SOCIAL PATTERNS OF LOSS TO FOLLOW-UP AND NON-ADHERENCE IN THE LIMPOPO PROVINCE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION PROGRAMMES

BY

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ABSTRACT

Introduction: Though the Prevention of Mother-to-Child Transmission (PMTCT) programmes have been widely implemented with increased availability and improving coverage of services, there have been concerns of increasing numbers of mothers who are loss to follow-up (LTFU) and those who failed to adhere to treatment after giving birth. This has led to increasing new infections of Mother-to-Child Transmission (MTCT) during post-natal periods (UNAIDS 2017). Extensive research has focussed on the ward-based implementation of the PMTCT programmes and clinical patterns of loss to follow-up (LTFU) and non-adherence to Human Immunodeficiency Virus (HIV) treatment and there is less research on social patterns and the lived experiences of HIV positive mothers in the PMTCT programmes. This study explored the lived experiences of HIV positive mothers and their perceptions of the Community Health Workers (CHWs), lay counsellors and professional nurses in the PMTCT programmes.

Methods: This study followed a comparative approach to explore patterns or experiences during the provision of HIV services, care, and retention of HIV positive mothers. The study adopted a mixed methods approach (qualitative and quantitative methods). This includes a novel qualitative unmatched case-control design, a phenomenology research design, and a cross-sectional survey. For the unmatched case-control approach, semi-structured interviews were conducted with 18 mothers who have been LTFU (cases) and 20 mothers who were undergoing care (controls). The in-depth interviews were conducted with 20 CHWs. For the quantitative methods, a cross-sectional survey was conducted with a total population of 40 professional healthcare workers (nurses and lay counsellors).

Results: The social patterns of LTFU and non-adherence are gender and family dynamics of HIV disclosure (fear, guilt and struggles with methods of HIV disclosure), and self-transfers to other health facilities (to clinics that are closer to home or due to poor or failed health systems). The social patterns include delays and interruptions of ART (unreadiness and unwillingness to initiate ART, denial of HIV and beliefs that their HIV is cured; and work responsibilities). The mothers experienced HIV medication barriers (fear of getting sick from the medication side effects, lack of support to cope with the side effects, taking alternative medicines, lack of food to take with the medication, lack of support when the medication runs out) and health system barriers (long waiting periods at the health facilities, and poor treatment from the healthcare workers). The study further found the following are associated barriers of LTFU and non-adherence to HIV treatment: the dearth of knowledge about MTCT, motherhood patterns (protectiveness, regrets and self-blame) and mix-feeding explained in terms of work/school responsibilities and lack of breastmilk and responding to the baby's cries. The nurses and lay counsellors experienced the following implementation challenges that are associated with LTFU and non-adherence to treatment: clients' attitude (75%), lack of resources (47.5%), poor support from the government (32.5%), poor systems (17.5%), and poor PMTCT guidelines and policies (10%). The CHWs struggled with tracing clients because of wrong contact/resident addresses or missing information and lack of support (clients, community, and government support).

Conclusions and Recommendations: The study presents evidence of social patterns and barriers concerning LTFU and adherence to HIV treatment that are influenced by several factors such as family, education, gender relations and healthcare systems. A planned intervention to tackle LTFU and adherence patterns is needed to meet goal 3 of the Sustainable Development Goals (SDGs) by the year 2030. The implications are to integrate and consider the humanities in the retentions of clients in the healthcare facilities to understand the social patterns that influence LTFU and non-adherence of treatment.

Key words: Social patterns, non-adherence, adherence, loss to follow-up, treatment, South Africa

ACRONYMS

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral therapy
AZT	Zidovudine
CBAS	Community-Based Adherence Support
CD4	Cluster of differentiation
CHBC	Community Home-Based Care
CHWs	Community Health Workers
COVID-19	Coronavirus disease 2019
CTX	Cotrimoxazole
EID	Early Infants Diagnosis
HCT	HIV Counselling & Testing
HIV	Human Immunodeficiency Virus
HTLV-III/LAV	Human T-lymphotropic virus type III
M2M	Mothers2Mothers
MTCT	Mother to Child Transmission
NVP	Nevirapine
PCP	Pneumocystis Carinii Pneumonia
PCR	Polymerase Chain Reaction
PHC	Primary Health Care
PMTCT	Prevention of Mother to Child Transmission
NGO	Non-Government Organisations
SANAC	South African National Aids Council
SEM	Social-Ecological Model
TB	Tuberculosis
UNAIDS	United Nations Programme HIV/AIDS
UNICEF	United Nations Children's Fund

UTT	Universal Test and Treat
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1

ORIENTATION OF THE STUDY

1.1. Introduction

Every year, the HIV pandemic continues to be a health burden affecting the health care systems around the world (Department of Health 2020; UNAIDS 2020; WHO 2020). With increasing new infections around the world every year, the HIV pandemic accounts for over 77 million infections since the start of the epidemic. (UNAIDS 2019a; UNAIDS 2020; WHO 2020). The year 2021 marked 40 years since the first case of HIV was recorded, and the surge of HIV continues to put more pressure on the health care systems around the world (UNAIDS 2021). In 2019, approximately 38 million people were living with HIV worldwide. South Africa remains the country with the highest HIV prevalence with over seven million infections (WHO 2020; UNAIDS 2021). Unfortunately, by the end of 2019, over 35 million people had died from HIV/AIDS-related illnesses around the world and over three million deaths were recorded in South Africa (UNAIDS 2020). Globally, adult women that are affected by the HIV pandemic constitute almost half of all the people living with HIV (Magadi 2011; UNAIDS 2018; Statistics South Africa 2019; Vandormael et al. 2019). An estimation of 19,9 million women aged 15 years and older were living with HIV around the globe in 2019 and more than 80% of this population resides in Sub-Saharan Africa. South African alone has 4.4 million women infected, which is the highest number or record of women living with HIV for a country in Africa and the world (UNAIDS 2019).

Despite the highly intensified global response against HIV, women are the most affected by the HIV pandemic (Magadi 2011). The increased HIV infections among women unfortunately increases HIV prevalence among children through Mother-to-Child Transmission (MTCT). Consequently, in 2019, over 1 million children were living with HIV acquired through MTCT worldwide (UNAIDS 2020). Taking the positive from the response to MTCT in South Africa, over 90% of HIV positive pregnant women received ARVs in the Prevention of Mother-to-Child Transmission (PMTCT) programmes in 2019, compared to 51% in 2010 (UNAIDS 2020). South Africa now has the largest ART programme in the world, allowing women the opportunity to fight MTCT and the spread of HIV (UNAIDS 2020).

The PMTCT programmes are part of a WHO global initiative and has been adopted by developed and developing countries, in South Africa the programme was adopted in 2000 (WHO, UNODC & UNAIDS 2021). The PMTCT programmes are HIV prevention programmes that assist and support women living with HIV by providing HIV-related services such as HIV testing, counselling and HIV medications, and prevention of unwanted pregnancies. The programmes offer HIV services and support for all HIV exposed women and infants with HIV care and treatment (UNAIDS 2016; WHO 2016; Department of Health 2020). In 2015, the Department of Health (South Africa) adopted Option B+ treatment regime in the PMTCT programmes, this was adopted from the recommendations by the World Health Organisation (WHO) in 2013 on the use of ART for HIV treatment and prevention. Regardless of Cluster of differentiation (CD4) count, Option B+ places all HIV positive pregnant women on ART for the rest of their lives from the day they are diagnosed with HIV (Department of Health (South Africa) 2019; UNAIDS 2016; WHO 2016).

The widespread coverage of the PMTCT services in the past decade helped prevent new HIV infections among women and children worldwide (Vandormael et al. 2019; UNAIDS 2019a; WHO 2020). The programmes have resulted in approximately 31% reduction of new HIV infections among children, preventing over 1 million new infections between 2010 and 2020 (UNAIDS 2021). In the year 2019, South African PMTCT programmes helped to prevent at least 3.8 million HIV exposed infants from being infected with HIV (UNAIDS 2020a). Without interventions, the risk of MTCT in developed countries is 15-25% and 25-35%. During pregnancy, the risk ranges from 5-10%, 5-20% during labour and delivery, and 10-20% during breastfeeding, and 30-45% within 18 and 24 months of breastfeeding (WHO & UNICEF 2014). The rate of MTCT can be reduced to less than 2%, and to 5% or less during breastfeeding, when HIV interventions are in place (WHO & UNICEF 2007). In 2020, the rate of MTCT in South Africa was under 4%, and this includes during breastfeeding (UNAIDS 2020b).

Globally, an estimated 3 million children aged 0-14 years old were living with HIV in 2013, this number reduced to 1.8 million in 2015, and 1.2 million in 2019- showing a 23% decline in new infections (UNAIDS 2020). South Africa has shown improvement in preventing HIV infections among children aged 0-14 years old since the year 2013, only 24,000 new HIV infections were recorded in 2013 (UNAIDS. 2013). This is compared to 12,000 new infections in 2020 and 10,000 in 2022 (UNAIDS 2021; 2022). The PMTCT programmes help in reducing the spread of HIV through MTCT during pregnancy, labour, or delivery and during breastfeeding (Abuogi, Smith & McFarl 2016; Department of Health 2019; WHO 2020). During post-natal periods, mothers are advised to use HIV treatment simultaneously with exclusively breastfeeding or exclusively formula feeding for the first six months after birth and other PMTCT activities to prevent MTCT (Department of Health 2019; UNAIDS 2017).

South Africa was on track to achieve the 90–90–90 targets, envisioned by the year 2020, which has already passed. The 90–90–90 targets implied that by 2020 90% of people living with HIV would have known their HIV status, 90% of people living with HIV would be on treatment and 90% of people living with HIV would be virally suppressed (UNAIDS 2014). South Africa has managed to achieve the first and third targets so far. The second target had been a challenge, South Africa recorded only 75% of people living with HIV that are on treatment (UNAIDS 2020). The second 90 target was the most significant to this study and to achieve the target, South Africa needed to eradicate barriers that influence HIV service utilisation, LTFU and non-adherence to HIV treatment. Hopefully, South Africa will reach the new HIV targets that are envisioned by the end of 2026. Learning from challenges that countries faced in reaching the previous HIV targets and the challenges posed by the novel Coronavirus disease 2019 (COVID-19), the new targets will concentrate on the inequalities that affect service utilisation (UNAIDS 2021). Identifying and eliminating factors or facilitators that influence LTFU and non-adherence to HIV treatment has proven to be a challenge for HIV programme planners and providers, in a quest to implement successful and effective programmes (Department of Health 2013b; UNAIDS 2017; WHO 2020). The study explores social patterns of LTFU and non-adherence by uncovering the narratives from lived experiences of mothers and healthcare workers in the PMTCT programmes.

1.2. Statement of the Problem

The success of the PMTCT programmes is delayed by continuous HIV infections of children from mothers who are yet to initiate ART or mothers who have stopped ART (Department of Health 2013; Abuogi, Smith & McFarland 2016; UNAIDS 2017; WHO 2017; Larsen et al. 2019). The HIV positive mothers are LTFU after giving birth, then halt ART, risking MTCT (UNAIDS 2017). The number of HIV positive mothers who are yet to initiate ART and those who stopped ART remain a concern even with extensive coverage of HIV services or prevention programmes (UNICEF 2012; UNAIDS 2017). A study by UNAIDS (2018) in South Africa and Zambia confirms that, among mothers who are LTFU after birth, only 53% adhered to ART after birth compared to 76% of women during pregnancy.

The implementation of the universal test and treat (UTT) programmes in South Africa, which was first introduced in 2013, has allowed screening of all population of pregnant women for HIV and provides early invitation of ART (UNAIDS 2015). However, the UTT or early initiation of ART is a challenge for some of the HIV patients who are struggling to accept their HIV status (Takarinda, Harries & Mutasa-Apollo 2016). This is confirmed by a South African study conducted by Davey et al (2020) on the association between same-day initiation of ART with increased LTFU. The study found that same-day ART increased the risk of LTFU. The study had 92,609 ART patients who were included in the study and 36% initiated ART on the same-day, and 33% of those who were initiated on the same-day were classified as LTFU within 55 days as compared to the LTFU patients who initiated later.

There is an increasing number of HIV infections through MTCT during the post-natal phase compared to the pregnancy or labour phase (Anoje et al. 2012; Leroy et al. 2013). In the year 2017, approximately 180,000 children were newly infected worldwide and about half of these infants were infected during breastfeeding (UNAIDS 2017). This is a concern because the rate of MTCT increases during the post-natal periods. Although the statistics have shown 31% reduction of new HIV infections among children between the year 2010 and 2020 (over 1 million new infections were prevented) presenting positive progress of infants linked to HIV care, the prevalence is still worryingly high (UNAIDS 2021). This calls for more interventions to motivate mothers to adhere to HIV treatment during their initial stages of pregnancy, labour, and breastfeeding (UNAIDS 2021). During the post-natal period, mothers should adhere to treatments while following the recommended infant feeding methods after birth to avoid the risk of MTCT through mixed feeding (Hazemba, Ncama & Sithole 2016). There is limited research on family and other social determinants of health influence, early participation, or practice of recommended infant feeding methods that take place after birth.

The patterns of LTFU and non-adherence to HIV treatment are linked with factors that begin with occasional clinic non-attendances (Pence et al. 2018). Most of the women living with HIV do not enquire about their health or the health of their infants, often enough to understand the related health risks of MTCT (Department of Health 2016). Numerous complexities influence health-seeking behaviour and consequently hinder the progress of the PMTCT post-natal programmes. Even with a wide coverage of HIV campaigns and counselling in South Africa, studies have shown that HIV positive mothers lack appropriate knowledge about HIV and the risk of MTCT after birth (Asefa & Beyene 2013; Abtew, Awoke & Asrat 2016; Hazemba, Ncama & Sithole 2016). Other studies have found that HIV-related stigma and discrimination in the PMTCT programmes result from lack of knowledge about HIV, MTCT and PMTCT activities (Frizelle, Solomon, & Rau 2009; Kalembo & Zgambo 2012; Mitiku et al. 2016). There is a need to understand the extent to which social patterns such as stigma, discrimination, and knowledge impact service use in the PMTCT post-natal programmes.

The mothers who receive adequate support and counselling can be aware of the risks of MTCT to their babies and adhere to treatment (Kalembo & Zgambo 2016). Appropriate social support for mothers to engage with their partners or families about important PMTCT activities can influence service utilisation (Frizelle, Solomon & Rau 2009; Yaha & Tambo 2018). In most cases, women habitually rely on their families or partners, especially for financial support (Mpinganjira et al. 2020). Financial instability may affect access to health care considering the travelling costs and other expenses that mothers need to adhere to instructions from healthcare workers after birth (Yaha & Tambo 2018; Mpinganjira et al. 2020). In South Africa, women experience financial burdens that are mostly influenced by the high rate of unemployment and poverty (Mpinganjira et al. 2020). Many studies have found that women who are not financially independent are often marginalized or controlled by their sexual partners, and therefore the decisions related to their reproductive health are influenced (Falnes et al. 2011; Mpinganjira et al. 2020). The narratives and social patterns that reveal the extent to which family and gender dynamics impact service access, utilisation, and adherence is not adequately researched, especially in the rural context.

