EXPERIENCES OF CONCEALING HIV POSITIVE STATUS TO IMMEDIATE FAMILY BY WOMEN AT SELECTED VILLAGES IN LIMPOPO PROVINCE

by

RAMATSIMELE PATRICIA MAKGABO

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DEDICATION

This mini-dissertation is dedicated to all women who are living with an HIV positive status collecting their medication at Lebowakgomo Clinic and the Community Health Workers from Itekeng Home Based Care.

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DECLARATION

I declare that **EXPERIENCES OF CONCEALING HIV POSITIVE STATUS TO IMMEDIATE FAMILY BY WOMEN AT SELECTED VILLAGES IN LIMPOPO PROVINCE** (mini-dissertation) hereby submitted to the University of Limpopo for the degree of Masters of Public Health has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution and all material contained herein has been duly acknowledged.

....
Makgabo R.P(Ms) Date

DEFINITION OF CONCEPTS

Concealment

Concealment is the act of hiding something. It is defined as a tendency to actively hide from others personal information that one perceives as distressing or negative (Owuor, Locke, Heyman & Clifton, 2016). For this study, concealment will be the process of hiding HIV positive status to immediate family members by women at a village in Limpopo Province.

Immediate family

According to Merriam-Webster Online Dictionary (2015), immediate family refers to the group of individuals who are living in the same household and usually led by one authority figure. For this study, immediate family refers to parents, spouse, children, siblings, grandparents and grandchildren of the women living with HIV.

Woman living with HIV

According to Morrow and Messinger (2006), a woman is a female human being. Women living with HIV are females who were infected with HIV as predisposed by a host of factors that are inclusive of but not limited to biological, social, cultural and economic reasons (Esplen, 2007). For the purpose of this study, this concept will be used to refer to any female human being living with HIV.

Stigmatizing illness

According to Pescosolido, Martin, Lang and Olafsdottir (2008), stigma is defined as an indication of separation on one individual from another on the basis of socially conferred judgment that may also be degrading. Stigmatizing illness is an illness that triggers a negative reaction and attitude from people, especially towards the infected person. In this study stigmatizing illness will refer to the HIV positive status of women living in selected villages in Limpopo Province.

ABBREVIATIONS

AIDS:	Acquired Immunodeficiency Syndrome
ART:	Anti-retroviral therapy
HIV:	Human Immunodeficiency Virus
IPA:	Interpretative Phenomenological Analysis
WLW-HIV:	Women living with Human Immunodeficiency Virus
WHO:	World Health Organization

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ABSTRACT

TITLE: EXPERIENCES OF CONCEALING HIV POSITIVE STATUS TO IMMEDIATE FAMILY BY WOMEN AT SELECTED VILLAGES IN LIMPOPO PROVINCE

Background: Disclosure of Human Immune Deficiency Virus (HIV) is still a challenge to people living with the disease because of the discrimination, stigma and judgemental attitudes. Women prefer to keep their illness to themselves and make it a secret. The revealing of HIV status relies on an individual who is living with the illness. The concept of non-disclosure is a vital issue that threatens immediate families in which there are people, especially women battling the non-disclosure of their HIV status.

Objectives: The objectives of the study were to explore and describe the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at the selected villages in Limpopo Province.

Methods: The qualitative and descriptive phenomenological method was followed. Due to saturation, ten women participated after being selected through purposive sampling from the database with the consideration of the inclusion and exclusion criteria. Data was collected through semi-structured interviews in Sepedi. The data was transcribed, translated and analysed through Interpretative Phenomenological Analysis.

Results: WLW-HIV continue to manage to live with a secret about their HIV status due to the unpleasant feelings they hold about the illness continue, still pointing fingers and sceptical about disclosing, particularly to their children. They further tell lies about their illness and hide their medications away from the members of their family. The reasons about concealing their status include among others fear of prejudice, lack of trust, fear of abandonment and rejection, fear of blame and humiliation, denial, misconceptions that people still hold about HIV and the view of it as a predicament. Others conceal because of the lack of support and the target of the disclosure.

Conclusion: The outcomes of the study have uncovered that there is still less awareness by members of the society about HIV/AIDS, which puts pressure on the WLW-HIV to effectively deal with an HIV positive status and disclose to their family members. These factors contribute to concealment and compromise the level of support that WLW-HIV would get from their family members, further impacting negatively on adherence.

Keywords: Concealment, HIV/AIDS, Phenomenological study, Stigma and Immediate family.

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

Disclosure of infection with Human Immune Deficiency Virus (HIV) is still a challenge for people living with the disease because of the discrimination, stigma and judgemental attitudes. Women prefer to keep their HIV positive status to themselves and make it a secret. The revealing of HIV status relies on an individual who is living with the condition. There are improvements in the healthcare services aimed at minimising the infection and spread of HIV, but the world still faces the challenge of concealment around the issue of HIV positive status.

The challenge of disclosure was identified between sexual partners and children. There is also rising concern about the disclosure processes of women living with HIV (WLW-HIV) to the immediate family as supported by the findings of the study by Nyandat and van Rensburg (2017). The concept of nondisclosure is a vital issue that threatens immediate families in which there are people, especially women battling with nondisclosure of their HIV status.

According to Southern African Aids Trust (2000), disclosure can play an important role in helping people who have accepted their HIV positive status and reduce the stress of coping on their own, increasing their access to medical services, care and support, helping people to protect themselves and others. Disclosure of HIV positive status may help women to negotiate safer-sex practices. It may further help to reduce the stigma and discrimination that surrounds HIV and help to encourage the person’s immediate families to plan for their future. Van Dyk (2012) further refer that privacy is the individual right to conceal health information to others. Privacy is an ethical principle of autonomy and dignity. There are security measures that restrict health professionals from disclosing HIV information for health data. There are laws and policies that authorize disclosure of a person, especially that of women living with HIV. They fall within three broad categories which are disclosures requiring informed consent, discretionary disclosures and mandatory disclosures.

According to Meintjes, Conradie, Cox, Dlamini, Fabian, Maartens, Manzini, Mathe, Menezes, Moorhouse and Moosa (2014), a person living with HIV should be provided with vital information before starting with anti-retroviral therapy (ART). That information includes the issue of ART as the lifelong therapy, the importance of medication adherence, and a list of ART side-effects, including what to do and whom to contact if serious side-effects occur. Each patient should have a personal treatment plan. In that personal treatment plan, concealment of HIV status to immediate family members is strongly discouraged. This treatment plan is the important determinant of treatment adherence and it assists in the provision of information to WLW-HIV. WLW-HIV are encouraged to be supported through the process of treatment and be part of support groups. At the clinic, healthcare professionals should have the contact details of each woman's treatment buddy.

In their findings on the process of United States parents disclosing their HIV positive status to their children, Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy, Nguyen and Schuster (2010) found both parents and children reported unplanned disclosure experiences with positive and negative outcomes. Parents sometimes reported that disclosure was not as negative as they feared. However, the within-household analysis showed disagreement between parents and children from the same household regarding disclosure outcomes. These findings suggest that disclosure should be addressed within a family context so that the children will also be involved. Involvement of the children will assist them to ask questions and have clarities concerning the illness. Parents should consider negative and positive outcomes during the disclosure process and children's capacity to adapt after disclosure when deciding whether to disclose. Nonetheless, it has its positive side, disclosure of HIV positive status can also be accompanied by negative consequences such as problems in the relationship with immediate family members. In some cases, especially in communities where women are disempowered, disclosure may lead to eviction, violence and in extreme cases, murder (Van Dyk, 2012). Thus given this background of women challenges of concealment the researcher decided to conduct this study to explore more on concealment of HIV positive status by women.

1.2 RESEARCH PROBLEM

This study was an offspring of the observations made by the researcher at a local clinic about the level of concealment of WLW-HIV to their immediate family members. Visser, Neufeld, de Villiers, Makin and Forsyth (2008) argue that pregnant WLW-HIV often do not disclose their HIV status to their immediate family members. As a social worker, the researcher receives several referrals from the healthcare professionals at the local clinic about the HIV status concealment of WLW-HIV and the challenge of defaulting treatment. Some of the women are unable to request their immediate family members to accompany them in cases where the treatment buddy is needed. These women's reasons may be that they have concealed their status to their immediate family members. In some cases, WLW-HIV will come with other people they know such as friends or neighbours to be their treatment buddies instead of their immediate family members.

Women living with HIV often default treatment, especially if they have to take it in the presence of their family members. Some of these women complain of sharing bedrooms whereby privacy is compromised. In cases where there is no privacy, treatment is also compromised. These women indicate that for them to take their medication in front of their immediate family members was going to be difficult because they were not aware of their health status. Some of these women ended up changing their medication containers and burning them so that their immediate family members may not realise the exact medication. There are challenges about WLW-HIV's non-adherence to ART due to the fear that their immediate family members might find out about their illness. As a result, such women are not able to access support from their immediate family members' support in times of need.

1.3 LITERATURE REVIEW

Lai (2011) defines literature review as a process that involves an overview of research on a given topic that aims to answer a particular research question. This process usually assists the researcher through answering the research question, sharing an understanding of how the process of research evolved in the area that the researcher aims to explore, and assisting the researcher's understanding and motivation for the desired research question.

The study reviewed the literature on the following issues which are discussed in detail in Chapter 2: HIV/AIDS and stigma, concealment of HIV status and the impacts of HIV/AIDS on women.

1.4 AIM OF THE STUDY

This study aimed to explore and describe the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province.

1.5 OBJECTIVES OF THE STUDY

The objectives of this study were:

To explore the experiences of concealing an HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province.

To describe the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province.

1.6 RESEARCH QUESTION

What were the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province?

1.7 RESEARCH METHODOLOGY

The researcher adopted a qualitative research approach and used a purposive sampling method to select ten participants from villages that are served by Lebowakgomo Clinic. The researcher further went on to conduct semi-structured interviews as directed by the interview guide to gather information from the participants. The information gathered was analysed through the steps as outlined by Interpretative Phenomenological Analysis (IPA) process. The researcher used the phenomenology study design which focuses on the experiences of concealing illness to immediate family members by WLW-HIV (Martin, Sugarman and Slayney, 2015).The researcher chooses to use the descriptive or hermeneutical phenomenology which its main aim is the description of the participant’s life experiences about the occurrences, in this regard, the experiences of concealing illness to immediate family members by WLW- HIV (Padilla-Díaz, 2015). Furthermore, research methodology is discussed in detail in Chapter 3.

1.8. SIGNIFICANCE OF THE STUDY

The study gives information and the reasons of the WLW-HIV to conceal their illness to immediate family members. Information gathered may help in the development of guidelines that are friendly for our population in terms of managing the process of disclosure. There may be the documentation of knowledge and information relating to the factors that are involved in the processes of concealing HIV status for the enhancement of adherence to HIV treatment and default prevention.

1.9 OUTLINE OF THE CHAPTERS

Chapter 1: Briefly discusses the overview of the study, the research problem, the aim of the study, objectives and the significance of the study.
Chapter 2: The literature review in the context of the research that was undertaken.
Chapter 3: Describes the research methodology and the study design
Chapter 4: Findings and literature control
Chapter 5: Summary, recommendations, strength and conclusions

1.10 CONCLUSION

This chapter provided an overview of the study, which focused on the introduction, research problem, and literature review, aim of the study, research question, objectives, research methodology, ethical considerations and significance of the study. Chapter 2 aims to review the literature that is significant for the purposes of this study.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

The first chapter of this study presented an overview of the study and was looking at the introduction, research problem, and the literature review, aim of the study, research question, objectives, methodology, ethical considerations and significance of the study. In this chapter, more focus will be on the literature review, whereby the researcher read, explored and understood more about the research problem from other researchers.

Disclosure of personal information concerning health status is a difficult matter because it involves life-threatening information and stigma. The researcher reviewed the literature about the stigma related to HIV positive status and the concealment of the disease. The researcher explored the possible factors that are as a result of the impact of HIV and its related dynamics.

2.2 HIV/AIDS STIGMA

In the findings of the study by Earnshaw, Smith, Chaudoir, Amico and Copenhaver (2013) that was conducted in New York, there is an internalised stigma which may manifest either as a sign of emotional or behavioural health and wellbeing. The study revealed an element of anticipated stigma, which is often related to positive physical health and wellbeing. The findings of this study further suggested that the stigma associated with HIV/AIDS poses a negative impact on the health and wellbeing of a person living with HIV.

