. For those patients who are LTFU, verbal persuasion by peers or home based carers may be useful to enhance their self-efficacy in this regard.

- **Physiological symptoms**

This concept emphasizes that a person's physical reaction to difficult situations can influence how prepared that person feels to handle the situation effectively. It stipulates that a person with high self-efficacy may interpret such physiological symptoms as normal and unrelated to their ability to adhere to therapy. It has been shown that it is a person's belief in the implications of physiological symptoms that alters self-efficacy, and not the physiological response itself. Patients in this study, however, reported that they default due to negative side-effects. Therefore if they become more aware that these effects are natural and temporary, they are more likely to adjust and remain in care. However, because side-effects are not included in the stipulated system factors, proper education about them will be included in the recommended strategy, per the IMB previously discussed.

- **Outcome expectation**

An outcome expectation is the belief that a particular behaviour will result in a specified outcome, and outcomes can be either positive or negative. The SCT suggests that an individual will choose an action that he or she believes will maximize positive outcomes and minimize negative outcomes. Some of the patients in the study mentioned that they do not believe that medication will improve their health since they are under impression that medication is only for bedridden patients.

In this context, if patients are aware that taking the medication consistently results in long healthy lives with limited health complications as compared to someone who is non-adherent, they are likely to remain in care and take their medication as instructed by the health provider. Similarly, those who have already defaulted, if informed about the positive health outcomes that result from taking medication, they will re-engage and adhere. All these sources of information that influence self-efficacy need health providers and peer supporters to be involved in various ways to educate and encourage the patients about all these in order for them to stay in care.

The following statements show the lack of self-efficacy of patients and hostile treatment from nurses, and according to SCT, without self-efficacy, it is hard to adhere to treatment:

“I could not continue taking pills daily because if my family recognize that I am taking HIV medication they will be furious with me”.

“if people can find out that I am taking HIV medication, they will isolate me, they will no longer talk to me and my children”.

“The nurses in the clinic are unwelcoming and unfriendly, I could not take it any further”.

“The nurses are rude, so I did not want to be treated like dirt anymore”.

These statements from patients indicate that they feel unwelcomed at the clinics due to nurses’ rude behaviour. These contribute to their unwillingness to remain in care. Because they lack sufficient knowledge about HIV and ART and behavioural skills, they are afraid to be stigmatized and therefore default from care. These findings show that nurses should strengthen patients’ health education and enhance their behavioural skills to improve their self-efficacy.

Below is what the nurses said about support from peer supporters, they emphasized that it encourages their patients to stay in care

“Peer supporters in our clinics encourage and offer support to other HIV-positive patients and this has really helped us to retain our patients”.
“Patients feel free and encouraged when they talk to peer supporters”.
“Our patients learn that adherence has positive health outcomes from our peer supporters and therefore encouraged to stay in care”.

“When patients witness that the peer supporters are HIV positive but yet look healthy, they become encouraged to stay in care”.

These statements illustrate that peer support groups are important to encourage and motivate patients to adhere to ART. An implication is that other clinics should prioritize recruiting for peer supports to provide emotional support for keeping HIV-positive patients in care.

Finally, patients made suggestions that may motivate them to stay in care and adhere to their ART medications. This shows that patients are willing to accept help. One patient said:

“I think nurses should make home visits and talk to us about the importance of retaining in care, it really helps talking to a professional, it gives hope”.

Patients wish for support from nurses, and they need courage from them as knowledgeable professionals. Nurses should try and divide their time to make home visits for HIV-positive patients who are not adherent.

6.2.4.1. Literature on the efficacy of SCT in health behaviour change

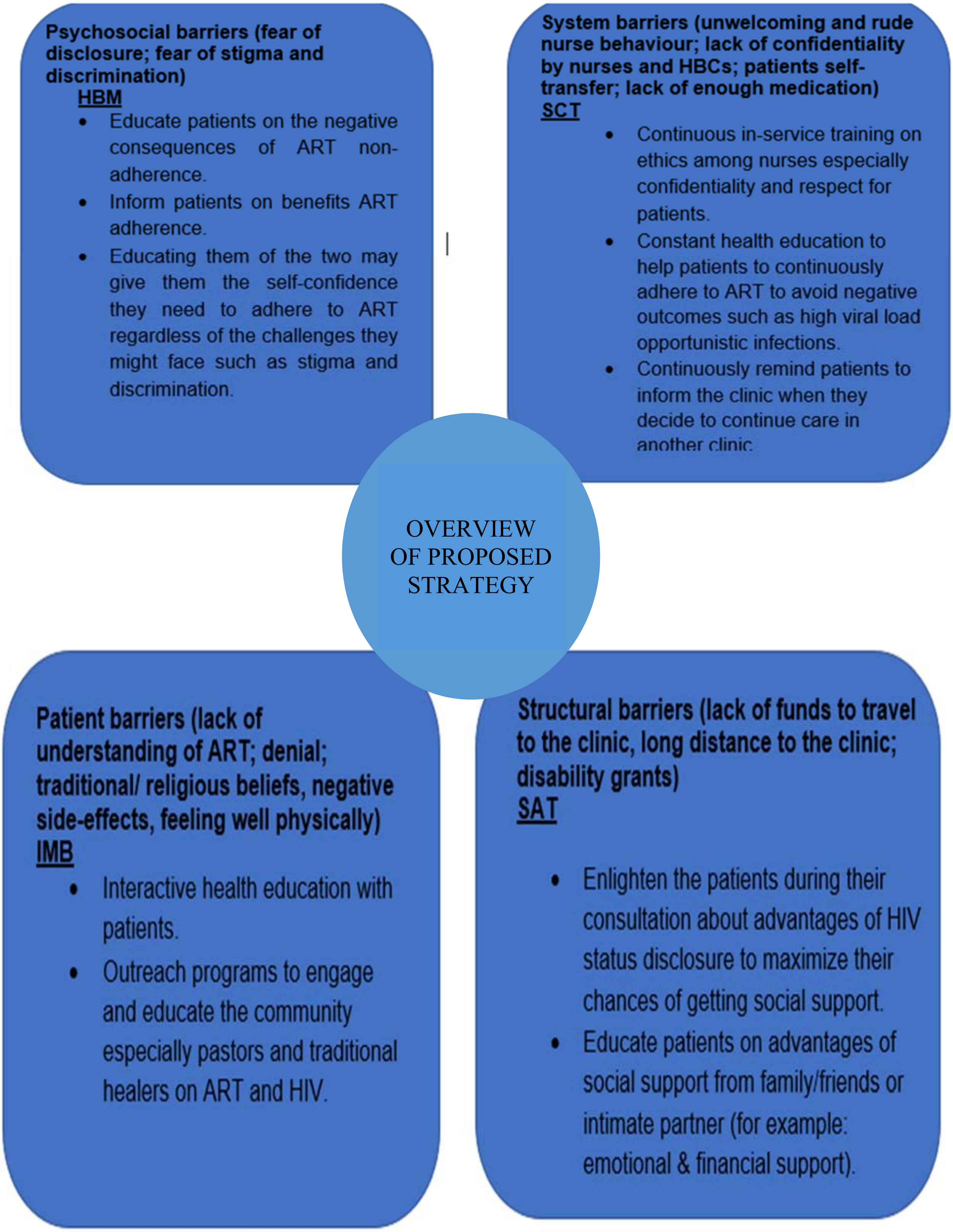
Social Cognitive Theory (SCT) has been proven to have a positive impact on health behaviour change. The literature below shows how SCT can be efficacious in improving HIV medication adherence.