Furthermore, implementing the PMTCT programmes has proven to be challenging for healthcare workers especially in rural settings (UNAIDS 2017). The programmes encounter barriers that are not only affecting HIV positive patients but healthcare workers as well. Healthcare workers` responsibilities are to implement successful PMTCT programmes to combat the spread of HIV through MTCT (Department of Health 2020). However, the healthcare workers struggle with the implementation of post-natal services and retention of HIV positive mothers who are enrolled in the HIV programmes (UNAIDS 2017). This is confirmed by a study by Grantl et al. (2017) who found that the CHWs experience barriers related to mistrust by patients, the patients were concerned about the confidentiality of their HIV status and that the CHWs were not expected to provide maternal and child health services. UNICEF and WHO (2017) report found that many countries have improved access to maternal child health during pregnancy and childbirth. However, there is less success achieved for post-natal care. Essential resources and support provide confidence and ease in the implementation processes of the programmes, with reliable retention approaches. Notwithstanding, health personnel experience poor working conditions and inadequate training or guidelines (Frizelle, Solomon & Rau 2009). The unsatisfying nature of the health care environment can promote poor morale that affects the values and norms of treatment adherence for people living with HIV (WHO 2017). The information or counselling obtained from the healthcare workers is believed to be limited or inadequate, poor, and incomplete (Kalembo & Zgambo 2012). Adequate support is compromised by several health care system issues such as poor treatment and communication from the healthcare workers, including poor service delivery that prolongs waiting hours, ineffective tracing, and recording systems (Etoori et al. 2020; Dirisu et al. 2020). These challenges can affect the relationship between healthcare workers and patients. It is important to understand the extent to which these patterns influence the health-seeking behaviours of HIV positive mothers in the PMTCT post-natal programmes.

Many studies in South Africa have focused on the implementation challenges of the PMTCT programmes (Frizelle, Solomon, & Rau 2009; Barron et al. 2013; Clouse et al. 2013; Mitiku et al. 2016; Clouse et al. 2017; Chauke et al. 2020; Davey et al. 2020;

Fedlu et al. 2020 Mpinganjira et al. 2020). Studies on challenges in the PMTCT post-natal are mostly conducted in Gauteng, KwaZulu Natal, Mpumalanga, Eastern Cape and Western Cape provinces of South Africa (Varga el al. 2006; Frizelle, Solomon, & Rau 2009; Nyasulu et al. 2013; Madiba & Letsoalo 2013; Madiba & Mphego 2014; Madiba 2015; Clouse et al. 2017; Fedlu et al. 2020; Ngyende, Bucyubaruta & Mugero 2020; Van der Merwe et al. 2020). Globally, there are no qualitative studies that focus comparatively on the lived experiences of HIV positive mothers who are LTFU and HIV positive mothers who are not LTFU in the PMTCT post-natal programmes, compared with the lived experiences of CHWs, and with nurses and lay counsellors. In South Africa, a few studies that compared HIV positive mothers with healthcare workers in the PMTCT programme include the work of Mpinganjira et al. (2020) and Ramoshaba & Sithole (2017). Therefore, this study is unique because it compares two groups of HIV positive mothers with two groups of healthcare workers (CHWs and group of nurses and lay counsellors).

The narratives and social patterns related to the CHWs experiences in the PMTCT outreach programmes are not well documented, this embraces perceptions regarding the relationship between CHWs and HIV positive mothers and the challenges that the CHWs experience in the outreach programmes. There are a few studies that explore the lived experiences of CHWs and link them with experiences of HIV positive mothers in the PMTCT programmes. Those that do exist do not offer a comprehensive and complementary linkage of the CHWs and the experiences of HIV positive mothers in the PMTCT programmes. For example, Sando et al. (2014) evaluated a community health worker intervention and the World Health Organization's option B versus option A to improve antenatal care and PMTCT outcomes in Dar es Salaam, Tanzania - a study protocol for a cluster-randomized controlled health systems implementation trial Kim et al. (2012) evaluated the Tingathe programme, a pilot intervention using community health workers to create a continuum of care in the PMTCT cascade of services in Malawi. Mgabo, Msuya and Mushi (2020) evaluated community health workers engagement in PMTCT: a cross-sectional study from selected fishing communities in Tanzania. Suryavanshi et al. (2018) explored challenges and opportunities for outreach workers in the PMTCT programme in India. Additionally, the inclusion of nurses and lay counsellors offer perceptions regarding HIV positive mothers` experiences in the PMTCT programmes, by exploring ward-based challenges that healthcare workers and HIV positive mothers face in the programmes. This study focuses on the social aspects that affect service utilisation, care, and retention of mothers in the PMTCT programmes. The study addresses the inequalities, barriers, or factors that influence the HIV service utilisation, which has resulted in LTFU and non-adherence to HIV treatment in the PMTCT post-natal period.

1.3 Aim of the Study

The study aims to explore social patterns of LTFU and non-adherence of the HIV positive mothers in the Limpopo province PMTCT programmes, to inform policy on PMTCT care, utilisation, and retention. Hence, this study intends to develop a sociological understanding of the LTFU and non-adherence in the PMTCT post-natal programmes.

1.3.1. Main objectives of the study

The following are the objectives of the study:

- To explore the underlying reasons for LTFU and non-adherence of HIV positive mothers in the PMTCT programmes from the perspective of the mothers, CHWs and professional healthcare workers.
- To determine accompanying intrapersonal (knowledge and beliefs) and interpersonal (gender and family dynamics) factors of treatment non-adherences and LTFU of HIV positive mothers.
- To explore community, social, and health care system factors that influence LTFU and non-adherences in the PMTCT programmes.
- To explore the retention strategies, intervention, and communications to improve care, treatment, and utilisation of the PMTCT services.

1.4. Significance of the Study

The foremost significance of this study is knowledge production to better understand why mothers are LTFU and how services might be designed to improve service utilisation and adherence. This study explored the dynamics of family and gender and motherhood challenges. It has produced new knowledge of social explanations and risks that promote LTFU and non-adherences in the PMTCT programmes. The study further hopes to provide knowledge on LTFU patterns from lived experiences of CHWs and healthcare workers in the implementation of the PMTCT programmes. This includes desired retention approaches and strategies to improve care, treatment, and utilisation of services in the rural settings of the Limpopo Province. The findings will help the Department of Health in achieving desired goals by exposing areas that need attention for counselling in the PMTCT programmes and training of healthcare workers and community outreach workers, to the benefit of women and children. This study promises valuable insights and recommendations to improve PMTCT service utilisation and retention.

1.5. Chapter Outline

This thesis consists of eight (8) chapters. This includes a chapter that captures the literature, a chapter that covers the research methodology, and chapters that present the research findings of HIV positive mothers, nurses, lay counsellors and CHWs in the PMTCT programmes and explores social patterns of LTFU and treatment non-adherence in the context of the Limpopo Province.

Chapter 1: This chapter introduces the study by articulating the research problem, objectives, aim of the study, and the significance of the study.

Chapter 2: This chapter presents the literature review on LTFU and treatment non-adherence in the PMTCT programmes. The chapter provides a detailed global, national, and provincial/regional account of HIV, MTCT, and PMTCT activities.

Chapter 3: The methodology is presented in this chapter to outline the research designs, description of the study settings, sampling procedures, methods that include data collection, data analysis, and ethical considerations.

Chapter 4: The chapter presents, analyses and interprets data from the HIV positive mothers, CHWs and nurses, and lay counsellors, as well as presents the underlying reasons for LTFU and HIV treatment non-adherence.

Chapter 5: The chapter presents, analyses and interprets data of qualitative findings (with mothers and CHWs) and quantitative findings (with professional healthcare workers). This chapter presents the associated barriers and challenges that the healthcare workers encounter when implementing the PMTCT programmes.

Chapter 6: The chapter presents the findings regarding strategies to improve care, treatment, and utilisation are presented in this chapter from the qualitative findings, mothers, and CHWs as well as quantitative findings (with professional healthcare workers).

Chapter 7: The chapter presents a synthesized discussion of qualitative findings (with mothers and CHWs) and quantitative findings (with professional healthcare workers).

Chapter 8: The chapter outlines the conclusion, general recommendations, and recommendations for further research.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

This chapter presents the literature on patterns of LTFU and non-adherence to HIV treatment. The chapter starts by introducing HIV, MTCT, and the PMTCT programmes, including the prevalence of LTFU and non-adherence to clearly understand the background of the research problem. The chapter unpacks literature on the reasons for LTFU and treatment non-adherence in the PMTCT programmes. The literature includes strategic models used for improving HIV care, HIV treatment and utilization of HIV-related services, and the challenges experienced by healthcare workers in the PMTCT programmes. The section on the sociology of health and illness explores how sicknesses are socially or culturally constructed and how societies understand and respond to illness or sickness (Conrad & Barker 2008). Consequently, this chapter provides the theoretical framework to explore the social patterns that outline the mothers and the healthcare workers' lived experiences. The Social-Ecological Model (SEM) theory-based framework is adopted in this study to understand patterns that influence LTFU and non-adherence to HIV treatment. The mothers and healthcare workers in the PMTCT programmes are exposed to a range of factors throughout the PMTCT cascade that is stimulus or influence of LTFU and non-adherence to HIV treatment (UNAIDS 2017).

2.2. Global and National Overview of HIV, MTCT and PMTCT Programmes

The HIV pandemic is one of the most prominent health tragedies that have affected many people around the world, especially women and children (WHO 2017; UNAIDS 2017). In South Africa, the first known case of HIV/AIDS was reported in the early 1980s, and since then South Africa had the fastest-growing HIV pandemic in the world with the most HIV infections (UNAIDS 2016). Preventing the spread of HIV in South Africa was initially a challenge and delayed due to a complex interaction of health politics that inspire policies that were against ART (Burton, Giddy & Stinson 2015). Eventually, in 2001, the South African Department of Health introduced the PMTCT programmes at 18 pilot sites after a strong pollical activism against HIV denialism. The programmes provided a single dose of nevirapine as an ART prophylaxis during labour (Barron et al. 2013). Initially, in 1983, it was assumed that AIDS infections among children were through casual contact (Centers for Disease Control and Prevention [CDC]) 1983b). However, in the same year, the assumption was ruled out and it was confirmed that children are directly infected by HIV through MTCT after birth, ruling out casual contact, food, water, air or surfaces (Centers for Disease Control and Prevention [CDC] 1983a).

Thereafter, in 1987, WHO confirmed the virus can be transmitted through MTCT, during breastfeeding (WHO 1987). Currently, it is widely known that a mother who has HIV can transmit the virus to her baby either during pregnancy or during childbirth/labour or breastfeeding after birth (UNAIDS 2017; WHO 2020). More than 90% of HIV infections in children aged 0-15 years occur through MTCT (UNAIDS 2019). Without treatment, HIV can be transmitted from a mother to her child during pregnancy (through the placenta), during labour/birth (through blood contamination) and after birth (through breastmilk or blood contamination) (UNAIDS 2017; WHO 2020). The risk of MTCT varies from 15% to 45% without intervention and with early ART intervention, the risk of MTCT can be reduced by 5% (WHO 2018).

The National PMTCT programmes aim to prevent HIV through the integration of PMTCT interventions such as antenatal care (ANC), health services for other chronic diseases like Tuberculosis (TB) and offer post-natal care for the mother and baby pair (Department of Health 2010; Department of Health 2020). Other PMTCT services are routine HIV counselling and testing of pregnant women attending ANC or mothers in the post-natal stage; involvement of supportive structure like partner and family support (Department of Health 2008; WHO 2015; Department of Health 2020). The programmes provide psychosocial support for women who tested positive for HIV and provide sexual health education and appropriate treatments and management of opportunistic infections and nutritional support (Department of Health 2013). The PMTCT programmes register HIV positive women for HIV services during their pregnancies, childbirth and after birth (UNAIDS 2017; WHO 2020). To determine the HIV status of infants, women need to bring their infants to the health facilities for Polymerase Chain Reaction (PCR) HIV testing. If the infant is positive, early use of ART is highly recommended (Department of Health 2016a/b/c; WHO & UNICEF 2016). In the post-natal period, the PMTCT programmes offer incessant follow-up services and provision of ART prophylaxis for mothers and their infants, with complete avoidance of mixed feeding (UNAIDS 2018).

In the year 2013, the World Health Organisation (WHO) recommended that pregnant women who are living with HIV would be enrolled for Option B+ which implies the immediate provision of lifelong treatment regardless of CD4 count (Department of Health 2020). Option B+ in the PMTCT programmes is the ART regimen given to HIV positive women during their pregnancy, delivery and breastfeeding, and it is continued for life (Department of Health 2013b). To implement Option B+ successfully, HIV positive mothers will have to take responsibility and adhere to clinic appointments and HIV treatment, this includes bringing their infants for follow-up appointments at their primary health care facilities (WHO 2017; UNAIDS 2017; Department of Health 2020). Wide coverage of services reduces MTCT through rapid uptake of HIV testing and counselling leading to continuous intake of HIV treatment (UNAIDS 2018).

When HIV positive mothers are identified in the PMTCT programmes, they are immediately placed on HIV treatment and after giving birth the mothers immediately register their infants for post-natal visits within three days. The infants will undergo PCR HIV testing at the health facilities to determine their HIV status. Afterwards, the infants will undergo weekly clinic visits and monthly visits until the age of twelve months. Thereafter, the infants will undergo clinic appointments with a period of three months when they are between the age of 12 months and two years. This allows them to go through HIV tests to find whether they are HIV positive or negative. Infants who are infected are urgently placed on an early use of ART (WHO 2010; Department of Health 2020).

According to Department of Health (2020), HIV exposed infants who are considered at high risk of HIV infections at birth are given Zidovudine (AZT) for six weeks and Nevirapine (NVP) prophylaxis for a minimum of 12 weeks. The infants can only stop NVP if the mother`s viral load is less than 1000 copies/ml and if not, the infant can continue taking NVP until their mother`s viral load is less than 1000 copies/ml, or the infant can stop NVP four weeks after the mother stop breastfeeding. In cases where the infants' PCR test reads negative, the provision of Cotrimoxazole treatment is stopped only for the infants who are formula-fed, this can happen if the infant test results are negative at the 10-weeks PCR test. Infants who are infected with HIV are given a single dose of NVP and AZT in seven days when the mothers started taking AZT at 28 weeks gestational age. Infants are also given a single dose of NVP and AZT if their mothers received a single dose of NVP during labour or AZT for 28 days (Department of Health 2020).

In terms of infant feeding practices, the exclusive breastfeeding method is highly recommended (Department of Health 2016a/b; WHO & UNICEF 2016). The other feeding options are exclusive formula feeding or replacement infant feeding (WHO & UNICEF 2016). The WHO recommends exclusive breastfeeding to avoid mixed feeding and the risk of MTCT. This is due to the high rate of MTCT that is associated with mixed feeding (UNAIDS 2018). Exclusive breastfeeding is when infants are breastfed for the first six months of life. The mothers can introduce other food sources after six months while continuing with breastfeeding for at least 12 months and up to 24 months or longer (Department of Health 2020; WHO & UNICEF 2016). Though infants are at a risk of acquiring HIV through breastfeeding, the WHO still recommends breastfeeding for mothers (exclusive breastfeeding for mothers living with HIV) because of its health benefits. Breastfeeding helps reduce the mortality rate and the risk of infants' malnutrition, diarrhoea, and pneumonia. In a case where the ART drugs are not immediately available for the mothers who are living with HIV, breastfeeding is still the recommended feeding option to increase the infants' chances of survival (WHO & UNICEF 2016). It is highly advised that healthcare personnel are well trained to enable them to provide quality and detailed counselling about the risks of MTCT during breastfeeding (Doherty, Sanders, Goga & Jackson 2011; Madiba & Mphego 2014).