World Health Organization (WHO) and Joined United Nations Program on HIV/AIDS states that 35.3 million people in Asia are living with HIV/AIDS. This illness is socially unacceptable in most countries .Women are labelled with adultery. These women are stigmatised and pushed out of the community. The illness is viewed as humiliation to the individual personality which makes disclosure impossible (Saki, Kermanshahi ,Mohammadi & Mohraz ,2015).

According to Borgart, Wagner, Green, Mutchler, Klein and McDavitt (2015) internalised HIV stigma involves a situation where the infected person believes that harmful statements from the people are true about them. Internalised stigma relates to poor adherence to HIV medication, depression and poor physical health. Anticipated stigma, on the other hand, refers to an expectation that an individual hold about a specific form of stigma or discrimination from others, especially if that individual is found to be HIV positive and has disclosed her status (Turan, Bukusi, Onono, Holzemer, Miller and Cohen, 2011).

According to the study by Liamputtong and Haritavorn (2014) that was conducted in Thailand, it indicates that women who have been diagnosed with HIV have diverse views about it. Some of WLW-HIV chooses to conceal their illness to their families, particularly their spouses due to stigma and discrimination. These women have a fear of being blamed or rejected by members of the family and are also worried about the welfare of their loved ones. The findings further show that some of the WLW-HIV experience discrimination from their mothers who deny sharing the same utensils used by them even though they are washed, with the fear that they will get infected.

According to the results of the study by Kulane, Owuor, Sematimba, Abdulahi, Yusuf and Mohamed (2017) that was conducted in Somalia about WLW-HIV indicated that there was a high level of stigma from their family and community members following their discovery of their HIV positive status. The stigma was further seen in the division of families of WLW-HIV, exclusion from their families and discrimination from landlords where they rented out or service recipients if they are in small businesses. This discrimination was in the form of either overpricing as a means of financial security for landlords in case other tenants move out, or denial of space for rental.

Mabisi (2018) conducted a study in Uganda where the results indicated that WLW-HIV often suffered the stigma they received from their families where a mere touching was viewed as an intention by the infected person to infect others and die along with them. The women have further demonstrated the application of ignorance in dealing with the stigma they received from family and community members. The study by De Klerk (2012) that was conducted in North-West of Tanzania indicates that the stigma associated with HIV/AIDS has always been in existence since the beginning of the pandemic.

In the case of Ghana, Dapaah (2012) argue that WLW-HIV are open to discussing their status and their illness experience with support groups and at the clinic during counselling as opposed to their families. The study has further revealed that more participants preferred absolute secrecy or even death to the shame and social exclusion that may follow if their condition is revealed. Due to stigma and discrimination associated with the illness, it is difficult for families to initiate illness-related discussions with loved ones. The interviews that were conducted with participants, many of whom were parents preferred meeting away from their homes, talked in lower voices (murmured), and they do not want the neighbours to know about their status.

In the argument made by Madiba (2017), HIV/AIDS is a stigmatised condition that is considered as the main contributory factor towards its spread in Sub-Saharan Africa. The stigma and fear of stigma can stop women from accepting preventive measures, getting tested, disclosing their status, accessing treatment and care and the adherence to medication. HIV stigmatisation comprises of avoidance, segregation, rejection, loneliness, violent behaviour, service denial, uncomfortable social relations and guilt.

The findings of the study conducted by Abrahams and Jewkes (2012) in Cape Town, South Africa have shown that participants were alert about stigma and displayed fear of stigmatisation and discrimination. The concealment of their HIV status was associated with fear of gossip and insults, daily conflicts as well as the fear of being perceived as a disgrace to their families, friends and the community at large. Tsebe (2016) conducted a study in Limpopo, the findings show that the community holds the mentality that WLW-HIV are at risk of death right away after the diagnosis. The findings show that the community have conclusions that the virus correlates with death. This mentality that associates death with HIV makes communities have negative attitudes towards people infected with HIV, further ill-treating, name-calling and alleging promiscuity towards them.

2.3 CONCEALMENT OF HIV POSITIVE STATUS

According to Rouleau, Cote and Cara (2012) WLW-HIV in Canada are concealing their status because they are under the risk of prosecutions for HIV concealment and exposure or transmission. Women are mostly affected in the environment and places where concealment exposure and transmission is criminalised. Women are always vulnerable because they are the ones who will know their HIV status often through antenatal HIV testing strategies. They are later blamed by their partners for introducing the illness in the family. Women meet the difficulties in talking about the use of condoms in their relationships because of gender-based violence, power inequities, sexual and cultural norms. This was further ascertained by Knight, Krusi, Carson, Fast, Shannon and Shoveller (2018) who argues that Canada experienced the increasing number of HIV positive defendant prosecuted for failing to disclose their status to their sexual partners. The legal framework that governs Canadian HIV non-disclosure is increasing the criminalisation of HIV concealment, failing to prevent the transmission while causing harm to other people.

WLW-HIV view concealment of their status as a plan to protect themselves from stigma and rejection. Concealment helps them to avoid lots of questioning and scrutiny from their immediate family members. Women develop a strategy of hiding their HIV status to all their family members including their sexual partners. WLW-HIV have feared that if their sexual partners can be aware of their status they will react with violence and accuse them of being responsible for the infection. This fear channels them to have coping mechanisms of disclosure either avoidance or secrecy to protect themselves from stigma and violence Greeff (2013).

In the study conducted in Tanzania by Lugalla, Yoder, Sigalla & Madihi (2012), it is stated that disclosure is hard and a complex personal matter that includes life-threatening, stigmatized and transmissible infection. There seems to be a level of normality when WLW-HIV does not talk about their illness when they look forward to or there is an occurrence of stigma and discrimination. The common practice of the concealment is created by the perception and reality that disclosure is not always helpful, encouraging or valuable to the individual. In the view of the public, concealment is less risky as disclosure poses a higher risk since individuals can never be certain of how the response and the reaction of the family members would be should they disclose. According to Seid, Wasie and Admassu (2012) WLW-HIV in the Northern-East of Ethiopia WLW-HIV are unable to disclose their status because they believe that their disclosure will result into physical abuse, lack of psychosocial support or a negative reaction from the family members. The study further showed that fear in most cases is an obstructive force to disclosure.

Maman, van Rooyen and Groves (2014) in their study that was conducted in South Africa, it was uncovered that other participants did not disclose their HIV positive status to any family members. The study shows that the participants chose to conceal their status because of the previous tension and anxiety they have experienced with family members. Some women conceal their status because of their love to protect their family members from fear and to protect their physical wellbeing. According to Ramlagan, Matseke, Rodriguez, Jones, Peltzer, Ruiter and Sifunda (2018) in their study that was aimed at examining the prevalence of HIV positive status disclosure and nondisclosure among HIV positive pregnant women in rural South Africa, shows that most of the participants were having partners but the higher number of the participants conceal their HIV positive status to them. Even those who were having partners but not staying with them often concealed their status to their partners.

Additionally, the findings showed that participants who were pregnant attending antenatal care and were diagnosed with the HIV positive status demonstrated a slight chance for disclosure. The study revealed the higher level of participants' concealment of their HIV positive status. Mampa, Malema and Lekhuleni (2015) showed in the study that was conducted in Limpopo that disclosure of an HIV positive status is still the main challenge for WLW-HIV. Most of the participants in their study indicated their preference for concealing their status than to expose themselves their personal information to the members of the family. Their main concern is the feedback they often receive from the people they will be disclosing their personal information to.

2.4 IMPACT OF HIV/AIDS ON WOMEN

Globally different impacts can affect WLW-HIV such as loss of income in the family because of death, unfitness to work because of the symptoms of the virus and on the other hand, the inability of the infected women to carry out their household chores. WLW-HIV with other symptoms related to the virus are often viewed as a burden to their family members for health care and households chores. Their inability to work can also cause more burden to the children and can affect their education negatively (UNAIDS, 2014).

The study by Reif, Whetten, Wilson, McAllaster, Pence, Legrand and Gong (2013) that was conducted in the Southern United States of America argues that deteriorating health as a result of HIV is associated with poverty. They further argue that communities with a compromised socio-economic status have a higher rate of HIV and a higher rate of fatality cases. Time without number, women are the ones faced with a high prevalence of HIV as compared to men. They continue to carry the greater burden of HIV in the Sub-Saharan Africa with an unclear pattern of change in the gap between men and women (Hegdahl, Fylkesnes and Sandøy, 2016). The contributory factors to these differences in most African countries include; the differential effects of age, marital status and occupation (Sia, Onadja, Hajizadeh, Heymann, Brewer and Nandi, 2016).

Mushi (2012) conducted a study in Muhimbili Health Information Centre, Dar-es-Salaam and it indicated that 49% of their patients who conceal their status usually experienced physical violence, 38% had anxiety symptoms while 25% reported a high level of depressive symptoms. In the study, the findings further indicate that even though during voluntary counselling and testing (VCT) services patients are encouraged to disclose their serostatus, on the contrary, the majority of women did not share their status with anyone. Most of the women feared that their partners will abandon them and some will also abuse them physically.

In a study conducted in Somalia by Kulane, et al.(2017) women hold a view that HIV causes the degradation of the social fabric of the society. They reported about the families that rejected their members who have HIV, including young children. Caring for a family member with HIV depleted material and emotional resources of affected families, leading to poverty and hopelessness. Social networks are broken down from every side over HIV.

According to Kiranga, Lumala and Musebe (2018) study conducted in Kenya, some factors make WLW-HIV conceal their status to their immediate families. Those factors were stated as fear, communication skills, privacy and anything to do with their spousal factors. In their study, WLW-HIV indicated that they conceal their status because they have fear of being stigmatised, fear that they will bring the virus at home, and having the virus can be viewed as immoral by other family members. Those women who are married have the fear that their spouses may become unfaithful; there may be a separation between couples, violence, shame, spouse moving out of the house, gossip and rumours that can be spread to the in-laws. The belief from WLW-HIV is that if no one knows about their status, they will live like ordinary people.

Disclosure of HIV positive status can reveal sensitive details of the person’s health status and other information that one want to keep as private. It can damage individual’s privacy and can have negative consequence, such as social isolation, labelling, discrimination and stigma. It can also cause an individual to lose employment and housing. Public health surveillance is needed for appropriate medical care and non-health purposes such as law enforcement policies or insurance. They will balance and protect the privacy and autonomy of individuals with HIV status (Karim, Churchyard, Karim & Lawn, 2010).

In the results of the qualitative study that was conducted in Johannesburg, South Africa, Gilbert and Walker (2010) revealed that families play a major role in positively or negatively supporting the family member living with HIV. The results further indicated that families often isolate or embarrass their family member who is living with HIV positive status at the extremes, refusing to share cutlery, cups, plates and bathroom with members infected with HIV. Others conceal their status with the fear of death in the case where they disclose, especially to their spouses. Others are discouraged to disclose due to lack of knowledge in the society where others associate HIV with leprosy and other deadly diseases, further justifying social discrimination.

The outcomes of the study by Mampa, Malema and Lekhuleni (2015) that was conducted in Limpopo Province, have demonstrated that the participants have negative thoughts about disclosure. The participants have shown fear of rejection as they are viewed as immoral persons with uncontrollable behaviour by the community. The participants further indicated their main challenge is the fear of being judged by their families and loved ones. The false impression about an HIV positive status results in loss of self-esteem and confidence.

Another study that was conducted by Sekgoka (2013) in South Africa, Limpopo Province, also suggested that some of the participants as sole providers in their families found it difficult to disclose because of their role in the family. Some of the participants were disturbed by their discovery of their HIV positive status while they had no occupational stress before. Other participants faced retrenchment because of many sick leaves and health-related excuses at the workplace.

The findings of the study further showed that other participants resigned because they were no longer able to work efficiently in their daily working programmes. Some of the participants experience low self-esteem because of an HIV positive status. There is further loss of hope in life because of realisation that there is no cure for the virus further leading to suicidal attempts as a result of hopelessness and the rejection by members of the family (Ramovha, Khoza, Lebese and Shilubane, 2011).

2.5 THE PREVALENCE OF HIV POSITIVE STATUS CONCEALMENT

According to the study by Vreeman, Gramelspacher, Gisore, Scanlon and Nyandiko (2016) that was conducted in United Kingdom, there is a higher prevalence of HIV concealment among black Africans and other non white ethnic groups. Despite the counselling offered at health facilities about the HIV disclosure, WLW-HIV still conceal their status to their partners. The prevalence of non disclosure was observed to be higher among people aged 60 years as compared to other groups in the United Kingdom.