An Indian study investigated whether social support, self-efficacy, and finding benefits in disease are related to physical functioning and adherence to antiretroviral medication among HIV-positive people.The results of the analysis showed that finding benefits and self-efficacy were directly related to adherence (Luszczynska, et.al., 2007). Similarly, results from a Chinese study by Li, et.al. (2011) suggest that self-efficacy is an important predictor for medication adherence. In another study, results revealed that low self- efficacy and lack of perceived treatment utility predicted poor adherence, and self-efficacy predicted adherence among younger individuals (Barclay, et. al., 2007). Similar findings were reported in a study conducted by Cha, Erlen, Kim, and Caruthers (2008), which showed that self-efficacy fully mediated the prediction of self-reported medication adherence.

These studies found self-efficacy to be vital in ART adherence. Self-efficacy can be instilled in HIV-positive patients by both nurses and peer supporters. This can be done during health education/health talk and motivation in the clinics. All the clinics in the district could have the capacity to carry this out. If the clinics adopt this strategy, patients will have the confidence and the capacity they need to remain in care and adhere to their ART.

6.3. Proposed strategy

This section will guide the clinics on how to address specific barriers experienced by patients to promote treatment adherence and retention in care in a unique cultural setting, the Sekhukhune district of the Limpopo Province. The proposed strategy clearly indicate what can be done to address various categories of barriers such as patients' barriers and system barriers. It further outlines which of the psychological models guided such strategy. If these strategies are implemented accurately, the quality of life for HIV-positive patients will improve. Figure 8 outlines the overview of the strategy proposed and the sub-sequent figures outline the detailed strategy as guided by various theories.



Psychosocial barriers (fear of disclosure; fear of stigma and discrimination)

HBM

- Educate patients on the negative consequences of ART non-adherence.
- Inform patients on benefits ART adherence.
- Educating them of the two may give them the self-confidence they need to adhere to ART regardless of the challenges they might face such as stigma and discrimination.

System barriers (unwelcoming and rude nurse behaviour; lack of confidentiality by nurses and HBCs; patients self-transfer; lack of enough medication)

SCT

- Continuous in-service training on ethics among nurses especially confidentiality and respect for patients.
- Constant health education to help patients to continuously adhere to ART to avoid negative outcomes such as high viral load opportunistic infections.
- Continuously remind patients to inform the clinic when they decide to continue care in another clinic.

OVERVIEW OF PROPOSED STRATEGY

Patient barriers (lack of understanding of ART; denial; traditional/ religious beliefs, negative side-effects, feeling well physically)

IMB

- Interactive health education with patients.
- Outreach programs to engage and educate the community especially pastors and traditional healers on ART and HIV.

Structural barriers (lack of funds to travel to the clinic, long distance to the clinic; disability grants)