Exclusive formula feeding is when an infant is given formula milk through the bottle and is not offered solid food for the first six months of birth (Doherty, Sanders, Goga & Jackson 2011; WHO & UNICEF 2016). This feeding option is for HIV positive mothers who can afford formula milk. Exclusive formula feeding is a better option to prevent HIV during the post-natal periods. However, mothers in resource-poor settings may struggle to afford formula or access to basic needs such as clean water or hygienic materials which are needed for proper use of formula feeding (WHO & UNICEF 2016). Thus, formula feeding is considered expensive in resource-poor settings with many mothers opting for breastfeeding due to the costs (Hunter-Adams, Myer & Rother 2016). Though there is low or no risk of MTCT when the mother exclusively formula feeds her infant, it is important for the mother to use this feeding method safely, and only feed her baby with formula milk from birth (Department of Health 2016; WHO & UNICEF 2016).

Nevertheless, infants who are only formula fed are at risk of poor growth or health as compared to infants who are breastfed. That is why it is recommended that infants who are formula-fed should adhere to follow-up visits for nutrition monitoring other dietary assistance (Doherty, Sanders, Goga & Jackson 2011). For mothers to make proper decisions regarding the infant feeding practice, they are recommended that they follow the Acceptable, Feasible, Affordable, Sustainable and Safe (AFASS) criteria and select the recommended feeding options (Department of Health 2008). Safe replacement feeding is recommended to make sure infants receive the proper nutrition that meets AFASS conditions (WHO & UNICEF 2016). Replacement feeding is when HIV exposed infants who are not receiving any breast milk is provided with a diet that has all the nutrients the child needs. The infant is given substitute commercial formula or home-prepared formula that have micronutrient supplements for the first six months, and after six months other complementary foods that are well prepared and rich with nutrients can be introduced (Doherty, Sanders, Goga & Jackson 2011; Madiba & Mphego 2014).

Research by Skinner et al. (2005) in South Africa regarding the barriers to accessing PMTCT services found that many families do not have access to clean water and that impacts negatively for mothers who use formula milk to feed their babies. Lack of clean water creates complications for the practice of safe replacement feeding that meet AFASS conditions. Sethuraman et al. (2011) conducted a qualitative study in Hai Phong and Ho Chi Minh City in Vietnam on the challenges for safe replacement feeding among HIV positive mothers. The research found that all the mothers that were interviewed did not meet the WHO conditions for safe replacement feeding and that the mothers introduced complementary feeding early. The study further revealed that the barrier to safe replacement feeding was lack of safe water and poor hygiene and the mothers complained about receiving little or no guidance on infant feeding from health care providers. In another study in Pretoria (South Africa), Matji et al. (2008) investigated the psychosocial and economic determinants of infant feeding.

They found that 74% of the women opted to use the formula feeding method even though only 30% of the women had access to public tap or piped water that is not well sanitized. The study further revealed that the mothers were influenced to select the formula feeding method during counselling and the counsellors did not use AFASS conditions when advising the mothers to formula feed their infants. Exclusive breastfeeding should continue for an infant who tested HIV negative but with limited food security, this should happen until the AFASS criteria are met or until the child reaches one year of age (Department of Health 2008). Mothers are recommended to continue breastfeeding their infants in cases where replacement feeding is not feasible because of financial constraints or lack of access to clean water (De Paoli et al. 2008).

Literature shows challenges regarding access to clean water and poor hygiene for mothers who used formula feeding or replacement feeding. These mothers fail to meet AFASS conditions (Doherty, Sanders, Goga & Jackson 2011; Madiba & Mphego 2014). There is a level of confusion and lack of guidance regarding which infant feeding method is best suitable for mothers living with HIV to prevent MTCT (Matji et al. 2008; Sethuraman et al. 2011). Also, there is evidence of polarisation between healthcare workers who believe complete avoidance of breastfeeding is the best way to prevent MTCT and those who believe counsellors should give women the correct information and allow them the opportunity to make the best decision on the feeding method that is appropriate for them (Matji et al. 2008; Sethuraman et al. 2011; Frizelle, Solomon & Rau 2009; Hunter-Adams, Myer & Rother 2016).

Mothers need to properly adhere to these feeding methods that are recommended or instructed to them by healthcare workers after giving birth (WHO 2017; WHO & UNICEF 2016). While it is difficult to monitor patient adherence to recommended feeding methods, adherence to ART and adherence to clinic appointments it is advised that the healthcare workers promote and continuously guide patients to comply with feeding instructions and their follow-up visits, and to take their medication as prescribed. This correspondingly involves picking up their treatment on time or checking if they are following the correct schedule or taking the right dosage (Department of Health 2016). Healthcare workers monitor HIV services and adherence to ART and other HIV programmes with proper training on HIV and ART (Nyasulu et al. 2013). In South Africa, the PMTCT programmes consist of well-trained lay counsellors and health care professionals that help strengthen the obstetric practices and reduce the spread of HIV and MTCT (Department of Health 2013a/b). Professional nurses are the highest ranked of all the nurses and the most qualified or trained about HIV, ART, PMTCT, and other HIV services (Mangi 2017). Unlike other nurses who occupy lower rankings, the professional nurses are responsible for the ward-based HIV services like HIV testing, counselling, and initiation of ART and constant provision of HIV medication for HIV positive or HIV exposed women and their infants (Georgeu et al. 2012; Mangi 2017). The nurses provide home-based HIV services especially for bedridden patients or patients who are LTFU or defaulters in the HIV prevention programmes (Georgeu et al. 2012). A systematic review of studies conducted in the USA and China reveals that reported adherence to ARVs improved with nurse-led home-based care (Wood et al. 2018).

The HIV lay counsellors provide HIV services like HIV counselling and testing for patients who are infected or exposed to HIV. This allows them to promote detailed HIV preventions measure to patients who have HIV and those who are at risk of HIV infection, including women who risk MTCT (Department of Health 2016). Haffejee et al. (2010) argue that lay counsellors do not only offer support services that are focused on HIV Counselling and Testing (HCT) they also have knowledge and capacity to identify mental health problems. Yet, there is often a lack of support for lay counsellors even when they are extensively used in HIV programmes (Dewing et al. 2014). Lay counsellors often feel that other healthcare workers do not appreciate their job due to the poor role definition of their profession and that unfairly leads to them performing multiple tasks above their counselling and testing duties (Horwood et al. 2010).

In South Africa, the health care systems have been drained by challenges that are brought by the influx of patients and limited resources (Department of Health 2016). With these limited resources and the increasing number of patients that are reporting in the health facilities, the health care providers struggle to keep up with the demands of work needed to save patients in need of immediate care (WHO 2002; Marindi 2019). The lack of resources compromises the quality of health care when it is limited or there is a lack of essential resources such as hospital beds, especially for patients suffering from chronic diseases. This health burden had resulted in the introduction of supportive programmes like the Community Home Based Care (CHBC) programmes.

Consequently, the need and implementation of CHBC programmes were first established due to increasing numbers of HIV/AIDS infections and related mortality (Marindi 2019).

To strengthen the failing health systems in Africa the WHO facilitated the renewal of the Primary Health Care (PHC) and developed the CHBC programmes (WHO 2002). These programmes are supported and provided by the Government and Non-Government Organisations (NGOs) to enhance the quality of health care and to provide support for professional healthcare workers (Marindi 2019). The CHBC programmes are part of the primary care services and confront various health demands, especially health systems providing chronic care services. These programmes provide services and care for patients affected by chronic diseases like TB and HIV considering the high prevalence and co-morbidity (Aantjes, Quinlan & Bunders 2014). Strengthening the health systems through community-based household and door-to-door activities educates and enhances the utilisation rates and effectiveness of health programmes (Department of Health 2013a/b).

The CHBC team has different individuals or groups, depending on the need in the community. The most notable CHBC teams are the community health workers, family caregivers, health and social welfare personnel, and community volunteers. Other stakeholders include spiritual leaders (church or traditional leaders), faith-based organisations, neighbours, or other community agencies, or organisations and community groups (WHO 2002). The successes of the ART programmes are attributed to the introduction of community-based HIV counselling and testing and Community-Based Adherence Support (CBAS) programmes. A multi-centre cohort study in South Africa by Fatti et al. (2012) evaluated the outcomes of a CBAS programme and showed improvement in the retention and care for adults receiving ART.

The CHWs play a vital role in the home-based programmes that are responsible for tracking and tracing patients who are LTFU and those who are defaulters (Suryavanshi et al. 2018). They monitor adherence by visiting households and ensure that patients are following the correct clinic schedule and the right medication dosage (Department of Health 2016). However, a cross-sectional study by Mgabo, Msuya, and Mushi (2020) in Tanzania on engagements of CHWs in the PMTCT programme found that the national health policy does not set clear roles for the CHWs nor clarify their monetary incentives. The CHWs perform multiple tasks, they assist patients by picking up their treatment to ensure that the patients who struggle to come to the health facilities adhere to treatment. The implementation of the PMTCT programmes has recorded some successes throughout the years and it is all thanks to the healthcare workers involved in the programmes day in and day out (UNIADS 2020). The HIV targets can be achieved with the assistance of these healthcare workers through widespread community and facility-based HIV testing, counselling, and adherence support.

2.3. The PMTCT Targets or Goals and Strategic Plans

The PMTCT goals provide insights and projections in the quest to prevent MTCT of HIV (WHO 2010). These goals are designed and committed to the development of norms and standards that promote effective interventions and excessive supports for countries affected by the surge of the HIV pandemic, especially countries from low socio-economic settings, to scale up the quality of PMTCT services (WHO 2010; UNAIDS 2017). Sustainable Development Goals (SDGs) envisioned until 2030 were set in place when they replaced the Millennium Development Goals (MDGs) which expired in 2015 (United Nations 2016). The goals are set as guidelines to prevent new paediatric infections to achieve what the MDGs failed to achieve (UNAIDS 2012).

Sub-Saharan Africa failed to reach the MDGs goals five and six that focused on reducing maternal mortality by three-quarters and mortality of children aged under five by two-thirds. This study is guided by the new goals from the SDGs, specifically goal three. This goal emphasises the importance of combating the spread of HIV and MTCT by addressing the challenges that the PMTCT programmes face in countries around the world, especially in Sub-Sahara Africa. Goal three of SDGs is specific to this study and hope to reduce the global maternal mortality ratio to less than 70 per 100,000 live births by 2030; end preventable deaths of new-borns and under-five children by 2030; and end the epidemics of AIDS by 2030 (Bose & Hawkes 2015). Additionally, with the 90–90–90 targets that have concluded in the year 2020 and have been replaced by the new targets, many countries including South Africa has failed to achieve the second 90 target. The 90–90–90 targets implied that by the year 2020, “90% of people living with HIV would have known their HIV status, 90% of people living with HIV would be on treatment and 90% of people living with HIV would be virally suppressed" (UNAIDS 2014). South Africa recorded only 75% of people living with HIV that were on treatment by the end of 2020 (UNAIDS 2020).

The new targets are called Global AIDS Strategy 2021-2026 and focus mainly on inequalities from the framework of three interconnected areas: the enabling environment (also known as the 10s) target, Service access (also known as the 95s) target, and service integration target. The enabling environment (the tens) targets imply that by the year 2026, less than 10% of the countries globally should have castigatory laws and policies that target people living with HIV; less than 10% of people experience stigma and discrimination, and less than 10% of people experience gender inequality or violence (UNAIDS 2021). As mentioned before, there is a need to understand the extents to which social patterns such as stigma, discrimination, and gender inequalities that impact service use in the PMTCT programmes.

The service access or the 95s target states that by the year 2026, at least 95% testing, treatment, and viral suppression are the targets, 95% access to combination prevention services, 95% access to sexual reproductive health services, and 95% coverage of prevention of mother-to-child transmission services (UNAIDS 2021). This study addresses the barriers that influence HIV service utilisation. These are the barriers that influence LTFU and non-adherence to HIV treatment in the PMTCT post-natal period. Lastly, the service integration target calls for 90% of people living with HIV to be linked to services important for their overall health (UNAIDS 2021). Effective ways of preventing new infections to achieve the HIV/AIDS targets or goals have been demonstrated in many research or reports (UNAIDS 2012). Through the failure of previously set goals and targets, new recommendations are developed to curb the spread of HIV (WHO 2017; UNAIDS 2021).

Start Free Stay Free AIDS Free 2020 was a strategic approach that aimed to end the MTCT and the AIDS epidemic among children by 2020. This was a global plan led by UNAIDS in 2015 to eliminate new HIV infections among children. The approach emphasises that children who are exposed to HIV deserve an HIV-free start. This can be achieved by promoting early initiation of HIV exposed pregnant women in ART programmes and retention of HIV positive mothers and their babies afterbirth. The goal was to eliminate and reduce new HIV infections annually to less than 40,000 by

2018 and 20,000 by 2020. To stay free, children need to be supported and need to be HIV-free throughout adulthood. This can be achieved through empowering vulnerable women and men, including adolescent (girls and boys) and young adults, and allowing access to effective prevention services. To achieve an AIDS free generation, children and adolescents living with AIDS should have access to ART (UNAIDS 2021). The scaling-up of PMTCT services has given health promoters a start in preventing the spread of HIV. However, even with the increased scaling-up of PMTCT services, the rate of LTFU and ART non-adherence is still high and poses serious concerns (UNAIDS 2017).

2.4. Non-Adherence to HIV Treatment and LTFU in the PMTCT Programmes

Adherence to treatment and clinic appointments help prevent MTCT and improve the health outcomes of mothers and their infants (UNAIDS 2017). For example, a cross-sectional study in Eastern Ethiopia by Fedlu et al. (2020) on adherence to ARVs in the PMTCT programmes found 83.2% of the 190 participants had good adherence to PMTCT. A similar study in Ethiopia by Asefa and Dirirsa (2018) investigated adherence of Option B+ in the PMTCT programmes and found that from a total of 180 mothers who were interviewed, 146 (81.1%) of the study participants had good adherence. This is supported by a study in South Africa by Peltzer, Sikwane and Majaja (2011), among 139 HIV-positive antenatal women and 607 post-natal HIV-positive women the study found that 85.6% of women in the antenatal phase and 98% women in the post-natal phase who initiated ART prophylaxis were on treatment. The study further showed that 61% of the women in the antenatal and 85.9% in the post-natal phase adhered to the appropriate medication schedule.

However, not every patient in the PMTCT adhere to HIV treatment or clinic appointments, risking MTCT and the overall health of both the mothers and her infant (UNAIDS 2017). Non-adherence to treatment is when patients who are on ART no longer take their medication, this also involves not following the correct schedule or taking the wrong medication dosage (UNAIDS 2016, 2017). For example, Ngyende, Bucyubaruta and Mugero (2020) conducted a qualitative study with 30 women between the age of 20-39 years in Johannesburg (South Africa) to explore women's perceptions of barriers impacting the post-natal PMTCT programmes. The study found that the barrier to the PMTCT post-natal programme was adherence to ART. The women reported that adherence to ART was challenging, especially in the beginning of the programme.