The findings of the study by Kinuthia, Singa, McGrath, Odeny, Langat, Katana, Ng’ang’a, Pintye and John-Stewart (2018) that was conducted in Kenya with 2522 mothers attending prevention of mother-to-child HIV transmission have shown that 71% of HIV-infected mothers and 1% of HIV-uninfected mothers had HIV-infected partners. Overall, 125 of the 2522 (5%) mothers included in the analysis reported non-disclosure of HIV status to their partners. The proportion of HIV-infected women who did not disclose their status was significantly higher 13% (53/ 420).

2.6 CONCLUSION

This chapter summarised the views of various scholars on the concealment of an HIV positive status by WLW-HIV. Pieces of literature still suggest that WLW-HIV are still reluctant to disclose their status to their immediate family members because of the stigma and lack of more knowledge about HIV/AIDS. There is still a negative belief about the illness. Chapter 3 will focus on the research methodology that the researcher followed through the process of the study.

CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

In the previous chapter, the researcher presented a detailed review of literature as deemed relevant for the present study. In the present chapter, the researcher presents a detailed discussion of the research method, design, research site, inclusion and exclusion criteria, sampling, data collection and analysis processes, quality criteria and ethical considerations.

3.2 RESEARCH METHOD

The researcher chose the qualitative method. Qualitative research is defined as an inductive type of enquiry in which the researcher generally explores meanings and insights in a given situation. It often makes use of purposive sampling, open-ended and semi-structured interviews in its data collection and analysis techniques (Mohajan, 2018). Qualitative research is an inductive other than a deductive research method that favours a naturalistic observation and interviewing other than the quantitative methods of research that are deemed de-contextualising. It further entails a significant degree of closeness and lack of alteration on the research conditions (Padgett, 2011). The researcher conducted in-depth interviews to explore and describe the concealment of HIV positive status by women living with their immediate families.

3.3 RESEARCH APPROACH AND RESEARCH DESIGN

The researcher followed the qualitative research approach in conducting the study. The researcher’s interest is on understanding the concealment of HIV positive status to the immediate family by women at selected villages in Limpopo province, hence the qualitative method approach to this study. The main function of a research design is to explain how the researcher will find answers to the research questions. The research design sets out the specific details of one’s enquiry. It often includes the data collection strategies, the sampling strategy, the frame of analysis, and the time frame (Kumar, 2011).

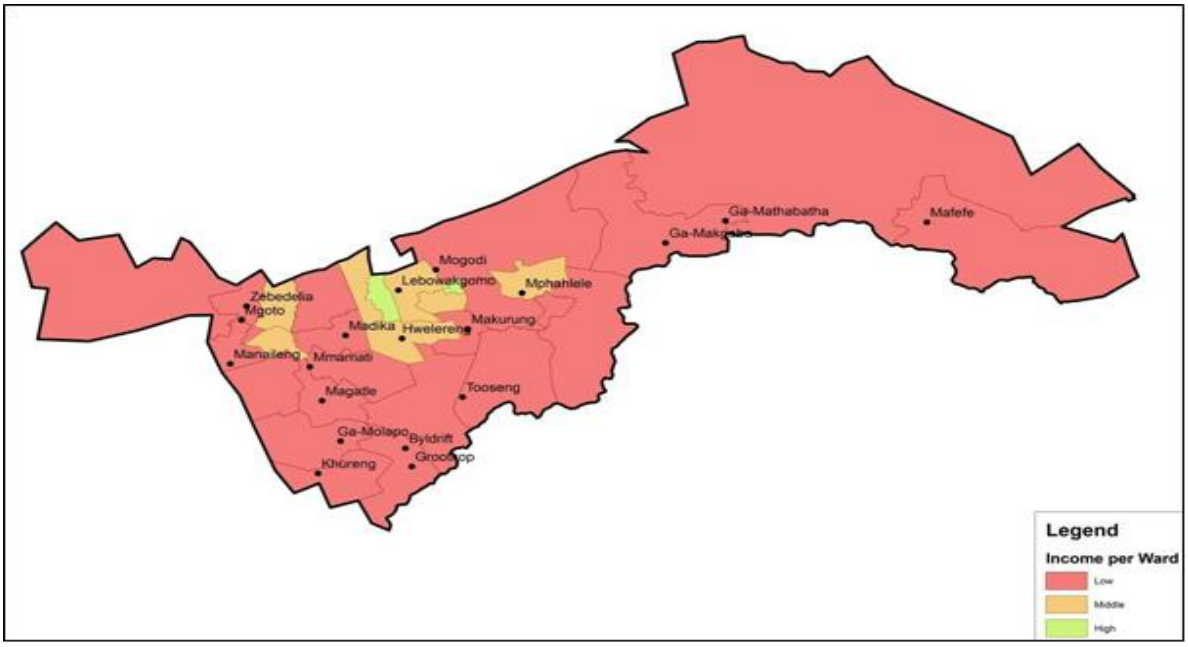
The researcher used the phenomenological study design which focuses on the experiences of concealing illness to immediate family members by WLW- HIV (Martin, Sugarman and Slayney, 2015). According to Padilla-Díaz (2015) there are different types of phenomenology. For this study, the researcher used the descriptive or hermeneutical phenomenology which is aimed at describing the participant's life experiences about the occurrences, in this regard, the experiences of concealing illness to immediate family members by WLW-HIV. A research study classified as a descriptive study attempts to describe systematically a situation, problem, phenomenon, service or programme, or provides information about, the living conditions of a community, or describes attitudes towards an issue. The main purpose of such studies is to describe phenomena in respect of the issue/problem under study (Kumar, 2011).

The researcher opted for the phenomenological study design due to its ability to capture as much in-depth information as possible as experienced by the participants. The design helped the researcher to understand human behaviour from the participant's point of view in a naturalistic setting. Phenomenological study design was used to better understand the lived experiences of WLW-HIV positive status concealing their illness to their immediate family.

3.4 Study site

The researcher conducted the study at selected villages that are served by Lebowakgomo Clinic that falls within Lepelle-Nkumpi Municipality, within the Capricorn District in the Limpopo Province. Those villages that are served at Lebowakgomo Clinic are Mamaolo, Makurung, Mogodi, Serobaneng, Phalakwane, Hweleshaneng, Podungwane and Sekurwaneng. The map of the study site is attached as Figure1 below. The language used by the residents in the study site is Sepedi.

Figure 1: Map of Lepelle-Nkumpi Municipality showing the selected villages served at Lebowakgomo clinic



3.5 Population

According to Sekaran and Bougie (2013) population is defined as the entire group of people, events, or things of interest that the researcher would like to investigate. The population for this study was on WLW-HIV who were concealing their illness to their immediate families at villages served at Lebowakgomo clinic in Limpopo Province.

The researcher had access to a database of 825 individuals who are taking ART from the Lebowakgomo Clinic. Out of them, 261 were males and 25 were children of 16 years and below, leaving a remainder of 539 women. From these women, 25 had not disclosed their HIV positive status. This is the population from which the researcher sampled 10 participants, which is 40% of the HIV positive women who did not disclose their HIV positive status.

3.6 Sampling

According to Gentles, Charles, Ploeg and McKibbon (2015), sampling is the act, process, or procedure whereby the researcher chooses the participants from the component of the population with the intention to determine parameters or characteristics of the whole population. The researcher used a purposive sampling method from a population of WLW-HIV at the identified site. Purposive sampling is the sampling technique in which the researcher depends on his /her judgement when choosing the members of the population to take part in the study (Black, 2010). Participants were selected from the database through the consideration of the inclusion criteria. The researcher interviewed all participants, one by one, until data saturation. Data saturation is reached when there is enough information from the participants such that there are no new information emerging from continuing with the interviews (Burmeister & Aaitken, 2012). As a result, 10 participants were selected and interviewed.

3.6.1 Inclusion criteria

Inclusion in the study was based on the following criteria:

- The participants were women concealing their HIV positive status staying with their immediate families.
- Those women are staying at villages served by Lebowakgomo clinic in Limpopo Province.

3.6.2 Exclusion criteria

Women who are mentally unstable even though they were concealing their illness to their immediate family members were excluded in the study.

3.7 Data collection

Data collection techniques are defined as processes that are employed by researchers through the process of research in order to systematically collect information about their object of study and the setting they occur in (Cln, 2013). Before the commencement of each interview, the researcher introduced herself to each participant and further explained the purpose of the study. She explained to each of them about voluntary participation and confidentiality. She further obtained consent in writing from each participant before commencing with the interview.

The researcher conducted semi-structured interviews with the participants. In conducting these interviews, the researcher took field notes on the following important aspects which improved the quality and value of the data gathered: the type of questions that were asked, questioning strategies and the interview environment. Furthermore, the researcher used an audio recording device to capture the data verbatim.

The researcher used the interview guide which contained the central question that was asked to all the participants followed by the possible probing questions. The interview guide was written in English and was translated to Sepedi. The women were interviewed in Sepedi which is their home language. The interview guide is divided into three sections which are section A, B and C. Section A consist of biographical data, section B consist of the central question and section C consists of the possible probing questions. The central question was: *What are your experiences of concealing HIV positive status to your immediate family members.*

Some interviews were held in the Social work services office, while others were done at the participants' homes for purposes of their privacy and comfort. The researcher used the interview guide which was translated from English to Sepedi as all the participants use Sepedi as their home language. See appendix 1 and 2 for the English and Sepedi versions respectively.

3.8 Data Analysis

According to Yung (2012), data analysis is the process that concerns itself with the derivation of meaning from the data collected. The data analysis process follows the Interpretative Phenomenological Analysis (IPA) steps. According to Smith and Osborn (2015), IPA is a qualitative approach that aims at providing detailed phenomena of people's lived experiences other than relying on pre-formulated theoretical views. The following steps were followed in the data analysis process as suggested by Eatough and Smith (2008):

- Step One: Managing the Information Collected

The researcher made a verbatim transcription of all the audio recordings and translated the transcripts from Sepedi to English. The transcripts were organised into folders for convenience during analysis. A sample of the transcripts is attached as A.

- Step Two: Memoing

This is the step during which the researcher has familiarised herself with the data collected through reading the transcripts several times.

- Step Three: Describing, Classifying and Interpreting

This stage involves noting the commonalities in the phenomena that are derived from the data. The researcher revised the field notes and transcripts to categorise the data into themes and sub-themes that have emerged, further interpreting and deriving meaning from those categories.

- Step Four: Representation and Visualisation

During this stage, the researcher presents all the interpreted data and the themes in an explainable manner such that it will make sense to the reader. These results are presented in a way that addresses the aim and objectives of the study as presented in Chapter 1.

3.9 Trustworthiness

This concept refers to the demonstration that the evidence for the results reported is sound and when the argument made based on the results is strong (LaBanca, 2010). According to Elo, Kääriäinen, Kanste, Pölkki, Utriainen and Kyngäs(2014), trustworthiness entails the availability of rich, appropriate, and well saturated data. The aim was therefore to minimise factors that may create bias in the research findings. Furthermore, the process of research was outlined in detail, in respect of the processes of data collection, sampling, analysis and reporting. According to Polit and Beck (2012), trustworthiness in qualitative research encompasses four aspects which are confirmability, transferability, credibility and dependability which are explained below.

3.9.1 Confirmability

This concept refers to the extent to which the results of a study can be confirmed or concurred to by other researchers. Confirmability further entails the objectivity, which is the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning (Elo, et al. 2014). In the present study, the data in the form of transcripts, and themes were submitted to the supervisor for confirmation and supervision of the data.

3.9.2 Transferability

Transferability can sometimes be coupled with generalizability, which according to Tracy (2010) is the ability of the study to be applicable and valuable across a variety of situations and contexts. Transferability entails the invitation of the reader of the research document to make connections between elements of a study and their own experience.

In this study, transferability was achieved through the researcher making a thick description of the research process that would allow the readers to understand how the results can be applicable to other settings.

3.9.3 Dependability

Dependability entails the stability and consistency of the results over time and across conditions. The concept also involves the ability of the same research processes that are done separately to yield the same results (Billups, 2014). Dependability was acquired by reporting the processes within the study in detail, thus allowing future researchers to repeat the work. The research processes were outlined for future reference.

3.9.4 Credibility

Anney (2014) defines credibility as the confidence that is placed in the truth of the research findings. It has more to do with the research findings' representation of the original data as presented by the participant's original data and the interpretation of the participants' original views. To ensure credibility in the study, the researcher had some review discussions with peers. Credibility was also ensured by the prolonged engagement with WLW-HIV and concealing their status to their immediate family through face to face interview.