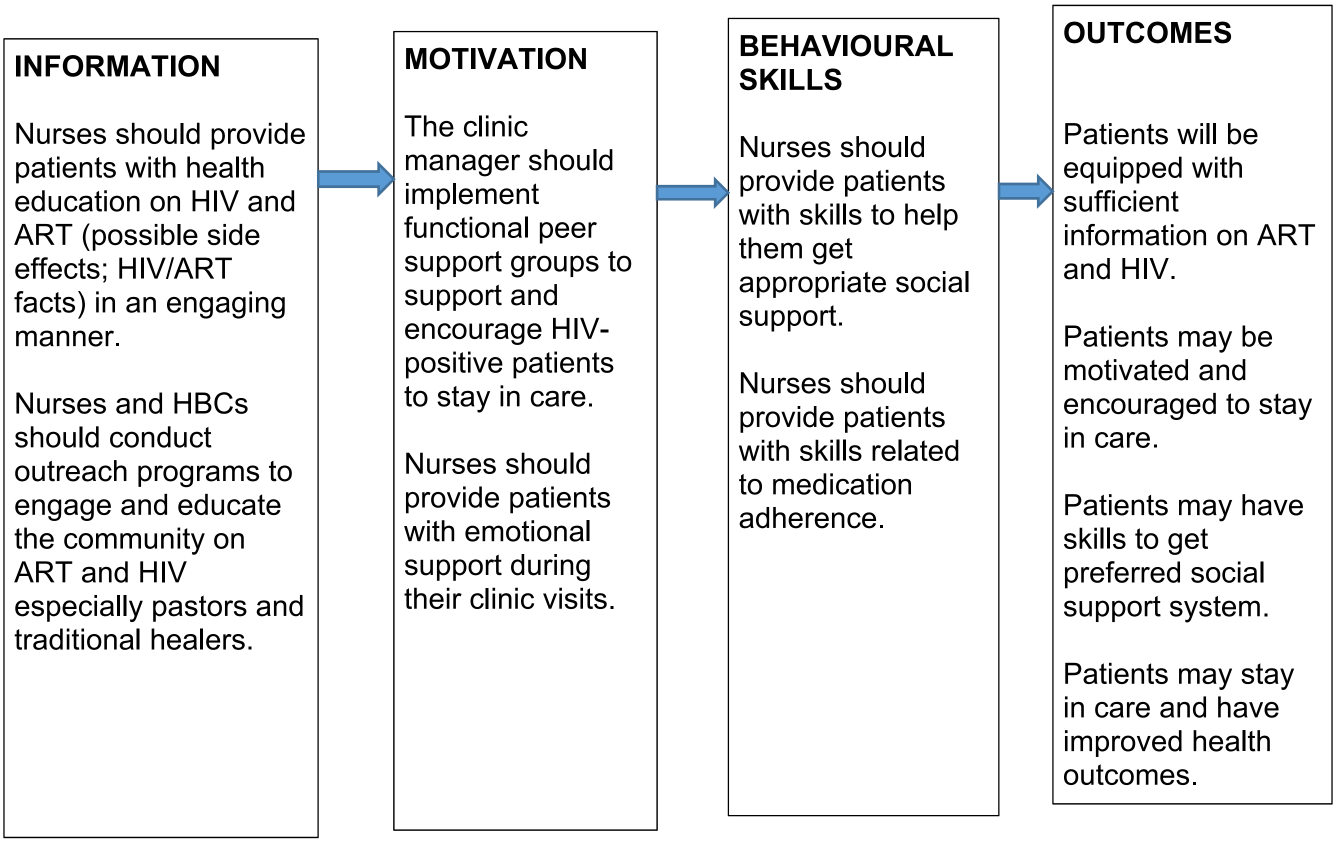
SAT

- Enlighten the patients during their consultation about advantages of HIV status disclosure to maximize their chances of getting social support.
- Educate patients on advantages of social support from family/friends or intimate partner (for example: emotional & financial support).

Figure 10: Overview of the proposed strategy

6.3.1.1. IMB

Patient barriers (lack of understanding of ART; denial; traditional/ religious beliefs, negative side-effects, feeling well physically)



INFORMATION

Nurses should provide patients with health education on HIV and ART (possible side effects; HIV/ART facts) in an engaging manner.

Nurses and HBCs should conduct outreach programs to engage and educate the community on ART and HIV especially pastors and traditional healers.

MOTIVATION

The clinic manager should implement functional peer support groups to support and encourage HIV-positive patients to stay in care.

Nurses should provide patients with emotional support during their clinic visits.

BEHAVIOURAL SKILLS

Nurses should provide patients with skills to help them get appropriate social support.

Nurses should provide patients with skills related to medication adherence.

OUTCOMES

Patients will be equipped with sufficient information on ART and HIV.

Patients may be motivated and encouraged to stay in care.

Patients may have skills to get preferred social support system.

Patients may stay in care and have improved health outcomes.

6.3.2. SAT

Structural barriers (lack of funds to travel to the clinic, long distance to the clinic; disability grants)

INTERDEPENDENCE AND SOCIAL SUPPORT

Nurses should encourage HIV status disclosure to maximize patients ‘chances of getting social support such as financial and emotional support.

Nurses should educate patients on advantages of social support from family, friends, and intimate partner .

OUTCOMES

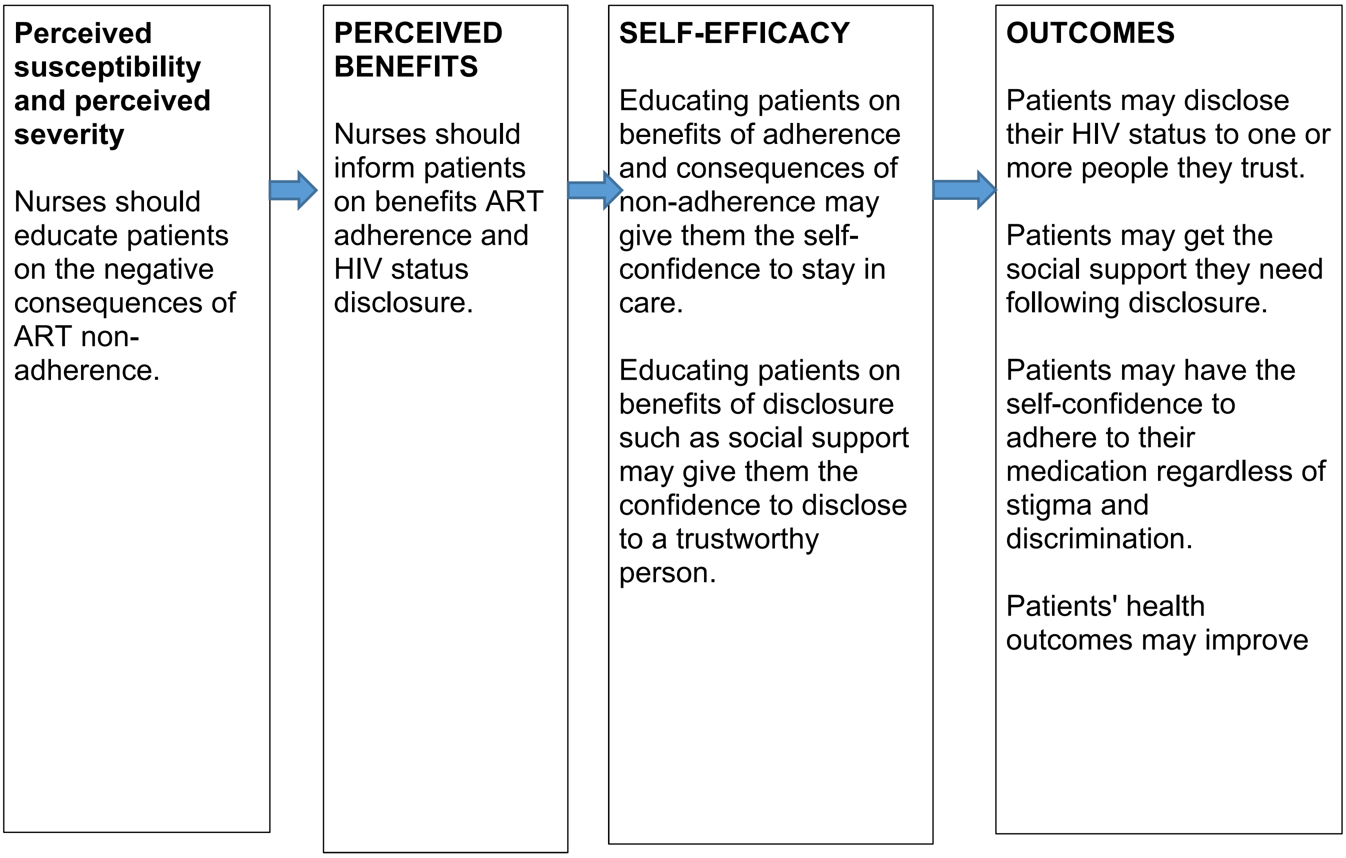
Patients may disclose their HIV-status to one person they trust to acquire social support they need.