Follow-up visits in the PMTCT programmes assist mothers to detect and monitor HIV infections early and receive the provision of HIV medications, as early initiation of treatment can prevent MTCT (UNAIDS 2012; UNICEF 2012). Consequently, HIV positive mothers in the PMTCT programmes are LTFU. The mothers who recorded as LTFU when they failed to attend scheduled appointments or visits for 90 days or more, that includes medical visits, food collection or antiretroviral drug collections (Department of Health 2010; WHO 2010; UNAIDS 2012; UNICEF 2012). Other patients are defaulter in the HIV programme when they fail to report back into care or comply with the treatment schedule within two weeks after the appointment date (Florian et al. 2015). Also, non-adherences among HIV patients are the inability to correctly identify the medication regimen and or experience HIV drug resistance (UNAIDS 2016). Patients who keep cancelling their scheduled appointments risk being LTFU if their behaviour patterns continue. This is confirmed by a study in the USA, which reveals that previously missed appointments predict the likelihood of patients' clinic attendance outcomes, and that poor past attendance increased the risk for future missed visits (Pence et al. 2018). The study shows that patients who had not missed appointments had a 9% no-show risk for the next scheduled appointment and patients who had missed four or more visits had a no-show risk of 31% for the next visit (Pence et al. 2018).

Unfortunately, many patients are recorded with LTFU status and have stopped or disrupted HIV treatment by the time of tracing. For example, in South Africa, since the start of the PMTCT programmes, the rate of LTFU and ART non-adherence has been high during the post-natal period (UNAIDS 2017). In the earliest implementation phase of PMTCT programmes, 70% of HIV positive women were LTFU four months after delivery and close to 81% were LTFU six months after delivery (Painter et al. 2004; Sherman et al. 2004). Recent research suggests similar findings, the rate of LTFU and ART non-adherence is high during the post-natal phase. For example, A study conducted by Etoori et al. (2020) in rural Mpumalanga province (South Africa) assessed LTFU outcomes of pregnant and post-natal women and found that of 895 pregnant and 1017 post-natal patients who were LTFU, only 75 (8.4%) were not on treatment. Similarly, an observational cohort study conducted by Clouse et al. (2013) in Johannesburg (South Africa) assessed LTFU of HIV positive women before and after delivery and found that LTFU before delivery was 20.5%, and among those still in care, only 47.9% were LTFU within 6 months after delivery. Another study conducted by Clouse et al. (2017) in South Africa on mobility and clinic switching of post-natal women who are LTFU found that 300 (38.1%) of the women were LTFU from the 788 women who initiated ART during pregnancy. About 37.6% of the women who were LTFU showed evidence of continued HIV care after LTFU and 67.0% of these women continued care at the same province or clinic they first or initially selected. A study conducted by Chauke, Huma and Madiba (2020) in South Africa found that LTFU among adults on ART at three months was 28%, within six months was 50% and at 12 months was 28%.

Other African countries confirmed cases of LTFU in the PMTCT post-natal programmes. For example, a study by Kiiryaa et al. (2021) in Uganda found that out of 452 mothers who initiated Option-B+ only 131 (29%) were LTFU after delivery. Research conducted with 15,099 participants living with HIV in Malawi found that about 229 (40%) of the participants who were LTFU were successfully traced and only 118 (54%) of the 229 (40%) participants who had stopped taking ART drugs, 67 (30%) had self-transferred to other clinics, 13 (6%) collected drugs from alternative sources and 9 (4%) had treatment interruptions (Tenthani et al. 2014). A similar study in rural Uganda by Kweyamba et al. (2018) on the follow-ups among HIV positive pregnant and lactating mothers on lifelong ARVs in the PMTCT programmes have found that 279 of the HIV positive pregnant and lactating mothers who were traced and interviewed and 103 (37%) were reported with LTFU status.

There are some mothers who do not bring their infants to follow-up visits afterbirths. The study conducted by Rawizza et al. (2015) with 31,504 pregnant women in Nigeria reveals that only 20,679 (66%) completed the entire PMTCT cascade and in post-natal care, only one infant's follow-up visit was recorded. A similar study conducted by Van der Merwe et al (2020) in South Africa (Western Cape province) assessed the intrapartum HIV rate after roll-out of universal ART found 25% of infants were lost to follow-up after birth. The mothers who fail to conform with ART medications and follow-up visits disrupt the PMTCT interventions and risk MTCT and getting sick (Department of Health 2016). Research in Zimbabwe by Sibanda et al. (2020) support this, their study reveals that the mothers were not adhering to proper HIV prevention measures during post-natal periods and that women who previously tested negative contributed to the largest MTCT during the post-natal period. Infants exposed to HIV through their mothers are usually affected and sometimes identified late when they experience serious morbidity or death (Woldesenbet, Goga & Jackson 2010). A systematic review by Brinkhof, Pujadas-Rodriguez and Egger (2009) on the mortality of patients who are LTFU in ART programmes found connections between LTFU and mortality of patients are associated with a high rate of LTFU. The examination study found 1602 patients had died from a total of 6420 patients who were investigated. From 1602 who died, the available data shows 47 deaths, of which 29 (62%) died of Acquired Immune Deficiency Syndrome (AIDS).

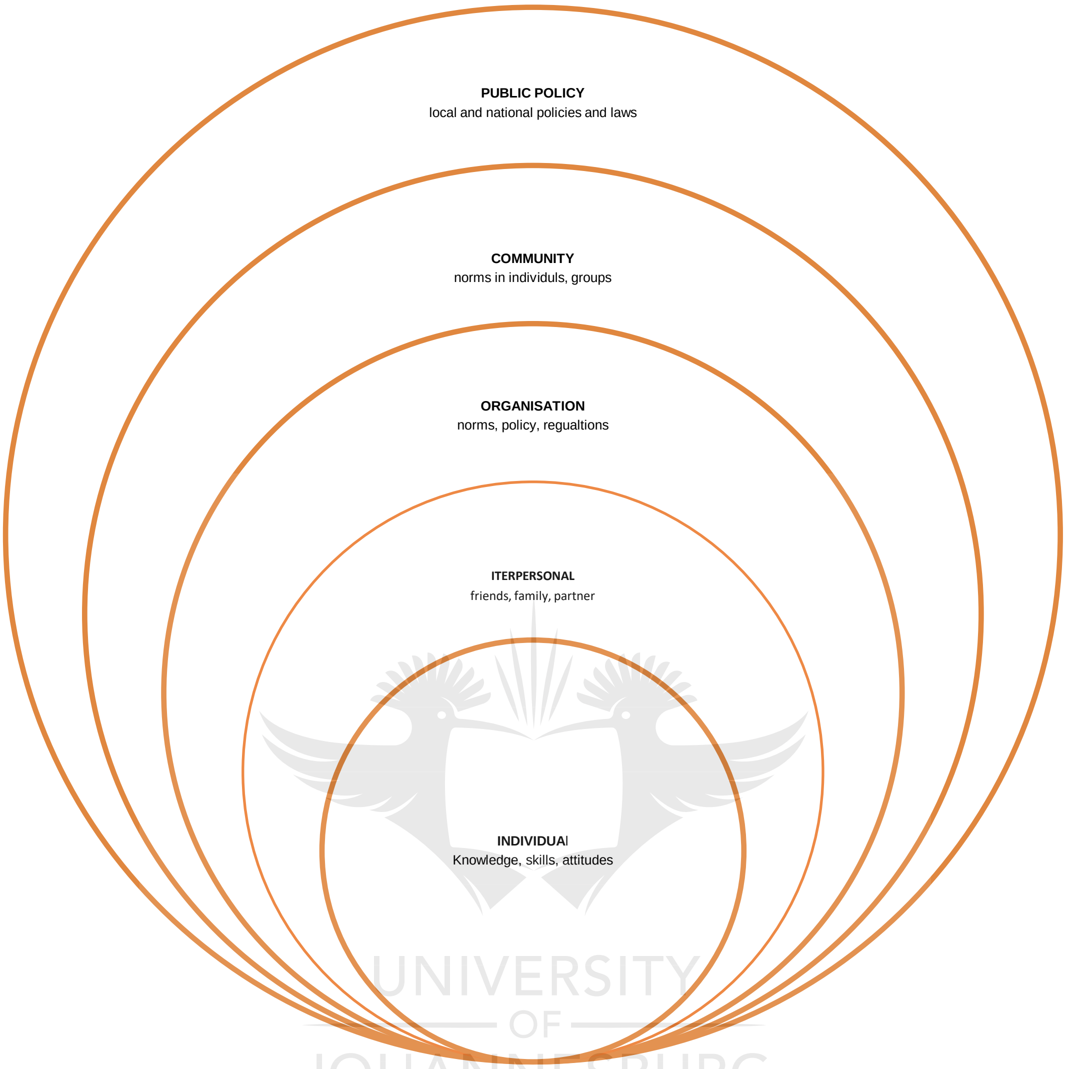
In the literature, non-adherence and LTFU of HIV positive women is evident in many studies as barrier to the PMTCT post-natal programmes (Clouse et al. 2017; Etoori et al. 2020). However, there are studies that reported good adherence to ART in the programmes (Asefa and Dirirsa 2018; Fedlu et al. 2020). Early and recent research on the PMTCT programmes (mostly quantitative) confirms that the rate of LTFU is high in the post-natal phase and that this pattern can lead to complications such as MTCT and AIDS-related mortality (Brinkhof, Pujadas-Rodriguez & Egger 2009; Van der Merwe et al. 2020; Sibanda et al. 2020). This evidence is shown from various African studies that are quantitative in nature, South Africa included. There are few studies in South Africa that focus on non-adherence to HIV treatment and LTFU of HIV positive mothers in rural South African post-natal programmes, especially in the Limpopo province (Mpinganjira et al. 2020; Ramoshaba & Sithole 2017). The factors and facilitators of LTFU and non-adherence to HIV treatment are further discussed in the next section.

2.5. The Patterns of LTFU and Treatment Non-Adherence

Existing literature recognizes that social factors can determines how people access and use services. This includes education, family, religion, economic stability, health care system and community (Conrad & Barker 2008; Timmermans & Haas 2008). Health behaviour can be influenced by fear of stigma and discrimination, geographical location, inadequate information, poverty, gender, family dynamics, power relations, beliefs, HIV disclosure and other health conditions that can influence health status (Conrad & Barker 2008; Timmermans & Haas 2008; Batisai 2020; Uys & Fritz 2020). The different health systems that are applied not only underpin the clinical aspect but also the social aspects of HIV and AIDS complexities. Integration of health or medicines with social aspects provides the opportunity to explore health-seeking behaviours and other social facets of healthcare practices (Batisai 2016; Batisai 2020; Uys & Fritz 2020). To understand social patterns of health, this study adopted the Social Ecological Model (SEM) theoretical framework (McLeroy et al. 1988; Stokols 1996). The social patterns of health explore conditions in the environments that influence the health status of individuals. The SEM explores the dynamic interrelations of personal and social factors that influence the behaviour of the individuals involved (Stokols 1996). The framework addresses the influence of health through multiple levels of intrapersonal/individual, interpersonal, community, organisational, and policy/enabling factors of social experiences (Stokols 1996).

The intrapersonal/individual factors are characterised by the knowledge, attitudes, skills and beliefs that influence behaviour. The interpersonal/relationship factors identify the processes of social identity and role definition such as partners, friends and family. The organisational/institutional factors dwell on the rules, policies, and formal and informal structures. This is not limited to incentives policies, referral systems, confidentiality/privacy, parental consent and stigma. The community factors focus on established norms and values, standards, and social networks, the availability and location of resources such as transportation, social/cultural norms, recreation facilities, health care services that promote health, social networks and social norms. Additionally, the societal policy factors address the cultural context, including local and national policies on health. The behaviour of the individuals involved can be influenced by one or more of the factors mentioned above. The SEM theory attaches human development to the socio-ecological model to understand the growth of individuals in an ecological environment (McLeroy et al. 1988). The model implies that an individual can influence behaviour and is also influenced by others in the surrounding environment. These factors are discussed further in the chapter with incorporated literature related to LTFU and non-adherence of treatment in the PMTCT programmes.

Figure 2. 1**:** The main constructs of the Social-Ecological Model (McLeroy et al 1988)



2.5.1. Intrapersonal/Individual factors

- Education, individual knowledge, awareness and attitudes about HIV and MTCT

Mothers who lack awareness and knowledge about HIV and MTCT of HIV can increase the rate of infections among children (Asefa & Beyene 2013; Abtew, Awoke & Asrat 2016). This is because knowledge and awareness about HIV and MTCT improve adherence to HIV treatment and the overall health of children exposed or infected with HIV (Abtew, Awoke & Asrat 2016). With adequate knowledge about HIV and MTCT, the mothers can be aware of the risks of MTCT to their born or unborn babies (Kalembo & Zgambo 2012). An investigation by Peltzer et al. (2009) in Mpumalanga (South Africa) found that there is a link between the mothers' knowledge about HIV and PMTCT activities, the use of HIV drugs by the mothers, and the administration of the HIV drugs for their baby.

Some mothers are aware and are knowledgeable about the danger of MTCT. This is confirmed by a study by Asefa and Beyene (2013) which found that 60.7% of the participants were well-informed about the risk of MTCT. Asefa and Dirirsa (2018) conducted a study in Ethiopia and found that the majority of the HIV pregnant women (80.6%) believed that HIV-infected pregnant women can transmit HIV through MTCT. An investigation by Peltzer et al. (2008) reveals that only 36.7% of the participants were under the impression that babies who are born to HIV-positive mothers can be infected. Peltzer et al. (2009) found 74.2% of the study participants were knowledgeable about MTCT during labour/delivery and 77.9% were aware that MTCT can occur through breastfeeding. A study by Bajunirwe and Muzoora (2005) support this and found only 12% of the participants lacked knowledge about MTCT during pregnancy (to an unborn baby), and only 8% of the participants were not aware or knowledgeable about how HIV is transmitted from a mother to her baby.

Nonetheless, there are mothers with inadequate knowledge about MTCT and other PMTCT activities and often overlook the means to understand prevention measures of MTCT (Woldesenbet et al. 2010). Rogers et al. (2006) conducted a study of 202 women in the PMTCT programmes which reveals that most of the women had prior knowledge about HIV and AIDS, but 48% did not know the prevention measures of MTCT. The study by Asefa and Dirirsa (2018) found 113 (77.4%) of the HIV pregnant women believed good adherence can decrease HIV transmission to their partners. A similar study conducted by Ramoshaba and Sithole (2017) reveal that most of the mothers were aware that MTCT can be prevented and acknowledged the importance of HIV treatment adherence as a prevention measure of MTCT.

Moreover, there are healthcare workers with inadequate knowledge about MTCT and PMTCT practices (Ogbonnaa, Govendera & Tumboa 2016). Haffejee et al. (2016) conducted a study in South Africa with 12 health care workers and found most respondents were unable to specify how a mother transmit HIV to a baby, but they were aware of MTCT. A study in Soweto (South Africa) by Mnyani and McIntyre (2013) reveals that the healthcare workers had poor knowledge and practice of PMTCT activities. Similar findings emerged in a study by Hentgen et al. (2002) in Madagascar which shows 73% of the healthcare workers were unaware of interventions to reduce MTCT of HIV and reveals that doctors were more knowledgeable than nurses concerning PMTCT activities. However, research study conducted in South Africa by Ogbonnaa, Govendera and Tumboa (2016) reveals that nurses and doctors were aware of the importance of HIV counselling and testing for all mothers. Consequently, the nurses and doctors in the study were not sure of the dosages of drugs used for PMTCT, 35% show poor knowledge of medication combinations, and 21% show poor knowledge of medication doses.