- Prolonged engagement

This is the process of building trust and rapport with the participants to obtain more detailed responses (Houghton, Casey, Shaw, Murphy, 2013). For the enhancement of credibility the researcher spent some time with each participant on the day of interview in order to built rapport and explain the purpose of the study and the interview procedure. The researcher promoted the process by giving enough time during data collection with the participants.

- Triangulation

This is a process of using multiple sources to draw conclusions (Casey & Murphy 2009). The researcher used methodological triangulation to gather data by means of different data collection methods which are in-depth interviews, observation, recording of data through audio tape and field notes of observations during the process of interview.

3.10 Bias

Smith and Noble (2014) define bias as the distortion of research results due to the factor that was not allowed for in their derivation. Bias may occur at any given stage through the research process. The researcher used bracketing with the intention to minimise bias through the process of research.

Bracketing in qualitative research helps in the minimizing of bias in the study. It is a method used by researchers to prevent the potentially harmful effects of unacknowledged bias related to the research. Bracketing helps the researcher to minimise errors and bias through all the research stages right from selecting a topic and population, designing the interview, collecting and interpreting data, and reporting findings. The opportunity for sustained in-depth reflection may enhance the acuity (Tufford & Newman, 2012). For this study, bracketing was carried out through writing reflective memos that outline the whole data collection process. These memos are meant to facilitate the process by giving the researcher an awareness of some of the emotional processes that may have surfaced during the process.

3.11 ETHICAL CONSIDERATIONS

Researchers have to display ethical behaviour or conduct when undertaking research investigations and when interacting with participants. This ethical behaviour is prescribed by a set of written rules called ethical considerations. They determine what can and cannot be done when doing research (Merriam-Webster Online Dictionary, 2012). The following ethical considerations were observed:

3.11.1 Ethical Clearance

The research proposal was submitted to the School of Health Care Sciences and the Faculty of Health Sciences for approval. Ethical clearance for the study was then requested from the Turfloop Research Ethics Committee (TREC) of the University of Limpopo. The ethical clearance certificate was provided and it is attached as Appendix 4.

3.11.2 Permission to conduct the study

The researcher conducted the study after receiving ethical clearance certificate from Turfloop Research Ethics Committee (TREC). Permission to collect data from participants was requested from the Department of Health and is attached as Appendix 5, a letter granting permission to collect data is attached as Appendix 6.

3.11.3 Voluntary participation and informed consent

All participants in this study were informed that there shall be no monetary incentives as their participation is voluntary. They were informed that they will be no punishment to withdraw from participating in this study at any point in time. The researcher further outlines the nature of the research, its intentions and her expectations from participants. An information leaflet is attached as Appendix 7 for English and Appendix 8 for Sepedi respectively. Those who agreed to participate were asked to sign a consent form and a consent form is attached as Appendix 9 for English and Appendix 10 for Sepedi respectively.

3.11.4 Confidentiality, privacy and anonymity

Confidentiality refers to the high classification of information such that access by third parties to such information is partially limited or totally prohibited (De Vos, Strydom, Fouche & Delport, 2011). The information given by the participants was not revealed to anybody other than the supervisor of this study, and the researcher has ensured that confidential information provided by the participants will be kept as such. Identifying credentials that may assist a third party to identify the participant shall be represented by pseudo credentials.

Privacy refers to the process of safekeeping the personal dignity and the minimisation of the intrusiveness of data collection methods by the researcher (Cohen-Almagor, 2005). The researcher ensured that the interview environment was private, safe and convenient for the participants to minimise distractions.

Anonymity means that the researcher or other people associated with the research project will not be able to identify the participants, as the information collected does not contain any identifiable information and the risk of being able to feature data to particular individual is low (Bickford and Nisker, 2015). To ensure anonymity in the present study, the researcher has ensured that the names, addresses and other identifying information were replaced with an alias and sequential numbering where needed.

3.11.5 Anticipated harm

There was a potential for harm during data collection when doing interviews with the participants. The possibility of harm during the interview was in the form of participant emotional breakdown. The harm was in the form of emotional breakdown during the interviews. In the event of emotional breakdown, support was provided .Other participants needed further management and were referred for professional help.

3.3.12 CONCLUSION

This chapter discussed the research methodology that was followed when conducting the study. The research design, study site, population, sampling method, data collection, data analysis, measures to ensure trustworthiness and ethical considerations were also discussed. Chapter 4 will discuss the research findings and literature control.

CHAPTER 4
FINDINGS AND LITERATURE CONTROL

4.1 INTRODUCTION

The previous chapter discussed the methodology, which is the roadmap that was followed during the study process; this chapter aims to present in detail the findings of this study, which was focused at understanding the experiences of concealing HIV positive status to the immediate family by WLW-HIV. The chapter further outlines the literature control that contextualises these findings. Amongst the factors discovered by this study is that the process of disclosure is difficult given the dynamics which are experienced by the WLW-HIV. The chapter presents the themes and subthemes which emerged during the research process.

4.2 DEMOGRAPHIC DATA OF PARTICIPANTS

The research was conducted in the selected villages that are within the catchment area of the Lebowakgomo Clinic, Limpopo province. Ten participants were selected through the purposive sampling process as discussed in the previous chapter and agreed to participate in the study. The three participants were residing at Serobaneng, two were from Makurung, three from Mamaolo, one from Hweleshaneng and one from Mogodi. They were interviewed through the semi-structured interview.

The sample comprised of 10 females between the ages of 22 and 62. All of the participants are on treatment for HIV for the duration which ranged from two months to 15 years. The participants’ level of education ranged from Grade 4 to Grade 12. One participant is employed as a domestic worker, one as a Community Health Worker; two are pensioners while six participants are unemployed. The study by Ramlagan, Matseke, Rodriguez,Jones, Peltzer, Ruiter and Sifunda (2018) that was aimed at assessing the determinants of HIV status disclosure among pregnant WLW-HIV indicates that women who are diagnosed during pregnancy are less likely to disclose their HIV status to the family. The participants responded to the questions by referring to their first-hand experiences. Table 4.1 summarizes the demographic profile of the participants.

Table 4.1: Demographic Data of Participants

Number	Age	Educational status	Marital status	Employment status
01	51	Grade 07	Married	Domestic Worker
02	49	Grade 06	Married	Unemployed
03	22	Grade 11	Single	Unemployed
04	29	Grade 12	Single	Unemployed
05	43	Grade 10	Single	Unemployed
06	56	Grade 07	Married	Unemployed
07	44	Grade 12	Single	Community Health Worker
08	47	Grade 11	Widow	Unemployed
09	60	Grade 06	Widow	Pensioner
10	62	Grade 04	Widow	Pensioner

4.3 Themes and Subthemes

The results of this study yielded four main themes and 12 subthemes. Themes in qualitative research are described as the key product that brings out practical results from the field (Vaismoradi, Jones, Turunen and Snelgrove, 2016). Themes are used as points and ideas that put together the group of repeating data that will help the researchers to answer the study question. The themes and subthemes are summarised in Table 4.2 below.

Table 4.2: Themes and sub-themes

NUMBER	THEMES	SUB-THEMES
1.	Managing to live with a secret	1.1 Women continuing concealment of HIV positive status. 1.2 Women pointing fingers, unpleasant and unhappy 1.3 Scepticism about disclosing to children
2.	The method used to conceal HIV positive status	2.1 Telling a lie about frequent visits to the clinic 2.2 Hiding of HIV medications
3.	Reasons for concealing their status	3.1 Lack of trust in disclosing HIV positive status 3.2 Fear of prejudice by family members 3.3 Fear of Abandonment and rejection by family members as consequences for disclosure of HIV positive status 3.4 Fear of blame and humiliation by family members as the result of HIV positive disclosure 3.5 Misconceptions about HIV positive status 3.6 The view of an HIV positive status as a predicament 3.7 Denial of one's HIV positive status
4.	Lack of support and a target of disclosure	

4.3.1 Theme 1: Managing to live with a secret

The study has revealed that some participants lived with their mothers, mother-in-law, siblings and their children while others lived and grandchildren. One participant lived with her husband while the other one's husband works in another province, one participant lived with her mother, siblings and child following the death of her grandmother who was buried for about a week at the time of the interview. Other participants have reported their preference to disclose their HIV status to their mothers as opposed to their siblings although none of the participants had disclosed their status to anyone in the family. The participants still used different strategies to conceal their HIV status from their immediate family.

A study by Owuor, Locke, Abigail, Heyman and Clifton (2016) states that most strategies of concealment used by participants was keeping all HIV-related resources away from living rooms and other spaces that they share as a family that they are concealing their status from. Njozing, Edin, San Sebastián and Hurtig (2011) indicated that counselling is the main factor that can encourages the patients to disclose after testing.

4.3.1.1 Subtheme: 1.1 Women continuing concealment of HIV positive status

This study has shown that none of the participants had disclosed their HIV positive status to their immediate family even though they stay in the same household. These WLW-HIV still keeps their illness as a secret because they view disclosure as associated with the dilemma.

Participant 04 added:

> *"I am able to hide my treatment because when is time for my medication I go to my room after that I sleep."*

Participant 05 supported:

> *"…. Now the problem is I am living a lie in my family. They only know that I am taking epileptic medication".*

The findings are supported by Elwell (2016) who argue that healthcare providers emphasize that most patients at Prevention of mother-to-child transmission consulting rooms are scared to disclose their HIV status to husbands because of fear of divorce. These patients have shame to even return to the clinic for follow-up consultations. They have viewed several situations that can unintentionally disclose their HIV/AIDS status and encourage stigma such as being seen at the hospital or clinic, entering a room designated for Prevention of mother-to-child transmission patients, having medical charts marked with their HIV diagnosis, and carrying ART treatment. Women developed a number of strategies to conceal their HIV/AIDS status and avoid stigma by travelling to distant clinics to ensure anonymity, and hiding of their ART treatment.

These findings are supported by the study conducted by Horter, Bernays, Thabede, Dlamini, Kerschberger, Pasipamire, Rusch and Wringe (2019) which state that anticipated stigma was persistent within people living with HIV status. For their participants to avoid stigma through being singled out or treated badly by those around them, they conceal their HIV status. Concealment is viewed as a normal solution that guarantees that life goes on as if nothing had changed. Their concealment of the status is also perpetuated by messages they receive from some of the health workers during their treatment initiation and follow-up consultations at their clinics. The secrecy approach prohibits helpful effects such as better social support from the family members and the decrease of stress level to the individual affected.

4.3.1.2 Subtheme: 1.2 Women pointing fingers, unpleasant and unhappy

Some of the participants view their status as the entanglements and punishment from their ancestors for their bad deeds. They believe and have the feeling that their late husbands are angry at them.

Participant 09 said:

> *"It is like I have been punished for my sins. I should have left everything and stay alone as a widow, now this is the end products. Maybe my husband was angry wherever he is."*

Participant 01 reported:

> ***"**I am a person who always went to the clinic for family planning. Every time when I went to the clinic, they would draw blood from us to test for HIV. For all this while, I was HIV negative. My husband only came home from Gauteng for Christmas in 2012 and we shared the blankets (referring to a sexual intercourse). He went back after the New Year and when I went to the clinic in June on my return date, I was not well I did the test. After testing me, they told*

> *me that I am HIV positive. I think he is the one who infected me with HIV and I don't even want to tell him or my children."*

Gyamfi, Okyere, Enoch and Appiah-Brempong (2017) indicate that the main factors influencing the decision to disclose HIV positive status is a desire to protect the family from shame. In the participant's communities, some illnesses are viewed as disgraceful and are caused by the supernatural forces when a person has upset the gods.

This study has not only indicated the level of disbelief but also the bitterness that goes with it. In one case, the participant reported with bitterness, how she thinks she has contracted the virus further blaming her husband for having infected her as he was living in another province while she was at home most of the time, not having any sexual contact with anybody except her husband. She has therefore reported about her difficulty with disclosing her HIV status to her living husband or her children.

The findings of the present study are supported by Wardlow (2016) who maintain that the participants relate the HIV/AIDS illness with immorality and divine punishment for their sins. For some of the participants, HIV/AIDS is the way through which God punishes the person who made sexual sin with a terrible and decayed body.

Higher volume of women diagnosed with HIV made them more vulnerable to blame, which further support the fact that women access HIV care in far greater numbers than men. In 2011, 60% of women in South Africa were receiving ART, compared to 41% of their male counterparts (Cornell 2013).

4.3.1.3 Subtheme: 1.3 Scepticism about disclosing to children

The results of this study have further suggested that the participants, irrespective of their children's age, were still sceptical about disclosing to them viewing them as still young. Some of the participants lived with their children whose ages ranged between one and 45 years. Even participants who have children around 45 years viewed them as still young to disclose to.