Patients may secure social support from their partners to overcome barriers and improve adherence.

Patients' health outcomes may improve.

6.3.3. HBM

Psychosocial barriers(fear of disclosure; fear of stigma and discrimination)



Perceived susceptibility and perceived severity

Nurses should educate patients on the negative consequences of ART non-adherence.

PERCEIVED BENEFITS

Nurses should inform patients on benefits ART adherence and HIV status disclosure.

SELF-EFFICACY

Educating patients on benefits of adherence and consequences of non-adherence may give them the self-confidence to stay in care.

Educating patients on benefits of disclosure such as social support may give them the confidence to disclose to a trustworthy person.

OUTCOMES

Patients may disclose their HIV status to one or more people they trust.

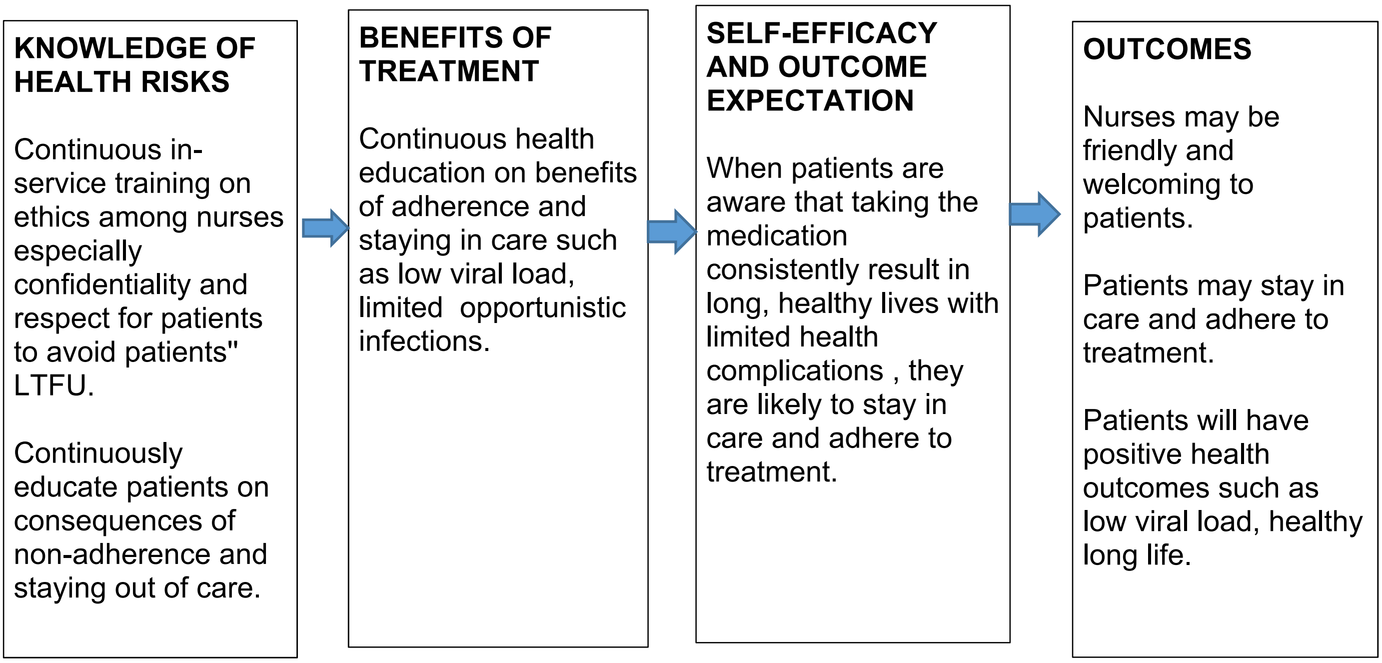
Patients may get the social support they need following disclosure.

Patients may have the self-confidence to adhere to their medication regardless of stigma and discrimination.

Patients' health outcomes may improve

6.3.4. SCT

System barriers (unwelcoming / rude nurse behaviour; lack of confidentiality by nurses and HBCs; patients self-transfer; lack of enough medication)



KNOWLEDGE OF HEALTH RISKS

Continuous in-service training on ethics among nurses especially confidentiality and respect for patients to avoid patients" LTFU.

Continuously educate patients on consequences of non-adherence and staying out of care.

BENEFITS OF TREATMENT

Continuous health education on benefits of adherence and staying in care such as low viral load, limited opportunistic infections.

SELF-EFFICACY AND OUTCOME EXPECTATION

When patients are aware that taking the medication consistently result in long, healthy lives with limited health complications , they are likely to stay in care and adhere to treatment.

OUTCOMES

Nurses may be friendly and welcoming to patients.

Patients may stay in care and adhere to treatment.

Patients will have positive health outcomes such as low viral load, healthy long life.

6.4. Conclusion

The proposed strategies in this chapter demonstrates that various psychological models outlined are useful to guide the strategy that will decrease the LTFU rate if appropriately applied. If these strategies are implemented adequately, there may be improvement on the LTFU rate and ART adherence in the clinics of the Limpopo province. The next chapter outlines the summary of the findings, the conclusions and the recommendations of the study.

CHAPTER 7: SUMMARY, CONCLUSION AND RECOMMENDADTIONS

7. Introduction

The purpose of this chapter is to present and discus the summary of the findings, the conclusions and the recommendations of the study. The results of chapter four resulted in the development of

a strategy presented in chapter 6. The proposed programme may improve the patients retention in care in the clinics of Limpopo Province hence promote good health outcomes such as low viral load, lower LTFU rates.