Mothers acquire information or knowledge about MTCT from lay referrals and health personnel at the health facilities (Maputle & Jali 2008). HIV positive mothers need adequate information from healthcare workers to make sound decisions about their health. Still, even with support from referrals and the healthcare workers the mothers lack sufficient knowledge about the risk of MTCT. Laar et al. (2018) argue that patients are only provided with counselling on their first visits and not on follow-up visits, suggesting that there are limited interactive relationships between healthcare workers and patients. Thus, poor counselling and inadequate information promote LTFU and non-adherence to treatment in HIV prevention programmes. This is confirmed by a study in Malawi (Tenthani et al. 2014), which found that 10% of the participants who stopped taking their HIV medication did not receive adequate education or information on how to use ARVs, they did not remember or understand what was communicated to them during the counselling sessions. Though the study shows 90% of the participants who received adequate information stopped taking treatment anyway, the remaining 10% (a participant who did not receive adequate information) were disadvantaged from the start regarding how to properly adhere to HIV medication (Tenthani et al. 2014).

Moth, Ayayo and Kaseje (2005) conducted a study in Kenya and found that most HIV counselling sessions take less than ten minutes, the study reveals 68% of the participants had five minutes of counselling, followed by those who had five to ten minutes (21%) and only 10.7% had more than ten minutes of counselling. The mothers need to attain enough time and attention during counselling sessions and follow instructions accordingly. When people are misinformed about the difference between HIV and AIDS, they make conclusions that are negative (UNAIDS 2012). Deressa et al. (2014) found that half of the respondents spent between 10 to 30 minutes waiting to see the counsellor, 53.8% in the health centres and 41% in the hospitals spent between 10 to 30 minutes before seeing the counsellor, and the average time spent with the counsellors was about 12 minutes for the entire group of respondents. Further examination found that 58% of the respondents justified that the time they spent during the visit was reasonable, and 29.4% reported that the time they spent during the visit was too long.

In the PMTCT programmes, services like HIV testing and counselling are affected when the healthcare workers offer poor HIV counselling (Ogudele & Coulter 2003). This leads to the provision of incomplete or inadequate information about HIV, and poor quality of HIV counselling hinders the success of the PMTCT programmes (Chopra & Rollins 2008). Peltzer et al. (2007) found that knowledge about the PMTCT programmes was low among the participants. Chopra et al. (2005) found 73% of mothers who were counselled about the advantages of exclusive breastfeeding only one HIV positive mother was informed about the HIV medication’s side effects and none of the HIV positive mothers were informed about how to cope with the side effects when they happen. About infant feeding options, the counsellors only asked important questions about safe formula feeding to two HIV positive mothers before they can decide on which feeding method to choose (Chopra et al. 2005).

Furthermore, there is a need to address motherhood among youth, and the issues of family planning during counselling (USAID 2005). A study by Mushi, Mpembeni and Jahn (2007) in Tanzania on knowledge about safe motherhood and HIV/AIDS among school pupils found a lack of intervention to address safe motherhood or reproduction at the teenage level, the knowledge about MTCT was low among the school pupils. The pupils lack knowledge about post-natal care for their babies and they were not prepared for birth, or the risk factors involved. Similar findings were presented in a study by Varga and Brookes (2008) in South Africa on preventing MTCT among adolescents and found rural adolescents are less likely to successfully implement most PMTCT-related practices than urban adolescents.

The past and recent studies confirm that most HIV positive women in the PMTCT programmes are aware of MTCT and know that a mother can transmit HIV through MTCT. Nevertheless, there is evidence that some HIV positive mothers still lack awareness and knowledge about MTCT (Bajunirwe & Muzoora 2005; Peltzer et al. 2009; Asefa & Beyene 2013; Deressa et al. 2014; Asefa & Dirirsa 2018). Evidently, most HIV positive women are aware of MTCT prevention measures and the importance of adherence to HIV treatment to prevent HIV transmission to their partners (Rogers et al. 2006; Ramoshaba & Sithole 2017; Asefa and Dirirsa 2018). However, there is concerning evidence of HIV positive women who lack awareness and knowledge about these MTCT prevention measures. There is not enough literature to address the relationship between awareness or knowledge about MTCT and health-seeking behaviours. The gap in the literature is the extent to which knowledge and awareness of HIV and MTCT impact the success of the PMTCT post-natal programmes. Though most African studies review the knowledge and awareness of HIV positive mothers, there are a few that associate awareness and knowledge about MTCT with LTFU of HIV positive mothers. Hence, this study associates awareness and knowledge about MTCT with HIV service utilisation in the Limpopo PMTCT post-natal programmes.

The healthcare workers in the PMTCT programmes are aware of MTCT, the literature confirms (Haffejee et al 2016; Ogbonnaa, Govendera & Tumboa 2016; Govendera and Tumboa 2016). Nevertheless, there is evidence that shows lack of awareness and knowledge about interventions to reduce MTCT. There are a few South African studies especially in the rural context of the Limpopo Province that explore Healthcare workers` knowledge and awareness` about MTCT in the PMTCT post-natal programmes (Haffejee et al 2016; Ramoshaba & Sithole 2017; Mpinganjira et al. 2020). The studies do not address the relationship between HIV positive mothers and healthcare workers in the post-natal programmes. There is not enough linkage between healthcare workers` awareness or knowledge about MTCT and non-adherence or LTFU of HIV positive mothers (Haffejee et al 2016; Ogbonnaa, Govendera & Tumboa 2016; Govendera and Tumboa 2016). The extent to which the knowledge and awareness of healthcare workers impact the success of the PMTCT programmes is not vastly documented. The studies show complexities involving HIV counselling and information sharing at the health facilities, showing patterns of inadequate time spent during sessions and information (Rogers et al. 2006; Haffejee et al. 2016; Ramoshaba & Sithole 2017; Asefa and Dirirsa 2018). Hence, it is important to explore the lived experiences of HIV positive mothers and healthcare workers to address the issues related to patients-healthcare workers relationships during counselling sessions.

Literature is vastly quantitative and is conducted in various African countries (Asefa & Beyene 2013; Deressa et al. 2014; Tenthani et al. 2014; Asefa & Dirirsa 2018; Ogbonnaa, Govendera and Tumboa 2016). There is a need to incorporate the lived experiences of HIV positive mothers to explore the knowledge and awareness patterns in the PMTCT post-natal programmes. Thus, there is not enough qualitative studies in South Africa that associate awareness or knowledge about MTCT and MTCT prevention measures, and the relationship with LTFU of HIV positive mothers in PMTCT post-natal programmes. There is lack of evidence to understand the relationship between awareness or knowledge about MTCT and the MTCT prevention measures or use of services. This study allows the mothers to describe MTCT and narrate their experiences or explicate how a mother transmit HIV to her baby and which preventions measures they are aware or use to prevent MTCT of HIV.

The lived experiences of HIV positive mothers and CHWs during counselling sessions is not immensely documented. Hence, there is an opportunity to research qualitative meanings or lived experienced of CHWs to understand and explore their knowledge and awareness of PMTCT activities, including counselling strategies during follow-up visits, tracking, tracing and retention processes in the PMTCT post-natal programmes. Furthermore, a gap to be explored is the awareness and knowledge about MTCT preventions measure by comparing lived experiences of HIV positive mothers who are LTFU and HIV positive mothers who are not LTFU, and with experiences of CHWs, nurses and lay counsellors in the PMTCT post-natal programmes. Palpably, there is a dearth of studies that compare different groups of HIV positive mothers with healthcare workers. The comparison can offer a contrasting perspective and deeper meaning and understanding of the challenges in the PMTCT post-natal programmes.

- Infants feeding patterns and associations with knowledge and beliefs

Adherence to HIV treatment includes following the PMTCT post-natal feeding instructions and other nutritional options in the programmes (WHO & UNICEF 2016; UNAIDS 2018). I have mentioned earlier in the chapter that the WHO recommends exclusive breastfeeding or exclusive formula feeding for HIV positive mothers and complete avoidance of mix feeding in the six months after birth. This is because the high rate of MTCT is associated with mixed feeding of infants in the first six months after birth (WHO & UNICEF 2016; UNAIDS 2018). Peltzer et al. (2007) conducted a study in South Africa to investigate the barriers of preventing HIV transmission from a mother to child and found there is low knowledge about exclusive breastfeeding and formula feeding. Lack of awareness about the risks involving mix feeding is one of the major problems that hinder the success of the PMTCT programmes (Hazemba, Ncama & Sithole 2016; WHO 2017). It is confirmed that the mothers fail to understand or explain exclusive breastfeeding or mix feeding practices (Mphego, Madiba & Ntuli 2014; Hazemba, Ncama & Sithole 2016). Ekanem and Gbadegesin (2004) conducted a study in Nigeria of women in the PMTCT programmes, the study reveals that 41.7% the women in the study did not associate HIV transmission with breast milk. Deressa et al. (2014) found that the majority of the respondents who participated in the study believe that the MTCT of HIV occurs through breast milk (72.4%).

The mothers who lack prior knowledge about recommended feeding methods often fail to follow instructions given to them by the healthcare workers (Mphego, Madiba, Ntuli 2014; Department of Health 2016c). In most cases, mothers feed their infants in public, which can affect adherence to feeding patterns instructed by healthcare workers; the mothers may mix feed their babies with other food sources to avoid raising suspicions among their peers or community members (Falnes et al. 2011). The mothers may fear inadvertent disclosure of HIV status, and hence decide to mix feed (Falnes et al. 2011; Madiba & Mphego 2014).

Infants feeding instructions are often affected by religious and traditionally accepted practices about how infants should be fed (Frizelle, Solomon & Rau 2009; Laar & Governder 2011). The family traditional practices influence mothers to mix feed their infants, this risk transmission of HIV through MTCT (Laar & Governder 2011). A study in India reveals that the structural-level challenges that CHWs experienced in the

PMTCT programmes included cultural norms around infant feeding (Madiba & Langa 2014). The pressure from the family to follow the traditional way of feeding prompts mothers to abundant instructions from healthcare workers. The mothers are bound to infect their infants if they lack the understanding that breastfeeding infants without treatment is risky for their babies (Madiba & Langa 2014; WHO & UNICEF 2016; WHO 2018). Madiba (2015) conducted a cross-sectional survey in South Africa with 202 HIV-positive mothers and found that adhering to recommended feeding options such as exclusive breastfeeding and exclusive formula feeding was difficult for mothers and that mothers who introduced complementary and traditional medicines were less likely to adhere to their initial infant feeding options. A study by Thorsen et al. (2008) found that cultural practices related to infant feeding influence adherence to infant feeding instructed by healthcare workers in the PMTCT programmes. Mix-feeding practice is promoted as a cultural practice where an infant is fed with multiple food sources in the first month of birth. Towle and Lende (2008) conducted a study in Lesotho and found that men were the decisions makers in most households and decided for the mothers on the duration to breastfeed. Burke (2004) conducted a study in Tanzania that found that some women are pressured by their families to introduce solid food to their infants after giving birth. Similar findings were presented in a study conducted in South Africa by London et al. (2008) advocating the rights of people living with HIV. The study found young mothers were mostly pressured by family members to follow infant feeding methods that are against infant feeding practices instructed or recommended by healthcare workers.

Infant feeding recommendations from the healthcare workers assist mothers in preventing the MTCT, the literature confirms (Madiba 2015; Suryavanshi et al. 2018; Nyati-Jokomo et al. 2019). However, there are healthcare workers with inadequate knowledge about PMTCT feeding practices (Mnyani and McIntyre 2013; Ogbonnaa, Govendera & Tumboa 2016). A research study on assessment of infant feeding policy and the PMTCT programmes by Chopra and Rollins (2008) in Botswana, Kenya, Malawi, and Uganda found that after receiving training 70% of healthcare workers failed to correctly describe the risks of MTCT during breastfeeding and the information regarding infant feeding options was mentioned in 48% of the counselling sessions. Chopra et al. (2002) conducted a similar study in South Africa and found that all the healthcare workers in the study could correctly estimate the risk of MTCT through breastfeeding, yet a number of these healthcare workers admitted to feeling confused about the risk of MTCT during breastfeeding and were not sure of what to tell the mothers. Coovadia and Bland (2007) conducted a review study and suggested that confusion about infant practices among healthcare workers had led to complete avoidance of the topic regarding infant feeding during PMTCT counselling sessions. A qualitative study by Ngyende, Bucyubaruta, and Mugero (2020) with 30 women between the age of 20-39 years in Johannesburg (South Africa) found that women complained about receiving inadequate counselling on infant feeding options, follow-up clinic visits, testing dates, and treatment adherence. Regarding infant feeding options, the study found that the PMTCT staff did not provide enough information about which method to use, whether they should use formula feeding or exclusive breastfeeding, the healthcare workers did not provide information on specific conditions for formula feeding.

Furthermore, there is a need to address motherhood among youth, and the issues of family planning during counselling (USAID 2005). A study by Mushi, Mpembeni and Jahn (2007) in Tanzania on knowledge about safe motherhood and HIV/AIDS among school pupils found a lack of intervention to address safe motherhood or reproduction at the teenage level, the knowledge about MTCT was low among the school pupils. The pupils lack knowledge about post-natal care for their babies and they were not prepared for birth, or the risk factors involved. Similar findings were presented in a study by Varga and Brookes (2008) in South Africa on preventing MTCT among adolescents and found rural adolescents are less likely to successfully implement most PMTCT-related practices than urban adolescents.

There are studies that identified gaps in PMTCT and knowledge about MTCT and infant feeding policy which affect the practice of recommended infant feeding (Chopra et al. 2002; Coovadia and Bland 2007; Mnyani and McIntyre 2013; Ogbonnaa, Govendera & Tumboa 2016). There are HIV positive mothers who are aware of MTCT through the mother`s breastmilk (Ekanem & Gbadegesin 2004; Deressa et al. 2014). But, in the same studies, there is evidence that shows lack of awareness and knowledge that breastmilk is associated with MTCT of HIV. The existing literature can benefit from the mothers' narratives of their experiences and explanations of how a mother transmits HIV to her baby in the post-natal phase. Religious and cultural beliefs are shown to have influences on infant feeding choices and external influences that engage in promoting these choices (Frizelle, Solomon & Rau 2009; Laar & Governder 2011). Recent studies show similar patterns, family infant feeding traditions still have cultural and religious significance and influence feeding practices. Understanding social patterns of infant feeding practices explores the deeper meanings of the challenges that HIV positive mothers experience in their daily life. These expose the extent of religious and cultural beliefs, then involvement of family, the influence of sexual partners and community influences on infant feeding choices. There is also little understanding of the motherhood patterns of infants feeding to uproot the deeper meaning from the narratives of mothers. Most of these studies are quantitative in nature and do not unpack the deeper meanings or the extent of infant feeding knowledge and awareness influences the use PMTCT infant feeding practices.

There are studies where women received inadequate counselling about infant feeding options, and healthcare workers who are confused about infants feeding methods, especially the risk of breastfeeding (Mnyani and McIntyre 2013; Ogbonnaa, Govendera & Tumboa 2016). Therefore, the interplay between the knowledge and awareness of mothers regarding recommended feeding methods is not well addressed or extensive as it should be. There is a need to understand the social patterns of infant feeding that mothers encounter in their daily life; the literature exposes the gap of knowledge and awareness regarding infant feeding methods that is safer to use or preferred by mothers. There is a gap in the literature on the interplay between the knowledge and awareness of mothers regarding recommended feeding methods and the health-seeking behaviour to understand if knowledge influences mothers to adhere to the feeding methods instructed by the healthcare workers. This gap in the literature pertains to the relationship between knowledge and health-seeking behaviours that influence patterns of infant feeding. There is also little understanding of the motherhood patterns of infants feeding to uproot the deeper meaning from the narratives of mothers in contexts of family, roles, health care systems, and other influences. Furthermore, a gap to be explored is the awareness and knowledge about infant feeding methods and patterns of preventing MTCT during infant feeding. This can be explored through a comparative analysis of the lived experiences of HIV positive mothers who are LTFU and HIV positive mothers who are not LTFU, and with experiences of CHWs, nurses and lay counsellors in the PMTCT post-natal programmes.