Participant 10 said:

> “*My daughter is around 45 years and having her own children. I cannot disclose to her because I see her as a child. I cannot talk about such news with her. How will she feel? She will think I was sleeping all over after the death of her father.”*

Participant 05 added:

> “*How will I begin to tell them? I’m left with boys who abuses dagga at home. Moreover, boys are boys. They are still young to be told this kind of news.”*

These findings are supported by Gyamfi, *et al* (2017) who argues that most of the reasons for concealment were inaccessibility to the disclosure target and the fear of upsetting or worrying the target of disclosure, especially if the disclosure target is the child of the person living with HIV. Children’s age was seen as the main barrier to disclosure. Most women view children younger than 13 years as immature and unable to understand the illness. Concealment of the status assists in avoiding the negative attributions and labelling from the community.

The scepticism has contributed to the lack of disclosure to their children. This is supported by Hunleth (2013) that children who lived in a low-income and heavily HIV-affected residential area in Lusaka, more of whom lived with their parents or guardians who had HIV face particular challenges, concerns, and insecurities when caring for and living with persons who is HIV positive.

4.3.2 Theme 2: Method used to conceal HIV positive status

This study has shown that due to the lack of intention in disclosing their statuses to their immediate family, WLW-HIV have developed some methods which they use. This will be illustrated further in the coming subthemes.

According to Kheswa (2017) both men and women use defensive reactions to maintain secrecy of their HIV positive status. Their participants who are WLW-HIV married or in cohabitation relationship, are unable to take their treatment when their husbands are around. They opt to skip the treatment due to fear of disclosure. They also choose the confidential ways of receiving their ART support and care. Home delivery of their ART medications is not preferable to them as they can be exposed to the family. The study also showed that participants had desired to be helped by community-based support from WLW-HIV who had received adequate training.

4.3.2.1 Sub-theme: 2.1 Telling a lie about frequent visits to the clinic

This study has revealed that participants opt to keep a secret about their HIV positive status and the dates on which they visit the clinic for follow-up visits as well as the reasons for their frequent monthly visits to the clinic.

Participant 06 said:

> *"I am feeling ashamed to talk about it. I was always making excuses when is my monthly check-up. Luckily enough I'm now taking care of my daughter's child, visiting the clinic with her is not much difficult as she is still young and receives immunisations."*

Participant 10 added:

> "*I learn every time I visited the clinic, even though going there is a problem. I have told my children that I am having high blood pressure and I am collecting chronic medication for it at the clinic."*

In another study by Clouse, Schwartz, Van Rie, Bassett, Yende, and Pettifor (2014), WLW-HIV and pregnant reported that their pregnancy is the justifiable reason to take medication and to attend the clinic. Their main concern is when they are no longer pregnant; they will not have reasons to go to a clinic which will result in defaulting the treatment. Other participants have indicated that they ended up lying about taking medication for high blood pressure.

The results of the study were supported by Ewell (2016) who argues that other participants, as a way of concealing their status to their families, often visit healthcare facilities secretly to collect medication so that their families will not know. In the study conducted by Kiranga (2018) WLW-HIV protects themselves from the negative consequences of disclosure by keeping their status as a secret. Fear of stigma pushes these WLW-HIV to avoid being seen in their local Health care centres. Some are missing their appointments while others change their treatment centres and travel many kilometres to receive their treatment as a way of reducing the risk of their HIV status being known locally.

According to Maeri, Ayadi, Getahun, Charlebois, Akatukwasa, Tumwebaze, Itiakorit, Owino, Kwarisiima, Ssemmondo, Sang, Kabami, Clark, Petersen, Cohen, Bukusi, Kamya, Havlir and Camlin (2016) even if their participants are still healthy, their clinic visits and their daily use of medication can expose them to the risk of unintentional disclosure. Some opt to hiding their ART treatment to their family members, which leads to defaulting and treatment interruptions.

4.3.2.2 Sub-theme: 2.2 Hiding of HIV medications

The results of this study revealed that WLW-HIV have developed the strategy of hiding their medications to their family members to avoid the unintentional disclosure when seen.

Participant 07 said:

> *“...I should be careful to protect my family at all times. I make sure that my medications are not lying around where anybody can see them.”*

Participant 01 added:

> “…*when going to sleep outside like going to the funerals overnight I take my medication in the empty bread plastic. Even at home, I put my medication safely in my travelling bag.”*

The study by Arrey, Bilsen,Lancor and Deschepper (2015) show that some participants have a way of concealing their HIV positive status and the treatment they are taking. Their findings have shown that even those who have been on treatment for 20 years still conceal their HIV status and hide away their ART treatment in different containers.

These findings are consistent with the argument by Musumari, Feldman, Tehasrivichien, Wouters,Ono-Kihara and Kihara (2013) who stated that some participants view stigma as the main barrier to HIV treatment adherence. However, this did not affect adherence that much as the participants have developed a way to handle their situation in keeping their HIV positive status a secret and taking their medications secretly when there is no family member around. Others developed the strategies to avoid disclosure to their partners and their children by seeking medical care in the remote facilities, hiding their medications or abandoning care to avoid suspicion and unintentional disclosure. Others disguise by changing the HIV medication containers while others alter their medication-taking routine or skip their daily doses.

This outcome is supported by Hornschuh, Dietrich, Tshabalala and Laher (2017) as they argue that individuals conceal their status because there is no trust in family members or friends. For them to adhere to their HIV treatment individuals develop different strategies to use when taking their HIV medications to avoid unintentional disclosure such as hiding their HIV medication away, or finding excuses so that they can take their medication away from other people.

4.3.3 Theme 3: Reasons for concealing their status

The study showed that WLW-HIV view the illness as the devalued social identities or attribute. They deal with the illness alone because of fear for unforeseen circumstances. Disclosure to their family is not yet their solution for the support system that they need. This theme will be discussed further in the following sub-themes.

The findings of the study by Kiranga (2018) that was conducted in Kenya, WLW-HIV finds it unnecessary to disclose their status to their spouses as they are not emotionally or financially supportive. According to AlegrÍa (2010), disclosure generates doubts about possible responses, since the person disclosing sensitive and personal information is unable to anticipate the meanings that the recipients will give to the issue. For the safety of these women to minimise the risks, they choose to conceal their status.

4.3.3.1 Sub-theme: 3.1 Lack of trust in disclosing HIV positive status

The results have shown that participants concealed their HIV positive status to their immediate family members because they cannot trust them. Most participants who still have their mothers but have shown a lack of trust in them. Some participants have also demonstrated their lack of trust in their siblings.

Participant 05 said:

> *‘’My mother talks too much without timing and she cannot keep a secret. She has talked to my siblings about the many secrets I told her before. Who knows? What if she can also talk about my status? I don’t trust her’’.*

Participant 04 added:

> *‘’My brother drinks too much, I cannot trust him when he is drunk. He can talk about my HIV status and make me regret for telling him. If I make him angry with something he can insult me while also mentioning my HIV status stories.’’*

Other participants have demonstrated the level of trust they had on their mothers who have passed on. They showed that they would have preferred to disclose to their mothers who are late, and cannot trust their partners, children or siblings.

Participant 07 explained:

> *“If my mother was still alive, I would be talking to her with whatever that bothers me. But because she has passed on, I feel like I am alone”*

Participant 08 added:

> *“If my mother was still alive, I would be able to talk to her and she was going to protect and support me without judging me.*

Nyandat and van Rensburg (2017) argues that WLW-HIV decision against disclosing their HIV-positive status to their partners may be motivated by issues such as ability to overcome difficulty associated with fear of abandonment, accusation of unfaithfulness, discrimination, violence and loss of spousal financial support. Women who work away from home fear disclosure because of the belief that they will be blamed for unfaithfulness. Mostly those who previously experienced violence from their partners were less likely to disclose their HIV status.

In the argument made by Arrey, et al (2015) there is a selective disclosure by WLW-HIV to the healthcare professionals due to the treatment they need. According to these women trust is critical during disclosure. The choice of whom to disclose to solely depend on the level of trust one has on the targeted individual. The concealment of HIV positive status is perpetuated by their fear of the taboo of HIV in Sub-Saharan African culture and the level of stigma.

4.3.3.2 Sub-theme: 3.2 Fear of prejudice by family members

The study has shown how some people still have fear of disclosing either due to the humiliation they anticipate from their families upon their disclosure, or the fear of discrimination and being judged. In cases where women are married, their husband’s family tends to blame the women for the disease and for the misery she brought in the family. On the other hand, when the husband is the one with the illness, women are blamed by their husband’s family for not being able to control their men from having extramarital affairs.

Participant 09 said:

> *“The children of these days, when they hear that I am living with HIV, they will be concluding that I am desperate because I am dying. If I tell my kids, they will not even eat the food I prepare, thinking that I will infect them with HIV. They will not even touch me anymore”.*

Participant 03 added:

> *"I have realised that members of my family will get hurt if they can know about my status. They will think about death because even myself I have done several tests because of denial*…."

According to Kiranga (2018) in the study conducted in Kenya, that WLW-HIV conceal their status because of fear. They have fear that they will be blamed for bringing the virus at home, being labelled as immoral and having violated the norm of faithfulness to one partner. These perceptions lead to fights between couples which cause rejection, abandonment and separation or divorce in the family. These women feel that if they conceal their status they can live normally like others.

The findings of this study was supported by Galanoa, Turatoc, Succia, de Souza Marquesd, Negrae, da Silvab, do Carmoa, Fátima Gouveaa, Delmasf, Côtég and Machado (2016) who indicate that being careful is the main aspect of the private life of individuals living with HIV/AIDS as issues connected to the illness are not discussed within family. From this perception, secrecy is a right that their participants have, but it is critical to understand the importance and purpose of the secret. Their participants mentioned many reasons to defend their continuation of secrecy, and some of the reasons were fear of prejudice, rejection, and social isolation.

4.3.3.3 Subtheme: 3.3 Fear of Abandonment and rejection by family members as consequences for disclosure of HIV positive status

The results have further demonstrated how people feel about their families with some participants indicating that they would be discriminated by their family members due to their HIV positive status. They believe that their family members will reject them after the disclosure of their HIV positive status.

Participant 06 said:

> *"My mother will not mind getting a place for me to stay alone because I am sick. She will not even allow my siblings or my sisters' children to touch anything I*

> *give to them. That is the reason I don’t even dream of telling her or anyone in the family. Even if my health can get worse, I would rather die”.*

Participant 09 added:

> *“I will be an orphan. Those children will disown me in front of their paternal uncles. I do not want to be embarrassed and lose my grandchildren.”*

These findings are supported by Bird and Voisin (2013) where participants fear that their status will make them be discriminated and isolated from the community support. Some of the participant’s fear that their status would start to be their main identity, which will exposed them to painful issues, change of important social relationships and harm the reputation of their previous accomplishments. The prospects of the person living with HIV became outshined by the negative labelling and the perception that the person living with HIV is about to die.

The findings of this study were supported by Hallbergc, Kimario, Mtuya, Msuya, and Björling (2019) which revealed that most of their participants concealed their HIV positive status. Their reasons for non disclosure included fear of being blamed, the belief that HIV status disclosure is against traditional practice, fear of divorce, fear of loss of traditional support, fear of being abused, stigma and loss of friends. These women become depressed due to stigma and they are discriminated against because Africans view the mode of transmission of the virus as unclean and evil.

In another study by Arrey *et al* (2015) participants disclosed to the health care professionals because in return they need treatment and care. Most of the WLW-HIV have fear of being stigmatized and mocked after they have disclosed their status to other people. They predict that there would be stigmatized reactions from people who will know their HIV positive status. While some WLW-HIV feared that if they can disclose their status, their family position and practice will be disrupted, as some of them will be abandoned, experience emotional violence from the uninfected spouses after the status was disclosed.

4.3.3.4 Subtheme: 3.4 Fear of blame and humiliation by family members as the result of HIV positive disclosure

The findings of this study suggest that one of the challenges that contribute to the concealment of the HIV positive status by the WLW-HIV is their fear of humiliation by their immediate family members. This further suggests that the participants view their family members as insensitive people who may humiliate them with their HIV status. The participants have therefore shown no interest and no intentions of disclosing to their immediate family members.