The research questions of the study were:

- What are the factors contributing to LTFU among HIV- positive patients from their perspectives?
- What are the factors contributing to LTFU among HIV- positive patients from nurses' perspectives?
- What are the strategies from patients' and nurses' perspectives that would address barriers to LTFU among HIV-positive patients?
- What are the theories of psychological behavioural change to guide the development of the proposed strategy to LTFU among HIV-positive patients?

7.1. Summary of findings

The aim of this study was to determine patient and nurse perspectives on LTFU among HIV-positive patients in the Sekhukhune District of Limpopo Province. This aim was accomplished, and I applied relevant theories of psychological behavioral change to guide the development of potential strategies to enhance ART adherence and retention in care. Patients in the study outlined various reasons that contributed to their decision to discontinue HIV treatment. The reasons included feeling well physically, non-disclosure, lack of confidentiality, negative side-effects, traditional/ religious beliefs, lack of understanding of ART, difficulty taking time off from work and lack of enough medication. Nurses perceived traditional/religious beliefs, patients self-transfer, fear of lack of confidentiality, lack of understanding of ART, disability grant, feeling better physically as the contributing factors to LTFU.

Patients and nurses also gave their opinions on different strategies to assist HIV-positive patients to stay in care. Nurses whose clinics have zero/ low rate of LTFU also shared the strategies that they use to retain their patients in care. The strategies included team work, health education, social support and in-service education on ethics. Patients mentioned health education and confidentiality assurance about their HIV status as possible strategies that could encourage them to re-engage and stay in care. Moreover, nurses whose clinics have a high rate of LTFU also suggested strategies that may work for them to keep patients in care, their strategies included development of social support groups, health education, and giving those who are compliant medication that will last them for several months. Notably, health education was found to be a commonly mentioned strategy by both patients and nurses.

Furthermore, specific intervention theories were applied to develop a strategy that would help clinics in the Sekhukhune district to retain patients in care and promote ART adherence. This models includes: Information Motivation Behaviour Skills Model (IMB) to address patient barriers; Health Belief Model (HBM) to address psychosocial barriers; Social Action Theory (SAT) to address structural barriers; and Social Cognitive Theory (SCT) to address system barriers. Taking into consideration the results of the current study and literature on the efficacy of various psychological models in health behaviour change, the developed strategy outlines the need to strengthen information, motivation, behavioral skills, and social support for patients to remain in care and adhere to ART. The study also proposed recommendations for the clinics, which states that nurses should provide patients with both the information and the motivation they need in a more engaging and respectful way. In the recommendation, It further proposed that nurses should encourage social support and HIV status disclosure. This will help patients to fully understand how HIV and ART work and to develop behavioural skills they need to adhere and remain in care. I will finally shared the proposed strategy and recommendations with the District Manager and the sampled clinics with the hope that they will be implemented will improve patients' health outcomes.

7.2. Recommendations

The findings of this study have revealed limitations and challenges encountered by both patients and nurses within the district. Some recommendations are therefore suggested to close the gaps identified and improve patients retention in care. The recommendations include responsibilities that should be achieved by the DOH district, the nurses, the clinic managers, and home based carers to improve patients' retention in care as well as ART adherence.

7.2.1 Recommendations for nurse clinic managers

- The clinic manager should provide nurses and home based carers with continuous in-service training on ethics, especially confidentiality and respect for patients.
- Nurses should provide patients with health education in an engaging, interactive, and respectful manner.
- Nurses should conduct outreach programs to engage and educate the community, especially pastors and traditional healers on ART and HIV.
- Nurses should implement peer support programs to offer social support to other HIV-positive patients.
- Nurses should educate patients on the advantages of social support from family/friends or intimate partner.
- Nurses should educate patients on the negative consequences of ART non-adherence and benefits ART adherence.
- Nurses should continuously remind patients to inform the clinic when they decide to continue care in another clinic to avoid having inaccurate LTFU rate.

7.2.2. Recommendations for patients

- Patients should be informed about advantages of HIV status disclosure and coached on how to disclose their condition in order to maximize their chances of getting social support from family and intimate partners.
- Patients should be made aware that receiving education and information on all the above mentioned aspects may give them the self-confidence they need to adhere to ART regardless of the challenges they might face such as stigma and discrimination.
- Patients should be informed about disadvantages of LTFU.

- Patients should be educated on advantages of ART adherence

7.2.3. Recommendations for Home based Carers

- Home based carers should conduct outreach programs to engage and educate the community, especially pastors and traditional healers on ART and HIV.
- Home based carers should be confidential about patients health matters.

7.2.4. Recommendations for families and communities

- Family members should be involved in the care of their relatives.
- Family members and community should be educated on HIV and ART and how to offer support

7.2.5. Recommendations for the DOH district

- The DOH district should provide nurses with training on motivational interviewing to furnish them with skills on how to provide health care in an engaging and respectful manner.

7.3. Limitations of the study

There were limitations that the researcher experienced during data collection in the district. First, due to the sensitivity of the study topic, patient participants were unable to open up and be comfortable in the beginning. It took some little time, therefore, to build a relationship with the patients in order for them to be comfortable enough to engage freely in the discussions. The other limitation was that the target population of 50 patients was very difficult to reach because some of the LTFU patients worked on the farms and in mines. Also, some of the LTFU patients were college students who relocated to different destinations after completing their studies, and most of their contact numbers had become invalid.

Moreover, some of the HIV-positive patients refused to participate. When approached, they insisted that they were not the person the researcher was looking for. The patients avoided talking to any unknown person because they were always suspicions and cautious that someone from the clinic would visit them and convince them to return to the clinic. Only four sub-districts were visited instead of five because data saturation was reached in the fourth sub-district. The sample had few men because clinics' patients are mostly women. Therefore, findings may apply primarily to female patients. Finally, the study findings cannot be generalized to the whole population, but only to the Sekhukhune district, since the study was not conducted nationally but was limited to only one district.

7.4. Conclusion

This chapter discussed the summary of the findings of the study as outlined in chapter four. It also outlined the conclusions of the study and indicated the recommendations made to all the stakeholders. The information outlined in the current study demonstrates that achieving adherence to HIV medication is an urgent issue for the public health services in Limpopo to consider for implementation. The findings of this study also point out important areas of improvement for the future. If the proposed strategies are implemented, there may be improvement on the LTFU rate and ART adherence in the clinics of the Sekhukhune district. It will also be helpful to conduct a study in the future, following the implementation of intervention strategies to determine its effectiveness. Notably, there have been no published studies in the South African literature that has used various intervention models to guide the intervention, which will address specific barriers that contributes to non-retention in care. Thus, the current study is innovative and also adds novel evidence to this existing literature; it also contributes new data from the rural Sekhukhune District.