- Medication side effects and routine

In the earliest period of the virus, people living with HIV in most cases showed visible signs and symptoms and were stigmatized or associated with the virus (Hawkins 2006; Johnson & Neilands 2007). The introduction of the ART regime in 1996 have shown positive results in minimising the negative physical appearance. Unfortunately, the HIV treatment came with appearance-related, and other side effects, and this influences adherence to HIV treatment (Hawkins 2006). Coping with HIV treatment side effects is associated with non-adherence, that non-adherence to treatment is used as a coping strategy (Johnson & Neilands 2007). A qualitative study by Katirayi et al. (2016) evaluated the lessons learned from the PMTCT programmes in Swaziland to explore the challenges that pregnant and lactating women experiences with accepting lifelong ART and found that women feared the side effects that are caused by ART. Abdisa and Tenaw (2021) conducted a study on the level of adherence to option B + PMTCT and the associated factors among HIV positive pregnant and lactating women in public health facilities in the Hawassa city, Southern Ethiopia, and found that the adherence level was associated with HIV medication side effects and 89% of the respondents who experienced the side effects were less likely to adhere to treatment compared to those who didn’t experience the side effects.

Similarly, Flax et al. (2017) conducted a qualitative study in Lilongwe District, Malawi with 32 HIV positive women who were LTFU on Option B+ to investigate factors that influence post-natal Option B+ participation and breastfeeding duration. The research found that the participants reported ART side effects as the reason for LTFU. A qualitative study in Nigerian by Erekaha et al. (2018) found that newly diagnosed women accepted lifelong ART, but the women in the postpartum and those who are LTFU had conditions to accept Option B+ and complained about ART side effects. Similarly, Kouassi et al. (2014) found that the patients who experience side effects were three times more likely to discontinue their HIV treatment compared to those who did not experience the side effects.

Research indicates that patients who have been on ART are more likely to fail in adhering to treatment when they experience broader medication challenges such as medication routines or adjustments, and fears as well as other daily life commitments (Katirayi et al. 2016; Abdisa & Tenaw 2021). An overview of published literature conducted by Ammassari et al. (2002) confirms this and found that the reasons the participants in the study failed to adhere to the ART was because of the routines prescribed on how to take medication, struggles with integrating the treatment schedule with daily life activities (36-57%), and forgetting to take the medications (30-66%). Abdisa and Tenaw's (2021) revealed that 88.2% of the respondents were adhering to Option B+ PMTCT. Yet, 10 (33.3%) had missed their ART medication and the reasons for non-adherence were difficult to remember the time for taking drugs, others face difficulty in remembering to take medications (52%) and others stopped taking their treatment when they start to feel better.

Furthermore, there are intricacies involving support and counselling for HIV positive women who experience side effects. King et al. (2021) conducted a study in Uganda to investigate the barriers and strategies to improve adherence to Option B+ and found that the participants clearly understand the benefits of adhering to treatment. This emphasising the importance of counselling related to HIV medication side effects as a critical factor of helping patients with their adherence. In Hadiya Zone, Southern Ethiopia, a study by Lodebo and Suloro (2017) found that 83.7% of the HIV positive pregnant women who participated in the study were adhering to Option B+ treatment in the PMTCT programmes. The research further reveals that the mothers who were counselled on the side effects of ART medications were more likely to adhere to the medication than those who were not well counselled about the side effects.

As shown in the literature, many African studies associated HIV medication side effects with non-adherence and that non-adherence to HIV treatment is a coping strategy, and that fear of HIV medication side effects is the reason for LTFU (Katirayi et al. 2016; Flax et al. 2017; Abdisa & Tenaw 2021). Also, literature associates non-adherence to HIV treatment with medication routine (Ammassari et al. 2002; Katirayi et al. 2016; Abdisa & Tenaw 2021). There is a gap in the literature to explore the extent to which medication side effects impact on the success of the PMTCT post-natal programmes. Although most African studies review side effect patterns, there is a dearth of studies that associate these side effects with LTFU of HIV positive mothers in the Limpopo PMTCT post-natal programmes. There are a few South African studies especially in the rural context of the Limpopo Province that explore healthcare workers` support regarding medication side effects. There is an opportunity to address the relationship between HIV positive mothers and healthcare workers in the post-natal programmes with regard to methods of coping with the side effects. Hence, it is important to explore the lived experiences of healthcare workers related to their relationships with HIV positive mothers during counselling sessions. Also, the lived experiences of HIV positive mothers and CHWs during tracking, tracing, and counselling sessions is not immensely documented. There is an opportunity to compare the lived experiences of HIV positive mothers who are LTFU and HIV positive mothers who are not LTFU, and with experiences of CHWs, nurses and lay counsellors in the PMTCT post-natal programmes.

- Religious beliefs and practices.

In South Africa, African traditional and Christian religious practices impact the uptake of PMTCT services (Laar & Govender 2011). Myths and misunderstandings are surrounding HIV prevention programmes, and people in many African societies often opt for alternative methods to treat HIV (Batisai 2016; Batisai 2020). With that said, most mothers choose traditional doctors or church leaders as their choice or alternative health care systems to treat HIV (Laar & Governder 2011). Peltzer et al. (2008) found 36% of the participants had consulted traditional healers for HIV treatment, they believe that traditional medicines are better compared to Western medicines. These beliefs can be disastrous when the traditional medicines fail to work, and their health conditions deteriorate. Most people believe that HIV is a curse from witchcraft, this is a dangerous assumption especially when the patients start to use alternative methods as their only option to treat HIV (Frizelle, Solomon & Rau 2009). These beliefs often lead to accusations that HIV is a curse from direct family members, neighbours, or friends (Varga & Brooks 2008).

Religious beliefs are strongly associated with beliefs that HIV is a punishment from God, therefore, mothers opt for the use of church medicines as treatment (Zou et al. 2009). When the mothers believe HIV is witchcraft or spiritual forces and use alternative treatments from the churches, these treatments may go against instructions from the healthcare workers (Varga & Brooks 2008). Some of the church leaders influence this behaviour, making people living with HIV believe that HIV is a curse or punishment from God and that the virus can only be cured through prayers (Zou et al. 2009). Regarding the influence of religious leaders, Doherty (2009) argues that promoting religious beliefs affect the PMTCT programmes especially when patients fail to follow instructions from the healthcare workers.

There are cultural taboos that prevent women from talking about issues related to sex. These cultural taboos affect the uptake of PMTCT services, and this means that women may not be able to speak about safe sex practices with their partners (Zambia Central Board of Health 2004). A study by Skinner et al. (2003) in South African found that there are cultures that consider disclosure of pregnancy to mother-in-law as inappropriate. The mothers only allow their pregnancy to be disclosed when it starts to be visible that they are pregnant. Similar findings were found in a study by Towle & Lende (2008) on investigating community approaches to preventing MTCT. The findings show that it is cultural taboo to disclose or announce pregnancy to the public. It is difficult to follow instructions from healthcare workers in the PMTCT programmes because of the cultural taboos and practices that many women have to follow in their family or community (Skinner et al. 2003; Towle & Lende 2008). King et al. (2021) conducted a study in Uganda found that the health of the babies is more valued than the mothers' health, there are beliefs that the baby's health is more important and prioritized. A recent study by Nkhonjera et al. (2021) in Malawi found that the retention of mothers was inspired or motivated by the aspiration to have a healthy baby. A study conducted by Mushi, Mpembeni, and Jahn (2007) in Tanzania on the knowledge about safe motherhood and HIV/AIDS among school pupils found that many pupils believed in pregnancy taboos. The pupils believe that the complications they experienced during pregnancy and childbirth were because they were not adhering to traditions. Hence, the patients stop ART to follow their beliefs about HIV and MTCT.

The studies confirm that religious and cultural beliefs influence mothers` decisions to utilise PMTCT services. There is evidence that some HIV positive mothers still believe that HIV results from witchcraft or spiritual forces and use traditional medicines to treat HIV, while other rely on prayers and other church related medicines to treat HIV (Towle & Lende 2008; Varga & Brooks 2008; Doherty 2009; Zou et al. 2009; Laar & Govender 2011). The influence of religious leaders is strongly associated with mothers` beliefs and impact negatively on the progress of the PMTCT programmes. Cultural taboos are also factors that influence the uptake of PMTCT services. These taboos include prohibition regarding safe sex practices with their partners and disclosure or announcement of pregnancy (Mushi, Mpembeni, and Jahn 2007; Towle & Lende 2008; King et al. 2021; Nkhonjera et al. 2021)

There is not enough literature to address the relationship between religious or cultural beliefs and health-seeking behaviours or utilisation of PMTCT post-natal follow-up services. The extent to which religious and cultural beliefs impact the success of the PMTCT post-natal programmes is not well document, especially in the rural Limpopo PMTCT post-natal programmes. The studies do not adequately address the relationship between HIV positive mothers and healthcare workers regarding the use of alternative medicines to treat HIV. The prevalence and benefits or impact of medicine pluralism in the PMTCT programmes is not vastly documented. The studies should highlight the communications during counselling to address the information sharing patterns at the health facilities. There is a need to incorporate the lived experiences of HIV positive mothers to explore religious and cultural beliefs patterns in the PMTCT post-natal programmes. Therefore, this study allows mothers to describe MTCT and narrate their experiences or explicate how they feel about using alternative medicines to treat HIV. The lived experiences of HIV positive mothers and CHWs during counselling sessions is not immensely documented to address religious and cultural patterns during tracing, tracing, and retention of HIV positive mothers. Furthermore, there is an opportunity to compare lived experiences of HIV positive mothers who are LTFU and HIV positive mothers who are not LTFU, and with experiences of CHWs, nurses and lay counsellors in the PMTCT post-natal programmes.

- Family and gender roles: Inequalities and lack of social support

Family structures/practices such as polygamy may increase the risk of HIV infections, which can be fuelled by the intricacy involving multiple partners in a marriage (Reniers & Watkins 2011). Many women in polygamous families view polygamous marriage as an important aspect of their culture. Consequently, these kinds of multiple partners relationships can pose problems of fear, stigma or issues related to HIV disclosure and that may impact service utilization (Frizelle, Solomon & Rau 2009; Reniers & Watkins 2011). Monogamous marriages are the most common in South Africa compared to polygamous marriages and also pose complexities for mothers enrolled in the PMTCT programmes (Reniers & Watkins 2011). In this modern time, relationship unions like cohabitations which are popular among young adults and middle-aged adults can pose the fear of stigma and discrimination, HIV non-disclosure, and gender inequalities (Reniers & Watkins 2011; Mpinganjira et al. 2020).

Women in a family often lack opportunities to communicate about sensitive issues like HIV status or involve their male partners in the PMTCT programmes (Mpinganjira et al. 2020). This often exposes the realities of gender dynamics of HIV disclosure, which can impose fear and other complications in a form of gender-based violence or lack of financial support from their partners to attend health services (Chinkonde, Sundby & Martinson 2009). In Nigeria, Adeneye et al. (2006) conducted a study on the knowledge and perception of HIV/AIDS among pregnant women in the PMTCT programmes and found that the women who participated reported practices from their partners that compromise safe motherhood, these practices are physical violence, delaying access to obstetric care, encouraging heavy labour to induce birth, unwillingness to use family planning, withholding financial help, and blaming women for complications in pregnancy. When interviewing HIV positive mothers who were LTFU, the study by Mpinganjira et al. (2020) reveals that mothers blame lack of support from their partners, who stopped them from continuing with ART. The study further shows health care workers also believe in a lack of support from the patients' partners, that they refuse to support the mothers financially. It reveals that physical violence and fear of divorce are the reasons mothers were LTFU.

In South Africa, many women are marginalized and unable to make independent choices regarding their health or that of their babies. For instance, a male partner may disagree with his female partner's decision to take HIV medications (Frizelle, Solomon & Rau 2009; Letsoalo & Madiba 2014). Falnes et al. (2011) argue that the male partners control the household finances in this poverty driven country (South Africa), where most women are unemployed and dependent on their partners or family for transport money or food. A mother's decision is not respected even during sexual activities with most women unable to negotiate for safe sexual practices like condom use, and consequently surrender to unprotected sexual intercourse (Letsoalo & Madiba 2014). Langen (2005) conducted a study in Botswana and South Africa on gender power imbalance and on women’s capacity to negotiate self-protection against HIV/AIDS. The study revealed that gender imbalance impacts women’s ability to negotiate for safer sex practices – like the use of condoms with their partners.

Several more studies conducted in Africa (Zimbabwe and South Africa) have demonstrated the importance of social support for women in the PMTCT programmes (Frizelle, Solomon & Rau 2009; Shroufi et al. 2013). Adequate support can help the mothers to cope with the stress of contracting HIV (Shroufi et al. 2013). Women are likely to adhere to clinic appointments and treatment when partners are supportive or involved (UNAIDS 2012). The male partners/husbands who reject HIV testing and counselling often influence the decisions of their female partners regarding the use of HIV services (Falnes et al. 2011). Dahl et al. (2008) explored the acceptance of HIV testing among women attending ANC care in South-Western Uganda. The findings reveal that the women refuse HIV testing because they feel the need to discuss whether they should test or not test with their partners.

According to Deressa et al. (2014), 60% of the respondents who participated in the study were aware and acknowledge that their partners tested for HIV and 35% of the respondents indicated that their partners did not test for HIV. The reasons their partners did not test for HIV was lack of time (29%), partner’s living in other areas (8.8%), partners tested before the current pregnancy (8.4%), the faithfulness of their partners (5.4%), the lack of awareness about the importance of HIV testing (4%), and the fear of the outcome (being positive for HIV (3.4%). Mullick, Kunene, and Wanjiru (2005) conducted a study in South Africa involving men in the PMTCT programmes and found that the majority of the men were not involved in the reproductive health of their partners and did not involve or consult with their female partners on matters related to family planning or antenatal issues. Garson (2005) conducted a study in Soweto (South Africa) and found high levels of anger among women that is directed toward their male partners for being in denial of their roles and responsibility in the PMTCT programmes.

Religious and other social or traditional constructs discourage male partners access to HIV services (Morfaw et al. 2013; Falnes et al. 2011). Factors such as denial and the fear of stigma influence male participation in the programmes from the antenatal stage and throughout the entire PMTCT cascade (Morfaw et al. 2013). Men usually fear being mocked by their peers when they accompany their wives to antenatal clinics (Frizelle, Solomon & Rau 2009; Falnes et al. 2011). Fear of disclosing their HIV status to partners is influenced by fear of stigma and discrimination that comes with the HIV status (Dirisu et al. 2020). A research study by Skinner et al. (2003) found that male partners are not involved in PMTCT activities especially during pregnancy and labour/delivery. Only a few male partners attend clinic appointments. Male partners who do not attend PMTCT services with their female partners in the PMTCT programmes pose serious problems for women who ask for consent to attend PMTCT services. Psaros (2020) conducted a study in South Africa and found that pregnant women who are depressed and experience stigma were less likely to seek social support.