Participant 04 said:

> *"My mother is not a good person at all. She will be happy to hear about my status and talk and laugh about it. She can even tell the neighbours about my status. My brother will tease me about my status, especially when he gets drunk. So I will rather keep the news of my HIV status as a secret.''*

Participant 10 added:

> *"I will not even dare telling anyone, even my children. Where will I begin? They will be angry about it and think I was sleeping around, especially after their father's death. My in-laws will celebrate and tell everyone in the community because they think I killed their brother so that I can sleep with other men".*

According to Malik and Dixit (2019) study conducted in India shown that disclosure of one's HIV positive status is seen as a crucial decision, which can result in either positive or negative consequences by the recipient. Their HIV positive participants oppose the issue of disclosure in order to protect themselves and their family from stigma. In the study they indicated different factors that influence the decision of not to disclose such as fear of anticipated discrimination, violence between partners, breaking of relationships and anxiety.

The study by Meseret, Dulla and Nega (2019) have uncovered that participants' non-disclosure was associated with doubts of how the partner is going to react to their status. Their doubt was associated with fear of separation with partners, fear of being labelled as the bad person; fear that confidentiality will be compromised due to anger. WLW-HIV who are in polygamous marriages, have the fear of being labelled negatively in the society as sexually loose. That can result in them been divorced by their partners, which therefore influences their decision of whether to disclose or not to disclose.

This findings of the study is supported by Nyandat and van Rensburg (2017) WLW-HIV decision against disclosing their HIV-positive status to their partner is motivated by several factors such as ability to overcome difficulty associated with fear of abandonment, accusation of unfaithfulness, discrimination, violence and loss of spousal financial support. Women who work away from home fear disclosure because of the belief that they will be blamed for unfaithfulness. Mostly those women who previously experienced violence from their partners were less likely to disclose their HIV status.

The findings of the study are supported by Ekrand, Bharat, Ramakrishna and Heylen (2012) that people living with HIV are blamed for the infection and 82% of their results shown that people living with HIV got what they deserved and 71% believed that HIV-infected people do not care if they infect others.

4.3.3.5 Subtheme: 3.5 Misconceptions about HIV positive status

The findings of this study have demonstrated the relationship between the misconceptions that people have about HIV and its contribution to concealment of the HIV status by WLW-HIV There are negative views that people hold about HIV such as the association of HIV and death or a lower life expectancy which contributes to non-disclosure by WLW-HIV, especially towards their children. The other misconception is that of associating physical contact with the possibilities of infection especially if that contact is with a person living with HIV or anything the person has touched.

Participant 03 said:

> *"Those people will only think about death; they will start to update their burial clubs preparing for my funeral."*

Participant 09 added:

> *"It's so embarrassing to talk about it. I have fear. These children will look at me nasty if they can know. They will no longer eat the food and they will no longer touch me if they can know my status."*

The study by Madiba (2013) suggests that most parents who have seen their relatives passing on because of HIV related causes were scared of disclosing to their children with the thought of instilling fear of parental death in their children.

According to Gausset, Mogensen, Yameogo, Berthé and Konaté (2012) public health prevention campaigns which were held previously spread negative insight and increased the fear of HIV. The old advertisements used in HIV/AIDS awareness campaigns described the illness as unbearable, scary and deadly, by putting their centre of attention to negative images of the sick, dying and blemished persons.

Ekrand *et al* (2012) state that despite the public health awareness that was held globally, their study still shows that 33% of their participants believed transmission of HIV is likely to happen when sharing a public toilet, sharing a glass of drinking water, sharing eating utensils with a person living with HIV. Other findings showed that HIV transmission is possible when shaking hands, working in the same office or sitting close to an individual living with HIV.

4.3.3.6 Sub-theme: 3.6 The view of an HIV positive status as a predicament

The study had shown that most of the participants feel their status should not be other people's burden. They hide their status to their loved ones to avoid giving them heavy load on their shoulders.

Participant 06 said:

> *"I now have a problem of having a dry mouth, sores and diarrhoea most of the time. I am relying on the clinic with these challenges."*

Participant 05 added:

> *"I was going in and out of the hospital and clinic with the help of my brother but I did not have the guard to disclose to him."*

The study by Mackworth-Young, Bond and Wringe (2020) indicates that HIV/AIDS in Malawi is associated with sex, illness and death. HIV diagnosis is viewed as experience that disrupts ones day to day life and identity. According to the findings of these study people aged 50 years and above living with HIV positive status are more likely to experience ill health which is more on declining of the functioning of the immune system, HIV-related illness and non-communicable disease than young adults. The illness also changes how they should manage their day to day lives.

Psaros, Barinas, Robbins, Bedoya, Safren, and Park (2012) show that one of the major concerns about the HIV positive status with WLW-HIV is their view of a distorted body image. They view the distortion as a result of long-term use of ART treatment. This directly affects their ability to get and retain sexual partners while for others, it contributes towards the ending of their intimate relationships.

According to Acheampong, Naab and Kwashie (2017) in the Indian context, group and family associations play an important role in determining an individual's self-image. Disclosing one's serostatus results into greater risk when compared to the cultures where such associations do not play such important role. The decision of disclosing one's serostatus is influenced by the attitude and beliefs of the people in the society. Women have to face several difficulties when they are living with HIV, such as stigma, blame and lack of social support. Living with HIV means dealing with the cultural and social impacts of the deficiency.

4.3.3.7 Sub-theme: 3.7 Denial of one's HIV positive status

Participants in this study have reported difficulties in accepting their HIV positive status, which leads to the suppression of anything to do with their status. Some of them have been living with the condition for over ten years while others have recently known about their HIV status. However, they face the same challenge of accepting their status the same, therefore making it difficult for them to disclose their status to their immediate family.

Participant 02 reported:

> *“I have always heard of HIV positive people and never thought I will be one of them one day. I have not yet accepted the fact that I am positive”.*

Participant 03 added:

> *“I have known about my HIV status in early 2018 and I still can’t believe that it is me who is HIV positive. I still don’t know about how I am going to break this news to my family because I still don’t believe that it is true”.*

The findings of the study by Lyimo, Stutterheim, Hospers, de Glee, van der Ven and de Bruin (2014) states that the stigma of living with HIV creates a huge obstacle for people living with the illness to accept themselves. The stigma and denial contribute to alcohol use which raises the levels of stress and depression. The study further showed that denial and alcohol use impacts negatively on poor adherence to treatment and the quality of life. The denial is therefore directly influenced by maladaptive coping processes.

In another study by Clouse, Schwartz, Van Rie, Bassett, Yende, and Pettifor (2014) adults who are living with an HIV positive status in sub-Saharan Africa, in denial of their HIV infection often experience lack of family or community support, transport limitation to the health-care facilities, stigma and the long queues at the health-care facilities are seen as the main obstacle to the maintenance of care.

4.3.4 Theme 4: Lack of support and a target of disclosure

The findings reveal that the reasons associated with the lack of disclosure of an HIV positive status by WLW-HIV is the lack of a person to disclose to and support.

Participant 03 said:

> *“It is so painful because you deal with the problem as an individual. Sometimes I wake up during the night and start crying alone.”*

Participant 08 added:

> *"It is difficult to be in a situation whereby you need support but you cannot talk about it. I will not risk talking to anybody about my status, I do not trust anyone."*

The outcomes of the study by Ssali, et al. (2010) have indicated that some of the main reasons for HIV disclosure are; to receive support and to prevent HIV infection, especially in the case where the target is a close family member. However, the study further suggested that the reasons for disclosure and nondisclosure differ depending on the targets of disclosure.

These findings are supported by Hardon, Vernooij, Bongololo-Mbera, Cherutich, Desclaux, Kyaddondo, Ky-Zerbo, Neuman, Wanyenze and Obermeyer (2012) who argue that during their post-test counseling in the health-care facilities, WLW-HIV are encouraged to disclose to their partners for support and prevention of transmission of the virus. Their analysis shows that some of the women were either divorced or widowed while many found it hard to tell their husbands because of fear of being blamed, abused or abandoned. 79% of the participants further revealed to be keeping their HIV status as a secret for their own safety.

4.4 CONCLUSION

This chapter presented the results of the study together with the themes and the subthemes that emerged from the findings as well as literature control. Four main themes and eleven sub-themes were extracted from the findings of this study. The themes include: managing to live with a secret, method used to conceal HIV positive status, reasons for concealing their status and lack of support and a target of the disclosure. This chapter will give way to the fifth chapter which will discuss the summary, conclusions, limitations and recommendations of the study.

CHAPTER 5

SUMMARY, RECOMMENDATIONS, STRENGTH AND CONCLUSION

5.1 INTRODUCTION

The previous chapter focused on the research findings and literature control. Four main themes and eleven sub-themes were extracted from the findings of this study and were discussed in the previous chapter. The themes include: managing to live with a secret, method used to conceal HIV positive status, reasons for concealing their status, lack of support and a target of the disclosure. The methods and reasons for concealment, as well as the factors that contribute to it, were discussed from the themes that emerged. The fears of abandonment, rejection, and humiliation following the disclosure were presented and discussed in the findings of the study.

This chapter focuses on the summary of the study, the conclusion, limitations of the study and recommendations based on the research objectives that were made.

5.2 SUMMARY

The study outlined a step-by-step process that was followed in the achievement of the outcomes. The study used a descriptive and phenomenological design which assisted in understanding the life experiences of concealing HIV positive status to the immediate family by WLW-HIV positive status. The semi-structured interviews were used through the data collection process. The Interpretative Phenomenological Analysis (IPA) was used to analyse the data that was collected, which helped in extracting themes and subthemes from data.

The study was significant in revealing the reasons for concealing HIV positive status by WLW-HIV. These women have shown that they have different fears about disclosing their status. The fear made them develop strategies of managing to live with their secret further using different methods of hiding their status to their families. Literatures still suggest that WLW-HIV are reluctant to disclose their status to their immediate family members because of the stigma and the preconceived knowledge that they hold about HIV/AIDS.

The qualitative approach was followed when conducting the study. The research design, study site, population, sampling method, data collection, data analysis, measures to ensure trustworthiness, and ethical considerations were discussed in Chapter 3.

Chapter 4 focused on the research findings and literature control where several themes and sub-themes were discussed. The first theme focused on how the WLW-HIV manages to live with a secret, under this theme, the following sub-themes emerged: women continuing with concealment of HIV positive status; women pointing fingers, unpleasant and are unhappy; and scepticism about disclosing to children.

The second theme focused on the method used to conceal HIV positive status where the following sub-themes of; telling a lie about frequent visits to the clinic; and hiding of HIV medications. The third theme involved the reasons for concealing their status. Under this theme, the following sub-themes were discussed: lack of trust in disclosing HIV positive status; fear of prejudice by family members; fear of abandonment and rejection by family members as a consequences for disclosure of HIV positive status; fear of blame and humiliation by family members as the result of HIV positive disclosure; misconceptions about HIV positive status; the view of an HIV positive status as a predicament; and denial of one’s HIV positive status. The last theme focused on the lack of support and a target of the disclosure.

The study was aimed at exploring and describing the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province.

The objectives of the study were:

- To explore the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province.

- To describe the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency Virus at selected villages in Limpopo Province

The objective of exploring experiences of concealing HIV positive status by women was met. The researcher asked the main question and the probing questions. WLW-HIV were able to answer the main question and the probing questions. To meet the objective of describing experiences of concealing HIV positive status to the immediate family by WLW-HIV, the women were able to describe their experiences in the findings, themes and subthemes as indicated in chapter 4. The study generated four themes from the data. The themes were discussed through literature control.

WLW-HIV described their way of managing to live with the secret to the family, the method they use in concealing their status to the family such as hiding their medications containers and giving family wrong information about the medication taken and the frequent visits to the clinic. WLW-HIV described their reasons for concealment of HIV positive status as a lack of trust to the family, the denial of their HIV positive status, fear and the misconceptions about HIV positive status.

5.3 RECOMMENDATIONS

From this study, the following recommendations are made:

Practice

- There is a need for health promotions and door-to-door campaigns that should enhance disclosure of HIV positive status and prevent concealment that directly affects treatment adherence.
- Health awareness campaigns should be rendered for the community to broaden their HIV awareness and foster their disclosure and adherence to HIV treatment.

- Psychosocial support is needed more on WLW-HIV from the Department of Health and other related stakeholders.

Education

- More capacitation should be conducted to develop the skills of primary healthcare providers for the betterment of the HIV disclosure process.
- Public Health Practitioners, having the idea of HIV positive status disclosure trends, especially for women, may need to assist in enlightening the policymakers in the development of disclosure policies that address the gender disparities and related social issues in the process of the HIV positive status disclosure.