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APPENDIX A: Information sheet

Patient and nurse perspectives on loss to follow-up in HIV care.

Dear Participant,

I am a PhD student at the University of Venda conducting a study entitled: **"Patient and Nurse Perspectives on loss to follow-up in HIV care"** You are requested to participate in this study by responding to questions I would like to ask you. The purpose of this study is to find out your perspective on loss to follow up in HIV care. The findings of the study guided the development of a proposed strategy to decrease LTFU among HIV-positive patients.

Your names will not be revealed in any reports resulting from the study. All your information will be kept confidential. Apart from the interviewer, no one will know what you shared in the interview. The interview will last for about an hour. When it comes to answering questions, there are no right or wrong answer, so be open and honest as possible. You have the right to not answer any questions that makes you uncomfortable.

Should you agree to participate in the study, I would ask you to read the accompanying consent form. You are free to choose not to participate in this study. Furthermore, you are free to withdraw your participation from the study at any time should you want to do so. The information gathered throughout this interview is confidential.

Your cooperation is highly appreciated.

Should you have any queries or need further clarity please contact the researcher on 0814726271

Yours faithfully

………………………… ……………………………

Mahlatse Modipane Date

APPENDIX B: Consent Form

Patient and Nurse Perspectives on loss to follow-up in HIV care.

I, …………………………………………., hereby consent to participate in a study entitled " "Patient and Nurse Perspectives on loss to follow-up in HIV care" I understand that I am participating in this study voluntarily and that I am free to withdraw my participation should I wish to do so at any time. If I want to stop participating, I can simply inform the researcher. The conditions of the study have been fully explained to me and I fully understand the circumstances of my participation.

……………………………….. ……………………………….

Signature of Participant Date

……………………………….. …………………………

Signature of Researcher Date

APPENDIX C: Interview guide for patients

Section A: Sociodemographic

Age in years as at last birthday ....

Gender

Female ....

Male ....

Education

1) None
2) Primary
3) Secondary (High School)
4) University

Marital status

1) Single
2) Married/cohabiting
3) Divorced/separated
4) Widowed

Main source of income ....

Monthly income (Rands) ....

Means of transport to clinic ....

Time taken to reach clinic from home (hrs)...

Cost to get to clinic (Rands)

....

Do you take time off work to come to the clinic? 0) No 1) Yes

Section B: Personal perceptions of health and ART treatment

1. Did you discontinue ART treatment, and if so, when?
2. Please share with me your reasons for discontinuing taking the antiretroviral treatment?
3. Are there any alternative treatments you are using to replace the antiretroviral treatment?
    a. Tell me about them (description).
    b. When did you start using this alternative treatment?
    c. Why did you seek alternative treatment?
    d. How much do you spend on alternative treatment?
4. Have you experienced any issues taking both alternative treatment and ART?
5. How do you feel about alternative treatment you are using compared to biomedical treatment you were receiving from clinics?
6. Why did you choose to take alternative treatments?
7. Do you currently receive or have you previously received a disability grant?
8. What relationship, if any, does the disability grant have on you dropping out of care?
9. What do you know about the importance of remaining on ART and in care?
10. What do you think can be done to re-engage you and other LTFU patients in care?
11. What do you think can be done to help patients remain in care?

APPENDIX D: Interview guide for nurses whose clinics have high LTFU rate

Section A: Sociodemographic

Gender

Female ……………………………………………………….
Male ……………………………………………………….

Education
1. Degree
2. Diploma
3. Other ……………………………………………………….

Section B: Perceptions about LTFU patients and strategies

In your opinion:

1. Why do HIV-positive patients drop out of care in your clinic?
2. What can be done to re-engage these patients in care?
    a. What are you already doing about re-engaging patients in care?
    b. What have you tried that did not work?
    c. What are you planning to re-engage patients?
3. What can be done to help HIV-positive patients remain in care?

APPENDIX E: Interview guide for nurses whose clinics have low LTFU rate

Section A: Sociodemographic

Age in years as at last birthday ....

Gender

Female ……………………………………………………….
Male ……………………………………………………….