In the existing literature, relationships or unions such as polygamous marriage and cohabitation elevate gender inequalities, fears of stigma or discrimination and HIV non-disclosure that results in non-adherence to HIV treatment or LTFU (Reniers & Watkins 2011; Mpinganjira et al. 2020; Psaros 2020; Dirisu et al. 2020). There is evidence that HIV positive mothers are marginalized and unable to make independent choices regarding adherence to clinic appointments or their overall health and that of their babies. Male partners control finances that influence adherence of HIV positive mothers especially in this poverty driven countries. Also, women are unable to negotiate for safe sexual practices. Lack of social support from male partners and their involvement in the PMTCT programmes is inadequate guided by denial and misconceptions about HIV and involvements of males in the PMTCT programmes services (Morfaw et al. 2013; Falnes et al. 2011). The past studies have shown patterns which are repeated or recurring, and these patterns are also shown in recent studies. There is extensive qualitative literature that does not adequately address the issue of gender inequalities in the PMTCT post-natal programmes (Chinkonde, Sundby & Martinson 2009; Frizelle, Solomon & Rau 2009; Falnes et al. 2011; Mpinganjira et al. (2020). The relationship between family structures and gender dynamics in the PMTCT post-natal programmes is not well documented especially in the rural context of the Limpopo province of South Africa. There is an opportunity to explore and contrast the narratives or lived experiences of HIV positive mothers who are LTFU with HIV positive mothers who are not LTFU and compare with perceptions of healthcare workers in the PMTCT post-natal programmes regarding social patterns of family and gender dynamics in the context of LTFU and non-adherence.

- Lack of readiness to initiate ART

In South Africa, pregnant women who registered at health facilities are required to get tested for HIV and those that are HIV positive are immediately initiated ART to undergo HIV treatment to improve their health and prevent MTCT (Department of Health. 2016c; 2019; 2020). A study by Danladi et al. (2020) in Nigeria reveals a positive attitude of pregnant women attending antenatal clinic regarding the readiness to take HIV treatment. The finding shows a positive perception of the PMTCT and that the women are ready to end the HIV pandemic by taking their medications (ART drugs). However, some mothers are not ready to initiate ART. Kouassi et al. (2014) found patients in the quantitative case-control believed they had not been well prepared by facility staff before ART initiation and were six times more unlikely to discontinue their HIV treatment. According to Kiiryaa et al. (2021), the risk of LTFU was higher among mothers who started ART on the same day that tested positive compared to those who started later. Young mothers who are HIV positive do not adhere to antenatal and post-natal care services (Orne-Gliemann et al. 2017; Ronen et al. 2017). Early motherhood and HIV increases the vulnerability of adolescent mothers and their children (Toska et al. 2020). Initiating ART is difficult for these young mothers because they often discover their HIV status when they are pregnant while attending clinic appointments and it can delay ART initiation (Nuwagaba-Biribonwoha et al. 2018; Ronen et al. 2017).

Tlebere et al. (2007) conducted a study in South Africa to explore factors that impact the utilisation of maternal health services and found HIV status to be a barrier affecting service use in the PMTCT programmes, which included the feeling of hopelessness. Women are not willing and ready to initiate or continue ART because they prioritize the health of their family members or the health of their children. They are unwilling or they are not ready to initiate ART because they have high workloads or responsibilities from the multiple roles they play in the households, family, and community. Women who are working may struggle with the adoption of the HIV medication regime especially when they have work responsibilities or household work, like cooking and taking care of their children (WHO 2009). A qualitative study that was conducted by Oguejia & Omotoso (2021) in Nigeria found that pregnant women could not attend the

PMTCT programmes because of the social roles they have to play in their families and are pressured to fulfil these roles or obligations, and some of these roles are perceived with cultural significance.

Some mothers are not ready to initiate ART, the existing literature confirms the risk of LTFU among mothers who started ART on the day they tested positive compared to those who started ART at a later stage. HIV status is difficult for women to accept especially early motherhood among adolescent mothers, their early initiations to ART lead to delays and LTFU. Other women prioritise their families or the roles they play in the family or community (Kouassi et al. 2014; Orne-Gliemann et al. 2017; Ronen et al. 2017; Kiiryaa et al. 2021). There are qualitative studies that address the patterns of unreadiness to initiate ART. It is important to demonstrate that these patterns are repeated and recurring. With introduction of universal test and treat (UTT), the literature is not extensive enough to adequately address the social patterns of unreadiness to initiate ART in the PMTCT, especially in the post-natal programmes. The studies can benefit from exploring the extent to which family roles and daily life responsibilities impact initiation to ART and adherence or service utilisation. There is an opportunity to explore and contrast the narratives or lived experiences of HIV positive mothers who are LTFU with HIV positive mothers who are not LTFU and compare with perceptions of healthcare workers in the PMTCT post-natal programmes regarding the social patterns of unreadiness or unwillingness to imitate ART.

2.5.2. Organisational/Institutional and community factors

- Dynamics of HIV disclosure, stigma and discrimination

HIV-related stigma is when people living with HIV are exposed or treated with unfavourable attitudes by other individuals because of their HIV status. This HIV-related discrimination is the bias or prejudiced treatment directed toward people living with HIV (SANAC 2015; UNAIDS 2015). The notions of stigma and discrimination were socially constructed and enforced by fears of HIV and AIDS, therefore enforcing unfavourable attitudes and prejudiced behaviours towards people living with HIV (OHCHR & UNAIDS 2007). Numerous studies confirm that fear of stigma and discrimination is one of the major challenges that influence service use, therefore, hinders the success of the PMTCT programmes (Frizelle, Solomon & Rau 2009;

Kalembo & Zgambo 2012; Department of Health 2013a/b/c UNAIDS 2015; Dirisu et al. 2020).

There are two categories of stigma namely: self-stigma or internal stigma and external stigma (SANAC 2015; UNAIDS 2015). Self-stigma or internal stigma is when a person living with HIV internalises the negative perceptions that people living with HIV endure and feel responsible or blame themselves for being HIV positive (SANAC 2015; Madiba, Ralebona & Lowane 2021). Living with HIV or AIDS makes people self-blame or feel less about themselves (Department of Health 2013b; UNAIDS 2015). Kouassi et al. (2014) found that the patients who were in interviewed in qualitative case-control subset of 23 cases and 23 controls found that stigma was the reason patient in the case group discontinued treatment or LTFU. According to research by Yator et al. (2020), internal stigma was associated with living with a partner.

The other form of stigma is external stigma where an individual living with HIV fears being stigmatised by a family member, sexual partner, or community members (Madiba 2013; SANAC 2015). A qualitative study that was conducted by Oguejia & Omotoso (2021) in Nigeria found that pregnant women feared being stigmatized because of their HIV status. Pregnant women feared stigma from their partners and their children. The study also found that health providers agree that pregnant women fear stigma and that affects the uptake of PMTCT services. Dirisu et al. (2020) conducted a study that found that the stakeholders believe that fear of stigma is associated with the fear of being seen at health facilities utilising HIV-related services. Adolescent mothers experience numerous barriers that make them lose interest in the PMTCT programmes and these barriers are HIV stigma, family decision making, and cultural norms surrounding infant feeding (Varga & Brookes 2008; Mahloko & Madiba 2012; Madiba & Josiah 2019).

Multiple reports and studies show that mothers fear stigma and discrimination from people in the community, family members, sexual partners, and health personnel (SANAC 2015; Dirisu et al. 2020; Mpinganjira et al. 2020; Madiba & Matlala 2012; Motshome & Madiba 2014; Madiba & Josiah 2019; Madiba, Ralebona & Lowane 2021). There is a clear relationship between the fear of disclosure of HIV status and the fear of stigma and discrimination. Calder et al. (2020) conducted a research study in Rural North-central Nigeria with 372 pregnant women living with HIV and reveals that the women who were not adhering to treatment feared HIV disclosure. Most of the mothers in the PMTCT programmes struggle with HIV disclosure to their family, partners, and friends (Madiba 2012; Madiba & Mokwena 2012; Mitiku et al. 2016). Yee et al. (2020) conducted semi-structured interviews with 23 caregivers in Myanmar and found that attending the PMTCT programmes was influenced by fear of accidental disclosure of HIV status to extended family and neighbours. Nonetheless, a study in Johannesburg (South Africa) by Varga, Sherman and Jones (2006) found female participants who have disclosed their status. The study found that 93.5% of the women disclosed their status to at least one person. The mothers who struggle with HIV disclosure are more likely to be LTFU or fail to adhere to HIV treatment because they fear that their status will somehow be exposed if they attend the appointments (Adedimeji et al. 2012). Some women who are HIV positive fail to or decide to not disclose their HIV status to their sexual partners or husbands because they fear negative reactions that might affect their relationships (Kalembo & Zgambo 2012; Mitiku et al. 2016).

The thought of disturbing or risking their relationship with their sexual partners or husbands force them to delay or refuse to disclose their HIV status. Among many negative reactions that make the women fear disclosing HIV to their sexual partners and husband are being ignored, isolation, disgraced in a public space or being to blame for HIV infection (Kalembo & Zgambo 2012). A qualitative study conducted by Anindita and Shaluhiyah (2016) in Indonesia on HIV disclosure to partners found that HIV positive women failed to disclose their HIV status to their partners because they were worried that the partner might leave the relationship. The other reason is that they fear that the partners might think they have been unfaithful in the relationship, that the virus came from having multiple partners. Jones et al. (2005) conducted a study in Johannesburg (South Africa) on poor follow-up rates of HIV-exposed infants indicating that male partners/husbands do not continue with follow-up visits because their female partners have not disclosed their HIV status.

When women actively use PMTCT services or engage in other PMTCT activities or recommendations they fear that their HIV status may be exposed to the public (Department of Health 2013b). Community-based support plays a significant role in the mothers’ ability to access HIV treatment. Poor support from the community influence poor uptake of PMTCT services (Frizelle, Solomon, & Rau 2009; Dzimiri, Dzimiri & Batisai 2019). Negative reactions or attitudes from community members extend myths and stigma that people living with HIV are contagious (Arrey et al. 2015). There is a clear relationship between gender inequality and stigma (SANAC 2015). There are men in the community who blame women for the outbreak of HIV and women have become even more reluctant to commit to HIV treatment or other PMTCT activities (Arrey et al. 2015). As stated in a study in Nigeria by Okonkwo et al. (2007), 69.2% of the respondents were discriminated against by the community when they utilize HIV-related services. A positive attitude from the community can influence women to participate in the PMTCT programmes (Arrey et al. 2015; Laar & Govender 2011). Some mothers fail to adhere to feeding instructions from the healthcare workers and because they fear negative reactions from community members (Laar & Governder 2011; Madiba & Letsoalo 2013). Busza et al. (2012) argues that the pressure that comes from the family members and the community promotes non-adherence to PMTCT feeding patterns like exclusive breastfeeding and exclusive formula feeding (Frizelle, Solomon & Rau 2009).

Evidently, in the existing literature, fear of HIV disclosure, stigma and discriminations from community, family members, sexual partners and health personnel is associated with non-adherence to clinic appointments and HIV treatment (Frizelle, Solomon, & Rau 2009; Laar & Governder 2011; Madiba & Letsoalo 2013; Dzimiri, Dzimiri & Batisai 2019). There is a gap in the literature related to the extent to which these fears and social support from family, sexual partners or spouses, and the communities influence health-seeking behaviours of HIV positive mothers in the post-natal phase (Frizelle, Solomon, & Rau 2009; Dzimiri, Dzimiri & Batisai 2019). The literature exploring the association between fears of HIV disclosure and services utilisation in the PMTCT post-natal programmes is not well documented, especially involving family and gender dynamics, and other individuals in the community. There is an opportunity to explore these social patterns in the rural Limpopo Province PMTCT post-natal programmes. The relationship between fear of stigma or discrimination and experiences of sigma or discrimination should be highlighted. The study can benefit from contrasting narratives or lived experiences of HIV positive mothers who are LTFU with HIV positive mothers who are not LTFU, and perceptions of healthcare workers in the PMTCT post-natal programmes.

- Distance and cost of living and transportation

The socio-economic factors have influenced HIV service utilization (Hiarlaithe et al. 2014; Yacobson, Malkin & Lebetkin 2016). For example, lack of money to cover the cost of transportation to reach health facilities has been shown to influence service utilization (Skinner et al. 2003; Tearfund 2008). Kouassi et al. (2014) found that patients who were LTFU were those with low income and perceive their social class as having poor adherence to following up visits. The cost of travelling to PMTCT services is a major problem for the mothers (Yacobson et al. 2016). A qualitative study that was conducted by Oguejia & Omotoso (2021) found money and time spent travelling to health facilities were barriers that the participants experienced in the PMTCT programmes. A recent study conducted by Nkhonjera, et al. (2021) in Malawi found that the healthcare workers believed that mothers do not have money to buy food for their children while at the hospital and that this is a problem when there is a long waiting time at the clinic.

Moth et al. (2005) argues that pregnant women in the PMTCT programmes experience financial problems and that the reason mothers are LTFU is that they struggle to pay for the services. In Malawi, a study by Tenthani et al. (2014) with 2930 women found 16% of the participants experienced issues related to transport money and that is the reason they stopped ART. Some of the women experience poor transportation routes as obstacles to reaching relevant treatment sites, others experienced difficulties with access to government social grants and were unable to get financial support (Yacobson et al. 2016). Jones, Sherman and Varga (2005) conducted a study in Johannesburg (South Africa) and found that the women who participated failed to attend follow-up sessions because they lack the financial means to travel to the health facilities. The study found that the women struggle to access government social grants that could help cover their financial worries and attend follow-up services. Adedimeji et al. (2012) report the findings from the focus group discussions with women in the PMTCT programmes. These findings reveal that women travel long distances and struggle to reach health facilities. The distance and lack of money for transportation from the rural area provide limited access to PMTCT services (Rawizza et al. 2012).

Many studies have confirmed that the issues of transportation to travel to relevant health facilities affect the general service use in the PMTCT programmes because they struggle to reach health sites (De Paoli et al. 2008; Kagee 2008; Tearfund 2008; Skinner et al. 2005). HIV counselling, testing, collection of test results, and medication are all affected by the issues related to the distance and travelling costs (Rawizza et al. 2012). A study in Malawi reveals that the participants mentioned travelling away (38%) and travel costs (16%) as the reasons they are LTFU (Tweya et al. 2014). Good health status can be managed with reasonable financial benefits (Yacobson, Malkin & Lebetkin 2016). The research shows evidence of patients who opt to walk to the health facilities on foot considering the distance between the health facilities and their home. This is mainly because they could not afford the transportation to the health facilities (WHO & UNICEF 2007). HIV positive women struggle with the distance to the health facilities and that took them over one hour to reach the health facilities (Peltzer et al. 2007). Asefa and Dirirsa (2013) conducted a study in Ethiopia and found that the majority of HIV pregnant women experience issues with the distance of the health facilities and from 190 respondents, 103 (57.2%) spent less than an hour walking on foot to reach health care facilities for their follow up appointments. Yee et al. (2020) conducted semi-structured interviews with 23 caregivers in Myanmar and found that the barrier to attending the PMTCT programmes was the cost of transportation.