Research

- More future public health research studies should be conducted as a qualitative research focusing on concealment on both women and men in rural areas.

5.4 STRENGTHS OF THE STUDY

- **Strengths**

The interviews were conducted in Sepedi, which is the home language of the participants. Therefore, all the participants were able to present their thoughts. The study has uncovered the dynamics and factors which are involved in the process of concealment, which may assist in the enlightening of future scholars in the issue around concealment and HIV positive status. It was a woman-to-woman interaction between the researcher and participants about the experiences and reasons for concealment was described and explored. WLW-HIV were open to speak freely with the person of the same gender. Women were interviewed in the clinic for privacy while some preferred to be in the comfort of their own homes when members of the family were absent as per agreement. The study was conducted in selected villages and during the process, saturation was reached.

5.5 CONCLUSION

This study shows the literature that supports the title, findings that were supported by literature control, summary, conclusion, limitations and recommendations of the study. It further presented key findings on the experiences of concealing an HIV positive status to the immediate family by women as it emerged from the study.

Recommendations highlighted by the researcher will have an implication on the contribution towards models of disclosure of an HIV positive status.

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APPENDIX 1: Interview guide (English)

Section A: Biographical information of the participants.	
Age	
Marital status	
Educational level	
Section B: Central Question	
What are your experiences of concealing HIV positive status to your immediate family?	
Section C: Follow-up Questions	
a) How is your relationship with other family members at home? b) What are your reasons of concealing your status to them? c) Have you ever thought about the impacts of concealing the illness? d) How do you feel with the issue of concealing your HIV status to your immediate family? e) What are your challenges of disclosing your status to them? f) What makes you not to disclose your status to them?	

APPENDIX 2: Interview guide (Sepedi version)

Karolo A: Tshedimoso ya boitsebišo bja motšeakarolo	
Mengwaga ya gago	
Maemo a gago a lenyalong	
O fihlile kae ka thuto	
Karolo B: Potšišo kgolo	
Ke eng seo o itemogetšego sona ka go fihlela ba lapa la gago ka kokwanahloko yeo o phelago ka yona?	
Karolo C: Dipotšiso tša go latela potšišo kgolo	
(a) Le phedišana bjang ka gae le ba bagwe ba le lapa? (b) Mabaka a gago a go se tsebiše maemo a gago a HIV go ba bagwe ba le lapa ke afe? (c) A o kile wa nagana ka ditlamorago tša go utela ba le lapa la gago ka seemo sa gago sa maphelo? (d) Maikutlo a gago ke afe mabapi le go se tsebiše maemo a gago a HIV go maloko a lelapa? (e) Ke dihlotlo dife tšeo di dirago gore o fihle seemo sa gago sa maphelo go ba lelapa la gago? (f) Ke eng seo se dirago gore o fihlele maloko a lelapa la gago?	

APPENDIX 3: TRANSCRIPTS OF EXPERIENCES OF CONCEALING HIV POSITIVE STATUS TO IMMEDIATE FAMILY BY WOMEN AT SELECTED VILLAGES IN LIMPOPO PROVINCE.

TRANSCRIPT OF SEMI-STRUCTURED INTERVIEW FOR PARTICIPANT:02	
Researcher	What are your experiences of concealing your HIV positive status to your immediate family members?
Participant	It is very hard, I am always crying alone. I just feel sorry for the man who impregnated me because I am unable to share my problem with him. I started knowing in because of this pregnancy when I was coming for ante-natal care. I did the test and they were positive. Tjoooo, it is very hard. Its so difficult for me to accept my status. It is not easy. I am staying with my mother and my five children at home and it is hard to talk to them. I just told my children that since I am attending antenatal clinic, at the Clinic after check up they have realised that I am not well. I was given the medication to help in child development. As for the boyfriend I will not take the chances. It is not easy. I have always heard of HIV positive people and never thought I will be one of them one day. I have not yet accepted that I am positive.
Researcher	How is your relationship with other family members at home?
Participant	The relationship is good. I love my children and my mother. My family is giving me support because of the pregnancy because they know nothing about the illness. I have observed that they thought maybe I am not well because of it as I am always crying especially when I am alone.
Researcher	What are your reasons of concealing your status to them?
Participant	My dear, where am I going to start? They will not believe what I am telling them. I am also not accepting my situation, how do I expect someone to understand while I am not accepting my own status. Yaah, life is the problem.
Researcher	Have you ever thought about the impact of concealing your status?
Participant	If you are scared that I will infect them, don’t worry I will never do that, I

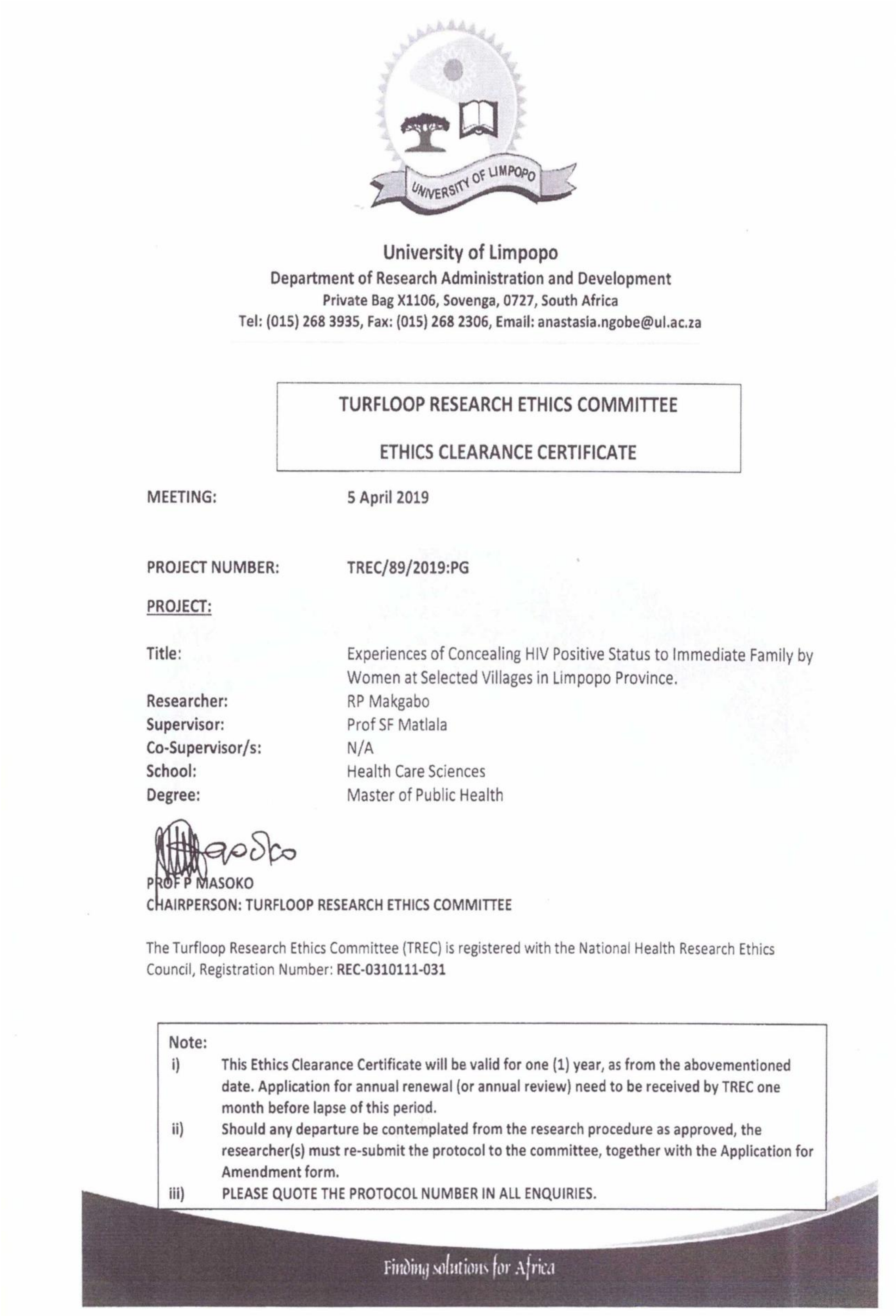
	am always careful when I am at home. I am just worried about the status of my boyfriend and his wife. If he is sick it means we are all sick, three of us. My boyfriend and his wife.
Researcher	Tjoo ,your boyfriend is having a wife?
Participant :	Yes, we were just playing and things turned to be serious.
Researcher :	Have you ever thought about the impact of concealing your status to your boyfriend?
Participant :	Yes, We are just going to be sick the three of us. I also do not know their status. How am I going to start when telling my boyfriend? He is helping me with the children I don't want to lose him.
Researcher :	How do you feel with the issue of concealing your status to your Immediate family?
Participant :	I am so stressed. I think I will be able to decide about what to do after giving birth.
Researcher :	What are the challenges of not disclosing your status to your Immediate family?
Participant :	The medication makes me to feel dizzy and I also feel nauseous.
Researcher :	Try to talk to them at the clinic. What time do you take your Medication?
Participant :	I take my medication after Uzalo soap at 21h00 after that I sleep.
Researcher	Who reminds you when its medication time?
Participant :	I have set the alarm on my phone as the reminder.
Researcher	What makes you not to disclose your status to them?
Participant	They will ask me so many questions that will stress me. Stress is not good for me now. It is also still early to talk about it. I am still stressed about this illness.

Researcher	Okay,
Participant	But, it will go with time.
Researcher	Okay, thank you for your time.
TRANSCRIPT OF SEMI -STRUCTURED INTERVIEW FOR PARTICIPANT: 03	
Researcher	What are your experiences of concealing HIV positive status to your immediate family?
Participant	I have realized that my family members will get hurt if they can know about my status. They will think about death, because even myself I have done several tests because of denial but I still do not believe, that it is true. I still don’t know how I am going to break this news to my family. I was pregnant for my first born child. I did the testing because it is compulsory when you are pregnant. The results came out positive; I did not believe it in the first time test. I returned back home shocked and feeling scared. It is not easy and I am still shocked. I knew my status in 2018 but even now to talk to my family about it, it’s not easy.
Researcher	How is your relationship with other family members at home?
Participant	As family we are okay. As for my illness, it will go with time sisters. Maybe I will be emotionally healed and I will be able to talk to them. As for now what they do not know it will not kill them.
Researcher	Meaning that you are not ready to talk about it.
Participant	Yes.
Researcher	What are your reasons of concealing your status to them?
Participant	I m scared they will get hurt, and think that I am also going to die very soon because it is not so long we have buried my cousin but you can still observe that they are still in serious pain when they talk about her. So if I can come again with the illness whereas people have the mentality that with HIV you will end up dead. My life will be more difficult than now.
Researcher	Have you ever thought about the impacts of concealing the illness?

Participant	I know and you have to understand that it is so difficult. I have thought about the impacts that one day when I am weak I will need their support and medical help. They are the once who will help me. But to tell the truth I can't, it's hard. Even the witch will never tell that I am the witch. Let me deal with my problem first.
Researcher	Don't you think it is better if they know so that they will give you support when you need it.
Participant	Support, where? Those people will only think about death, they will start to update their burial clubs preparing for my funeral.
Researcher	How do you feel with the issue of concealing your HIV status to your immediate family?
Participant	It is so painful because you deal with the problem as an individual. Sometimes I wake up during the night and started crying alone. I do not have someone to talk to. The person who makes me feel more pain is my daughter. If I can think too much about her I find it difficult to sleep. I did not believe it. Even now I do not believe it. I feel like something is not right.
Researcher	There are support groups at the clinic, didn't you join them?
Participant	Eish, I am not ready you know (with negative attitude).
Researcher	What are your challenges of not disclosing your status to them?
Participant	Those people need serious health talk. If I can talk, they will jump into conclusion that death is coming in the house. I am scared they can even start discriminating me.
Researcher	What makes you to think that way?
Participant	I am the one who knows my family, they are hard headed and ignorant about many things.
Researcher	What makes you not to disclose your status to them?
Participant	They will be hurt, I will be discriminated, they will think about death. Eish, it is still difficult. Let me deal with my problem first. Let me get emotional healing after healing emotionally, I will have learned more

	from the clinic and I will be able to explain more to them.
Researcher	I do understand you my dear. If you are ready you will talk to them.
Participant	Yes,
Researcher	Okay. Thank you

APPENDIX 4: TREC ETHICS CLEARANCE CERTIFICATE



UNIVERSITY OF LIMPOPO

University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3935, Fax: (015) 268 2306, Email: anastasia.ngobe@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE

ETHICS CLEARANCE CERTIFICATE

MEETING: 5 April 2019

PROJECT NUMBER: TREC/89/2019:PG

PROJECT:

Title: Experiences of Concealing HIV Positive Status to Immediate Family by Women at Selected Villages in Limpopo Province.
Researcher: RP Makgabo
Supervisor: Prof SF Matlala
Co-Supervisor/s: N/A
School: Health Care Sciences
Degree: Master of Public Health

PROF P MASOKO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

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

Note:

i) This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.
ii) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.
iii) PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Finding solutions for Africa

APPENDIX 5: LETTER REQUESTING PERMISSION FROM THE DEPARTMENT OF HEALTH.