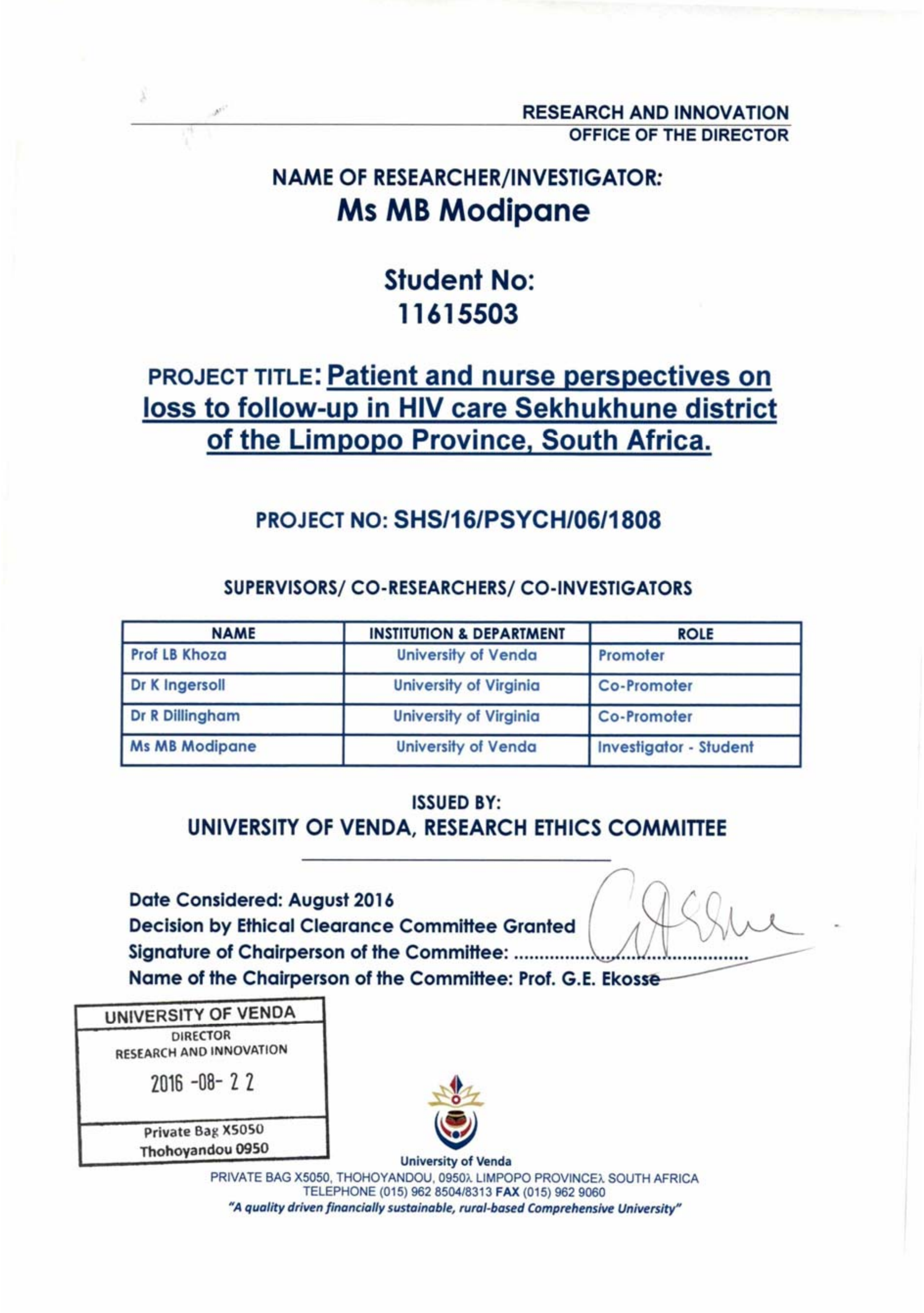
Education

4. Degree
5. Diploma
6. Other ……………………………………………………..

Section B: Perceptions about LTFU patients and strategies

1. What do you know about the rate of LTFU in your clinic?
2. Did your clinic experience higher LTFU rates before now?
3. If yes, please share with me what you think contributed to patients' loss to follow up in your clinic then?
4. What efforts did you and your team make to achieve low rates of LTFU today?
5. Do you have patients that have been re-engaged in care?
6. If yes, what did you do to re-engage those patients in care?
7. What tips and advice would you give to clinics that are struggling with high rates of LTFU?
8. What do you think are the top 3 strategies you use to retain or re-engage patients in care?

Appendix F: Ethical clearance certificate



RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Ms MB Modipane

Student No:
11615503

PROJECT TITLE: Patient and nurse perspectives on loss to follow-up in HIV care Sekhukhune district of the Limpopo Province, South Africa.

PROJECT NO: SHS/16/PSYCH/06/1808

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof LB Khoza	University of Venda	Promoter
Dr K Ingersoll	University of Virginia	Co-Promoter
Dr R Dillingham	University of Virginia	Co-Promoter
Ms MB Modipane	University of Venda	Investigator - Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: August 2016
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: ....
Name of the Chairperson of the Committee: Prof. G.E. Ekosse

UNIVERSITY OF VENDA
DIRECTOR
RESEARCH AND INNOVATION
2016 -08- 2 2
Private Bag X5050
Thohoyandou 0950

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950λ LIMPOPO PROVINCEλ SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 **FAX** (015) 962 9060
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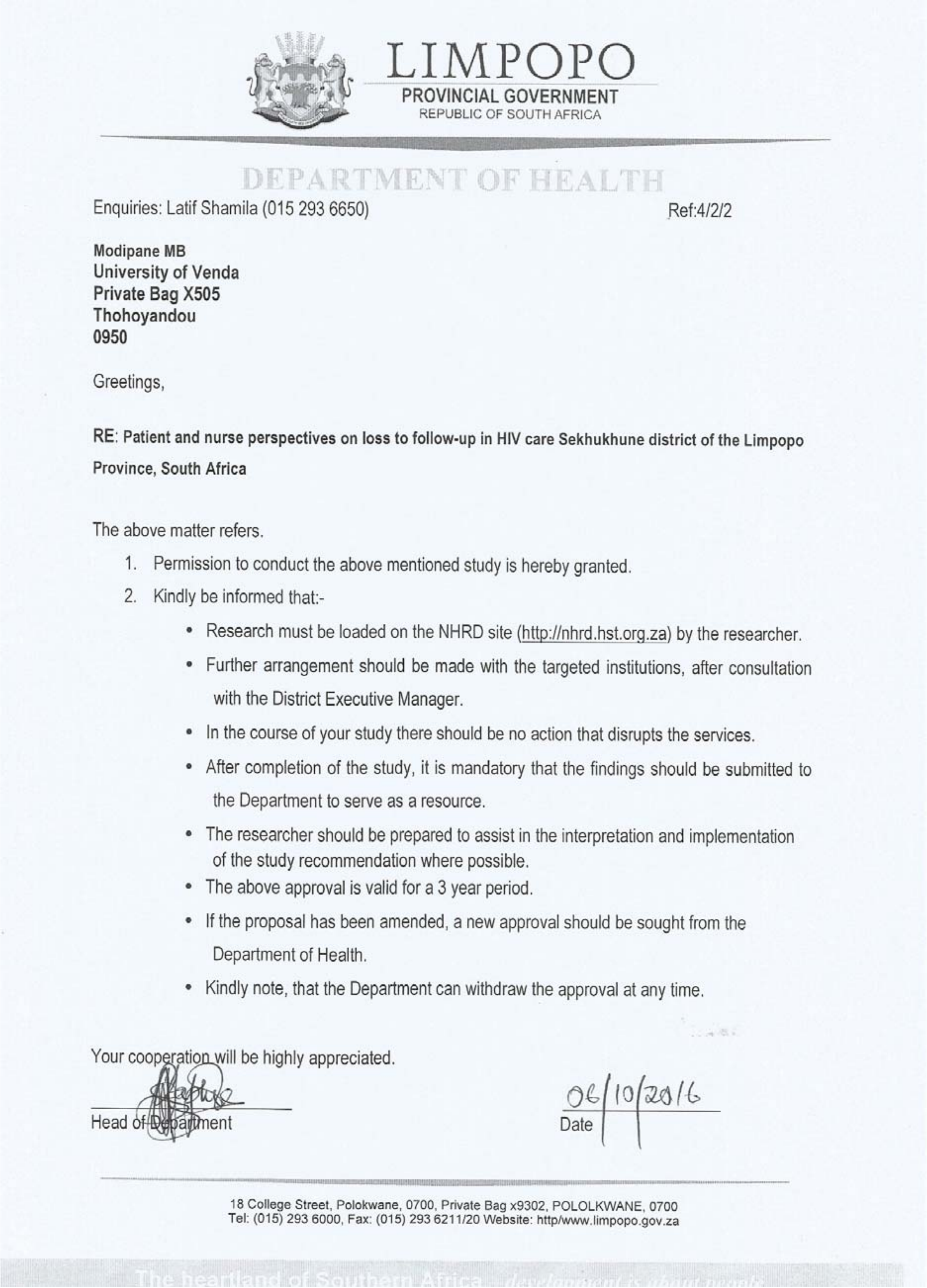
APPENDIX G: Approval letter



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila (015 293 6650) Ref:4/2/2

Modipane MB
University of Venda
Private Bag X505
Thohoyandou
0950

Greetings,

RE: Patient and nurse perspectives on loss to follow-up in HIV care Sekhukhune district of the Limpopo Province, South Africa

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

06/10/2016
Date

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

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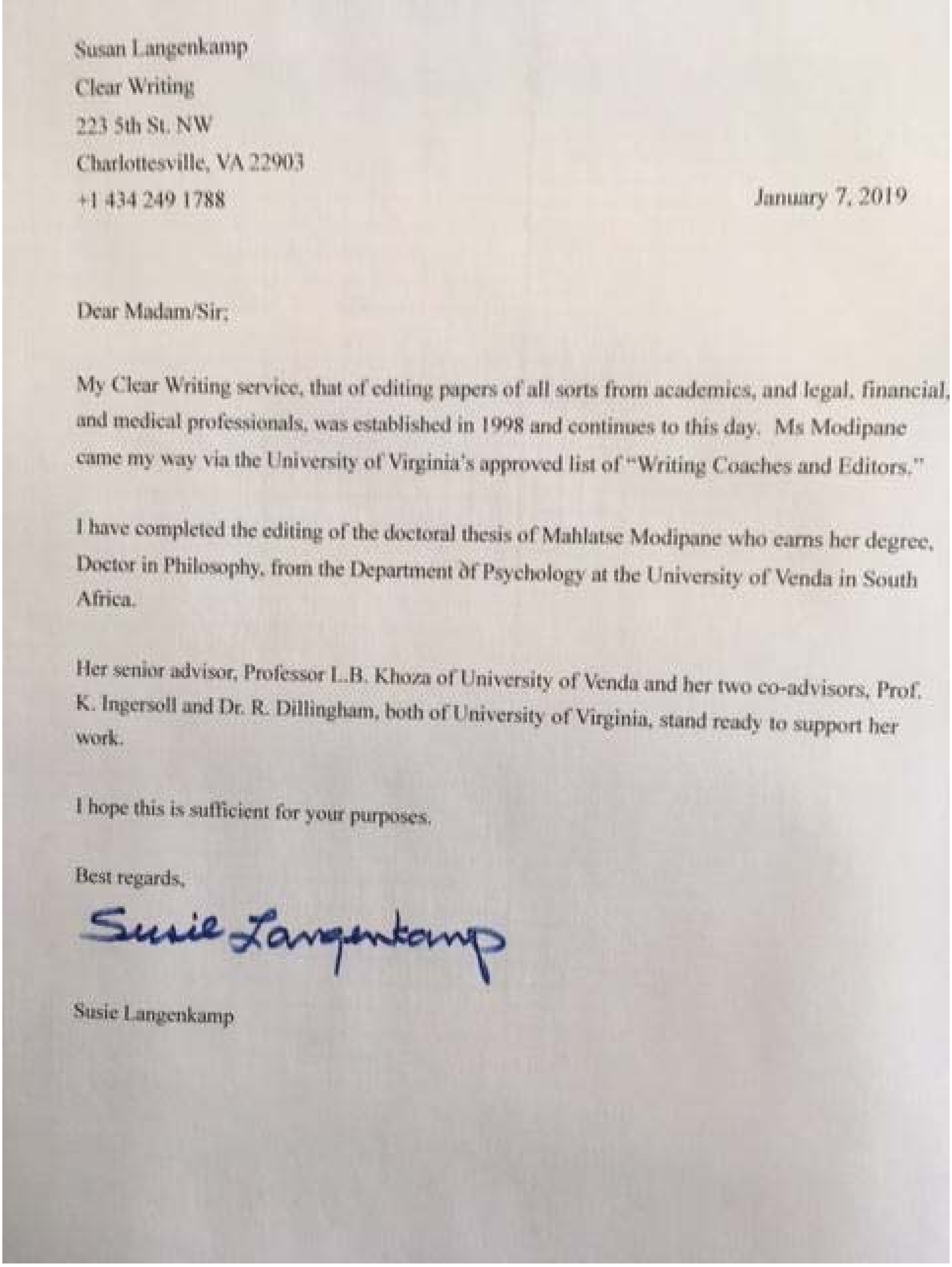
APPENDIX H: Language Editor



Susan Langenkamp
Clear Writing
223 5th St. NW
Charlottesville, VA 22903
+1 434 249 1788

January 7, 2019

Dear Madam/Sir:

My Clear Writing service, that of editing papers of all sorts from academics, and legal, financial, and medical professionals, was established in 1998 and continues to this day. Ms Modipane came my way via the University of Virginia's approved list of "Writing Coaches and Editors."

I have completed the editing of the doctoral thesis of Mahlatse Modipane who earns her degree, Doctor in Philosophy, from the Department of Psychology at the University of Venda in South Africa.

Her senior advisor, Professor L.B. Khoza of University of Venda and her two co-advisors, Prof. K. Ingersoll and Dr. R. Dillingham, both of University of Virginia, stand ready to support her work.

I hope this is sufficient for your purposes.

Best regards,

Susie Langenkamp

Susie Langenkamp