Enq : Makgabo R.P

Cell : 078 0394999 / 0764499076

Email : lotanangrp@yahoo.com

08 POTOKO STREET

RETHABILE GARDENS

POLOKWANE

0699

31 July 2018

DEPARTMENT OF HEALTH

LIMPOPO PROVINCE

PRIVATE BAG X9302

POLOKWANE

0700

Dear Sir/Madam

RE: REQUEST FOR PERMISSION TO COLLECT DATA

I, Makgabo R.P, the Social Worker at Lebowakgomo Clinic hereby apply for permission to conduct a research study titled “**Experiences of Concealing HIV Positive Status to Immediate Family by Women at Selected Villages in Limpopo Province**”. The research study is conducted in partial fulfilment of the requirements for the attainment of a Master of Public Health at the University of Limpopo. I have obtained an ethical clearance from the Turfloop Research Ethics Committee of the university.

The aim of this study is to explore and describe the experiences of concealing stigmatizing illness to the immediate family by women living with Human Immunodeficiency virus at a village in Limpopo Province.

The objectives of the study are:

To explore the experiences of concealing HIV positive status to the immediate family by women living with Human Immunodeficiency virus selected villages in Limpopo Province.

To describe the experiences of concealing HIV positive status to the immediate family by women living with Immunodeficiency Virus at selected villages in Limpopo Province.

To ensure confidentiality, privacy and anonymity of the patients there will be no names and identities provided. Anonymity and confidentiality will be ensured by providing neither the names nor the identifying information of the patient records in the research project. Confidentiality will be ensured during data collection sessions so that nobody will be able to associate the provided information with participants.

The results of the study may inform service provision and undoubtedly improve health promotion, prevent diseases and enhance the lives of patients with regards to HIV infection. The study may further assist in the improvement on the policies that aim to enhance HIV disclosure, further strengthening adherence and minimising stigma associated with HIV management.

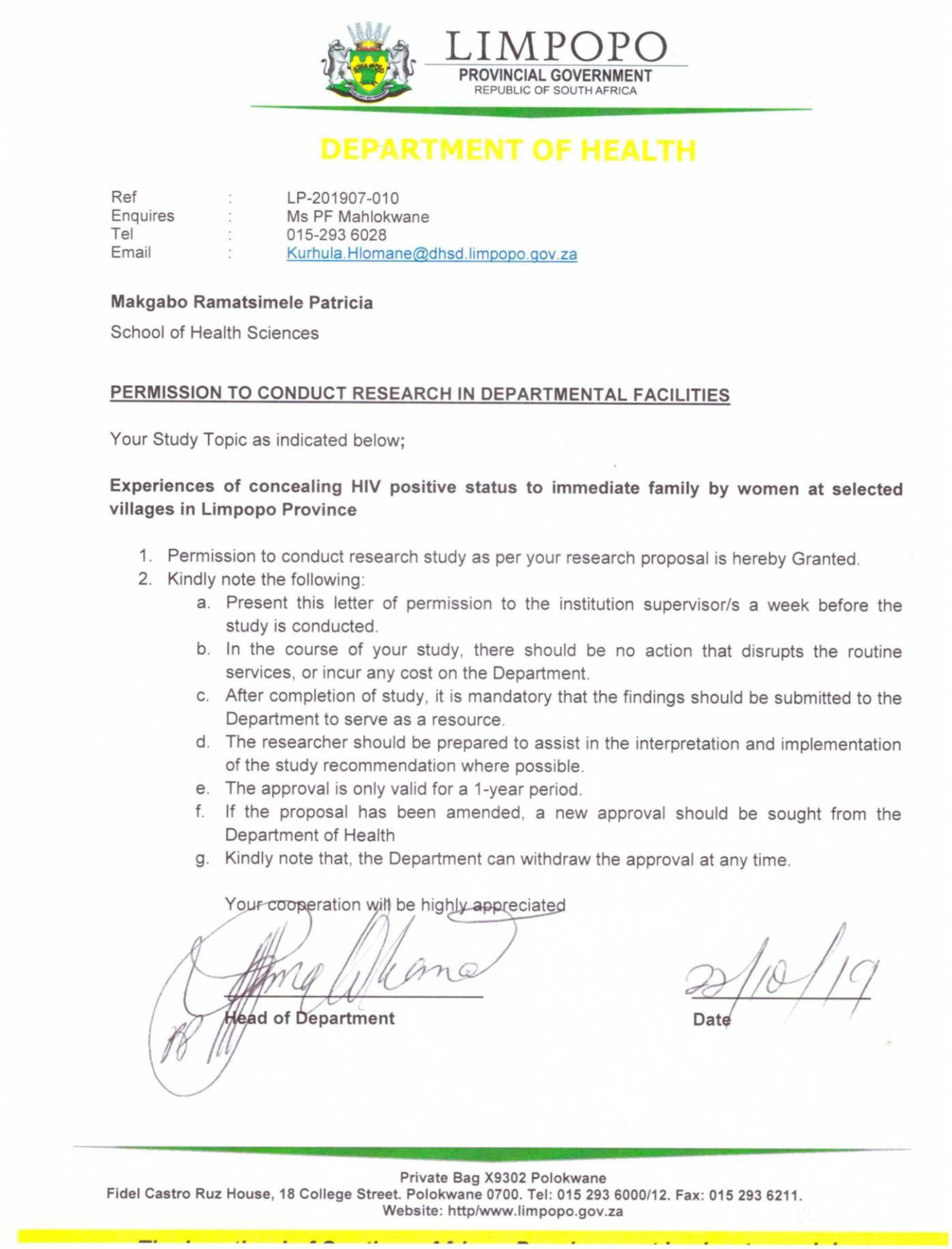
Research findings will be made available. Should any clarity be needed with regard to the research study, please feel free to contact me.

Thanking you in advance.

Yours sincerely

Patricia Makgabo (Research student)

APPENDIX 6: LETTER GRANTING PERMISSION FROM LIMPOPO DEPARTMENT OF HEALTH



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Ref : LP-201907-010
Enquires : Ms PF Mahlokwane
Tel : 015-293 6028
Email : Kurhula.Hlomane@dhsd.limpopo.gov.za

Makgabo Ramatsimele Patricia
School of Health Sciences

PERMISSION TO CONDUCT RESEARCH IN DEPARTMENTAL FACILITIES

Your Study Topic as indicated below;

Experiences of concealing HIV positive status to immediate family by women at selected villages in Limpopo Province

1. Permission to conduct research study as per your research proposal is hereby Granted.
2. Kindly note the following:
    a. Present this letter of permission to the institution supervisor/s a week before the study is conducted.
    b. In the course of your study, there should be no action that disrupts the routine services, or incur any cost on the Department.
    c. After completion of study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    d. The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    e. The approval is only valid for a 1-year period.
    f. If the proposal has been amended, a new approval should be sought from the Department of Health
    g. Kindly note that, the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated

Head of Department

22/10/19
Date

APPENDIX 7: INFORMATION LEAFLET (ENGLISH)

Department of Public Health

University of Limpopo

Private Bag X1106

Sovenga

0727

Date______________________

Dear Participant

Thank you for showing interest in participating in this study that looks at the experiences of concealing stigmatising illness to the immediate family The purpose of this study is mainly to understand the experiences of women living with HIV concealing their illness to their immediate family members.

Your responses to this individual semi-structured interview will be treated as highly confidential, and the researcher will treat your identity and name as confidential and will not in any way disclose them with the results of this study. Please be informed that participation in this study is voluntary, and you thus have the right to terminate the continuations of the interview at any time.

Kindly answer all the questions to the best of your ability; hence, your participation in this study is very important. Thank you for your time.

Sincerely

______________________ __________________

Makgabo Patricia Date

Masters Student

APPENDIX 8: LETLAKALA LA TSHEDIMOŠO GO BATŠEAKAROLO

Department of Public Health

University of Limpopo

Private Bag X1106

Sovenga

0727

Date_______________________

Motšeakarolo yo a hlomphegago

Ke leboga go bontšha kgahlego ga gago ka go tšea karolo mo nyakišišong yeo e sekasekago le go fa kwišišo ka ga mokgwa woo basadi bao ba phelago ka kokwanahloko ya HIV ba fihlelago ba malapa a bona ka ga malwetši a bona.

Dikarabo tša gago mo poledišanong ya bobedi bja rena di tla swarwa bjalo ka sephiri, gape monyakišiši o tla swara boitsebišo le leina la gago bjalo ka sephiri gomme a ka se di tšweletše le dipoelo tša nyakišišo ye. O lemošwa gore botšeakarolo mo nyakišišong ye bo ka boithaopi, gomme o na le tokelo ya go emiša poledišano ya rena nako efe kapa efe.

O kgopelwa go araba dipotšišo go ya le ka moo o ka kgonago, ka ge botšeakarolo bja gago mo nyakišišong ye bo le bohlokwa. Ke leboga nako ya gago.

Ka boikokobetšo

______________________ __________________

Makgabo Patricia Date

Moithuti wa Masters

APPENDIX 9: CONSENT FORM TO BE SIGNED BY THE PARTICIPANT

CONSENT FORM

I____ hereby agree to participate in this research project which focuses on the Experiences of concealing HIV positive status to the immediate family at selected villages in Limpopo Province.

The purpose, terms and conditions of the study have been thoroughly explained to me and I thus understand my rights and freedom in participating in this study. I also understand my freedom and the right I have to terminate the continuation of this study should I feel like discontinuing with my participation at any time.

I understand that the outcomes of this study will not benefit me personally, and I also understand that my identifying details provided in this form will not, in any way be linked to the results of this study. I understand that my name and my answers in this study will remain confidential.

Signature ____________________

Date _______________________

APPENDIX 10: FOROMO YA TUMELELANO YEO E SAENAGO KE MOTŠEAKAROLO

FOROMO YA TUMELELANO

Nna ____ ke dumela go tšea karolo mo nyakišišong yeo e sekasekago le go fa kwišišo ka ga mokgwa woo basadi ba go phelago ka kokwanahloko ya HIV ba fihlelago ba malapa a bona ka gona. Maikemišetšo le mabaka ao a beilwego ka nyakišišo ye a hlalošitšwe ka botlalo gomme kea a kwešiša. Gape ke kwešiša le ditokelo le bolokologi bja ka mo botšeakarolong bja nyakišišo ye. Ke kwešiša gape le bolokologi le tokelo ya ka ya go emiša ka tšwelopele nyakišišong ye ge ke nyaka go emiša ka go tšea karolo nako efe kapa efe.

Ke a kwešiša gore dipoelo tša nyakišišo ye di ka se nkhole ka bonna, ke kwešiša gape le gore tshedimošo ya ka ya boitsebišo yeo e filwego foromong ye e ka se amantšhwe le dipoelo tša nyakišišo ye. Ke a kwešiša gore leina la ka le dikarabo tša ka di tla swarwa bjalo ka sephiri.

Signature ____________________

Date ________________________

APPENDIX 11: EDITORIAL CERTIFICATE

Ex-Air Residence
University of Cape Town
Rondebosch
7700
26 July 2020

University of Limpopo
The Registrar
Private X1106
Sovenga
0727

TO WHOM IT MAY CONCERN

I, Given J Hlongwani, write this letter to confirm that I have edited the mini dissertation of **Ms RAMATSIMELE PATRICIA MAKGABO** which is being submitted in partial fulfilment for the degree on Master of Public Health under the topic:

EXPERIENCES OF CONCEALING HIV POSITIVE STATUS TO IMMEDIATE FAMILY BY WOMEN AT SELECTED VILLAGES IN LIMPOPO PROVINCE

I can confirm that the proposal meets the required standard to be presented as an academic paper for its purpose.

For any queries or concerns regarding the work I have performed, I can always be contacted on the below email address.

Kind regards,

Given J Hlongwani
PhD candidate in Applied Linguistics (UCT)
givenfor@me.com / hlngiv001@myuct.ac.za