Skinner et al. (2003) found that in the rural Eastern Cape Province (South Africa) that mothers who live in poverty-stricken areas struggle with access the health facilities because the roads leading to the health facilities are poorly constructed and difficult to cross in rainy seasons. Poor or lack of transportation networks including road signage that provides directions to the health facilities has made it difficult for mothers to attend their clinic appointments. In South Africa, the barriers to accessing PMTCT services found poor roads leading to the health facilities make it difficult for patients to access PMTCT services. Underdeveloped areas have poor transport systems and poor telecommunications, and people lack resources to travel the long distance to health facilities, the transport is expensive especially for families with low or no income (Skinner et al. 2005).

The mothers experience financial difficulties that prevent them from following the infant feeding recommendations or instructions from the healthcare workers in the PMTCT programmes (De Paoli, Mkhwanazi, Richter, & Rollins 2008; Thorsen, Sundby & Martinson 2008). Poor finance trajectories can impact negatively on infant feeding instructions from healthcare workers, adhering to exclusive formula feeding for six months can be challenging when mothers run out of money to purchase formula milk and consequently mix feed their babies (Hiarlaithe et al. 2014). A mother who chose to formula feed her infant might lack money to buy formula milk or to continue with this feeding method. This mother will then look to replace the formula feeding method or might not have other options to replace breast milk when she runs out of formula milk (Thorsen, Sundby & Martinson 2008). In South Africa, the government has stopped providing free formula milk for HIV positive mothers and this has been a setback for mothers who want to formula feed their infants but cannot afford formula milk (De Paoli, Mkhwanazi, Richter & Rollins 2008).

In the literature discussion, there is evidence that lack of money to cover the cost of transportation to the health facilities influence adherence to clinic appointments in South Africa and other African countries (Hiarlaithe et al. 2014; Yacobson, Malkin & Lebetkin 2016). There are African countries were HIV positive women struggle to pay for the PMTCT services while other struggle to access government social grants. Transportation networks, including road signage that provides directions, and roads to the health facilities are poorly constructed or damaged and even difficult to travel during harsh weathers, and difficult to cross in rainy seasons (Skinner et al. 2005). As alluded to earlier, financial difficulties prevent HIV positive mothers in African countries from following the infant feeding recommendations like formula milk or hygienic product to prepare formula milk (De Paoli, Mkhwanazi, Richter, & Rollins 2008; Thorsen, Sundby & Martinson 2008). The qualitative literature does not adequately address the social patterns related to the geographical location and socio-economic factors that influence service use, and the involvement of family, government, and other support structures in the rural context of the Limpopo Province PMTCT post-natal programmes is not well researched. The extent to which financial support from family and sexual partners or spouses influence health-seeking behaviours is not well documented, especially involving negotiating for financial assistance. The is an opportunity to explore and contrast the narratives or lived experiences of HIV positive mothers who are LTFU with HIV positive mothers who are not LTFU and compare with perceptions of healthcare workers in the PMTCT post-natal programmes regarding the influence of geographical location and socio-economic factors in the PMTCT post-natal programmes.

- Health care systems or structural barriers

The shortage of medical supplies and human resources such as nurses and doctors delay the progress of the PMTCT programmes (Department of Health 2008; Mute, Akondé & Doumbia 2011; Kweyamba et al. 2018). General service delivery is impacted by shortages or lack of trained and skilled healthcare workers (Burke 2004; Department of Health 2008; Tearfund 2008). The PMTCT service delivery protocols are affected by long waiting periods and delays which are driven by shortages of resources (Mute, Akondé & Doumbia 2011; Kweyamba et al. 2018). Kouassi et al. (2014) conducted a mixed methods case-control study and found that in the questionnaire interviews with 632 patients who were LTFU only 4.1% indicated that they were LTFU because of waiting hours. In the same study, the qualitative case-control in-depth interview with 23 case and 23 controls found that patients who were LTFU complained about the waiting hours – that the appointment waiting time is too long.

There are health facilities that have few nurses per facility operating in the PMTCT programmes that are offering all HIV services for mothers (Mute et al. 2011; Dirisu et al. 2020). Skinner et al. (2003) reveals that when the PMTCT programmes were integrated, additional staff to assist in the programmes were not allocated to the clinic. The clinic was understaffed at the time and the available nurses and assistant nurses complained that they were unable to provide quality PMTCT services because they lacked the capacity in terms of trained health personnel to assist in the PMTCT programmes. Skinner et al. (2005) found that in South Africa regarding the barriers to accessing PMTCT services, the health facilities where PMTCT services are integrated experience pressure from the influx of work because they were understaffed to provide quality services to the local population. Ezeudoye, Ibe & Nwufo (2021) conducted research study in Nigeria on the adequacy of PMTCT facilities to provide PMTCT service delivery. They found that only 2 (2.5%) of the PMTCT health facilities had adequate doctors and pharmacists.

The shortages of lay counsellors, space and infrastructure hinder the quality of Voluntary Counselling and Testing (VCT). This is because services like VCT are important for the success of the PMTCT programmes to ensure that pregnant women, mothers, and their infants receive HIV testing and counselling; and initiate ART early if the infants are exposed to HIV (Frizelle, Solomon & Rau 2009). Shortages of healthcare workers who provide VCT for mothers and their infants hinders the quality of the PMTCT services and may influence LTFU and non-adherence to treatment (Kweyamba et al. 2018). Doherty et al. (2003) conducted a study in South Africa and found that utilisation of HIV tests and counselling is low in provinces like the North-West (14%), and the Eastern Cape (34%). This was due to the delayed integration of lay counsellors into the HIV programmes in the provinces. Ezeudoye, Ibe, and Nwufo (2021) conducted a study in Nigeria on the adequacy of PMTCT facilities to provide PMTCT service delivery. The study assessed the availability of the PMTCT services and found 61 (75.3%) of the health facilities have voluntary HIV/AIDS counselling but 20 (24.7%) of the health facilities did not have this service. Nutritional counselling service was reported available in 65 (80.2%) of the health facilities but reported not available in 16 (19.8) facilities. HIV testing was said to be available in 72 (88.9%) facilities but not available in 9 (11.1%) facilities.

The issue of inadequate spaces to conduct HIV counselling and other confidential clinic sessions hinders the uptake of PMTCT services (Skinner et al. 2003). A study by Raburu (2004) found that 92% of the study respondents complained about the lack of privacy in counselling rooms. The rooms have the presence of multiple people during counselling sessions. Doherty et al. (2003) investigated HIV counselling in South Africa and found challenges related to space used for HIV counselling. They found that these rooms are inadequate and lack privacy for patients living with HIV. In addition, the counselling rooms sometimes serve as a storeroom, and there are frequent disruptions. Lack of privacy during clinic appointments promote fear of HIV disclosure (Doherty, McCoy & Donohue 2005). Kweyamba et al. (2018) support that the lack of space for confidentiality during counselling compromises mothers' HIV status to the public, they fear disclosure of the HIV status due to the broken confidentiality and anonymity ethic conduct. Another issue was that HIV patients were often moved from one building to another especially where PMTCT services are separated from other buildings. This results in vulnerability to the stigma that may result from unintended disclosure of the HIV status (Thorsen, Sundby & Martinson 2008). Deressa et al. (2014) found that the challenges or the barriers that affect the uptake of PMTCT services was that the health facilities lack separate and adequate space to conduct or provide PMTCT services.

Relevant resources such as additional infrastructure and testing kits are important in ensuring that the PMTCT programmes are implemented successfully (Etoori et al. 2020; Dirisu et al. 2020). As claimed by a study conducted in India, the CHWs revealed shortages of HIV testing kits, shortages of antiretroviral drugs, and infant NVP prophylaxis hindered the PMTCT programmes (Suryavanshi et al. 2018). Ezeudoye, Ibe, Nwufo (2021) conducted a research study in Nigeria and found that in most of the health facilities there are adequate HIV test kits, drugs, patient's cards and registers. Skinner et al. (2005) found a lack of telephones to communicate or make referrals or tracing. The healthcare workers are unable to communicate with each other and other stakeholders creating important implementation issues in the PMTCT programmes.

The healthcare workers encounter a mountain of challenges when promoting health services for patients to adhere to clinic appointments and treatment (Frizelle, Solomon & Rau 2009). They lack support from stakeholders regarding the resources to successfully implement the PMTCT programmes, to perform at their maximum capacity and allow for the provision of quality services for the mothers and their infants. In South Africa, the retention of staff may be influenced by poor incentives and remunerations (USAID 2005). Low retention of staff in resource-poor settings are also influenced by poor working conditions for health care workers (Manzi et al. 2005). A study by Marindi (2019) in Soweto (South Africa) reveals that community-based care workers are subjected to poor working conditions that result in long working hours. These conditions are influenced by inadequate resources and have led to an increasing level of precarity in the workplace.

When HIV positive patients experience negative treatment or poor attitudes from the healthcare workers, they may not return to the clinic for follow-up sessions. A qualitative study by Painter et al. (2004) in Cote d'Ivoire reveals that the women failed to attend follow-up visits because they were afraid of the staff. One of the HIV positive mothers described how she searched for the right staff member to assist her because she was afraid to ask other healthcare workers, fearing that they might reprimand her in the public space. King et al. (2021) conducted a study in Uganda and found that the women in the PMTCT programmes experienced negative attitudes and behaviour of healthcare workers. A poor relationship between nurses and patients is a challenge facing the PMTCT programmes (Cumber et al. 2016). Mpinganjira et al. (2020)

conducted a study in Salima and Mangochi districts, Malawi, with 30 HIV positive mothers and 30 healthcare workers and reveals that the mothers were LTFU due to poor treatment from the healthcare workers; the mothers complained that the health care workers shouted at them when they missed their appointments. The study further confirms that some of the health care workers who participated in the study admitted to having projected negative attitudes towards the mothers by shouting at their patients and showing poor communication skills.

Similar findings were presented in a qualitative study by Oguejia & Omotoso (2021) in Nigeria and found poor interactions between service providers and the patients. The participants complained about poor treatment from the healthcare workers, as one of the barriers to the uptake of services. Yee et al. (2020) conducted semi-structured interviews with 23 caregivers in Myanmar and found that the mothers were satisfied with the services at the PMTCT clinic and reported that they received quality care. They added that the healthcare workers should improve their communication but there were mothers who believed that the healthcare workers were supportive. In a study conducted by Deressa et al. (2014), the majority of the respondents who participated in the study were not satisfied with the treatment from the healthcare workers. The respondent complained about the long waiting time to receive services and poor treatment from the healthcare workers toward their clients.

The CHWs track patients, trace patients, register households, and promote health, and according to WHO, CHWs provides health-related services to the community including health education/promotion (WHO 2018). Consequently, the work of CHWs poses many challenges that impact service delivery. The work of CHWs is outlined as an important part of an outreach team in the HIV programmes. But in many cases, the CHWs find it difficult to perform their work freely and this impacts the tracking, tracing and retention of HIV positive patients who are defaulters or LTFU. A multi-country study in Uganda, Malawi and Zimbabwe by Cataldo et al. (2018) investigated the experiences of the CHWs when tracing patients who are in the PMTCT programmes. The study found that when the CHWs ask the women who are LTFU the reasons for not coming back to health facilities, they state that they choose not to be traced and provide a false address at enrolment. A recent study by Nkhonjera et al. (2021) in Malawi investigated factors that influenced LTFU of HIV exposed infants and feared

HIV disclosure to family relatives and provided fake names on the registers to avoid being tracked and traced by the health facility staff.

The CHWs programmes are important and need to be well-coordinated to reach desired personal and health facility goals or objectives. One of the CHWs jobs is to convince patients to continue or restart treatment with the facility (White, Govender and Lister 2017). A study by GrantI et al. (2017) in five primary health care clinics located in KwaZulu-Natal (South Africa) investigated the trust of CHWs and acceptance to provide maternal and child health services. It found that the CHIWs experience barriers related to trust in confidentiality and are not expected to provide maternal and child health services. The PMTCT home visits increase the risk of exposing the HIV status of women enrolled in the programmes and they may thereafter be subjected to gossiping behaviour by the community members (Thorsen, Sundby & Martinson 2008). Another study conducted in five African countries (Cote D'Ivoire, Democratic Republic of Congo [DRC], Malawi and Uganda) by Besada et al. (2018) was done on the roles played by community cadres to support retention in PMTCT Option B+. The study reveals concerns about the confidentiality practices among volunteer cadres for patients who are LTFU and living with HIV.

Various African studies in the literature have shown shortages of resources as the reason for non-adherence of HIV positive women in the PMTCT programmes, which leads to long waiting periods or delays of health services (Mute, Akondé & Doumbia 2011; Kweyamba et al. 2018). These shortages are influenced by delayed integration of healthcare workers such as lay counsellors and nurses or availability of services such as nutritional counselling. Infrastructure shortages lead to lack of privacy in counselling rooms risking to vulnerability in form of stigma or unintended disclosure of the HIV status (Kweyamba et al. 2018; Doherty et al. 2003; Ezeudoye, Ibe & Nwufo 2021). Healthcare workers are subjected to poor working conditions and long working hours. There is extensive evidence that shows negative treatment or poor attitudes from healthcare workers towards patients as reasons for LTFU of HIV positive women. Furthermore, the CHWs struggle with tracing patients who are LTFU, and experience barriers related to trust in confidentiality and are not expected to provide maternal and child health (Cataldo et al. 2018; Nkhonjera et al. 2021). There are fewer studies that focus comparatively on the lived experiences of HIV positive mothers and lived experiences of the health personnel (CHWs, nurses, and lay counsellors) in the PMTCT post-natal programmes. Therefore, there is an opportunity to explore narratives from the lived experiences of the CHWs in the PMTCT post-natal programmes and the perceptions of nurses and lay counsellors in the ward-based PMTCT programmes. There is a dearth of studies that explore the relationship between healthcare workers and HIV positive mothers who are LTFU and those who are not LTFU, and the extent to which implementation challenges in the rural context of the Limpopo Province PMTCT post-natal programmes influence service use.

- Monitoring, data recordings and uses

When patients are LTFU, they are mostly identified from the clinic registers or electronic systems. Thereafter, the health personnel responsible for tracking and tracing of patients will try to call them and if the patient cannot be reached by telephone the patient will be reached by home visits that will be conducted (Etoori et al. 2020). Health facilities in South Africa are required to have a register to record patients' appointments, either paper-based or electronic (Gourlay et al. 2015). A list of patients who are defaulters or LTFU through patients' files is captured on the facility-level electronic database. If a patient is LTFU or has defaulted it will show on the data system and the healthcare workers responsible for tracing will generate a daily or weekly list of these patients and then track and trace the patients (WHO 2012).

It is important to evaluate and document the outcomes of LTFU in the PMTCT programme to successfully measure or quantify the magnitude of LTFU (Kouassi et al. 2014). A study in rural South Africa by Etoori et al. (2020) explored the challenges with tracing patients who are late for clinic appointments in ART programmes and found implementation challenges for effective tracking and tracing of patients. The study found missing data, missing documentation, poor record-keeping and issues related to roles in the tracking and tracing cascade. A systematic review by Brinkhof, Pujadas-Rodriguez and Egger (2009) found that the challenges associated with the high rate of LTFU included missing telephones numbers and home addresses. Cataldo et al. (2018) conducted semi-structured interviews in Uganda, Malawi, and Zimbabwe with CHWs who track and trace patients on Option B+ in the PMTCT programmes; and found that the CHWs believe that the patients choose not to be traced by providing false information and home addresses.

The challenges of incomplete data or lack of data are a result of inconsistent report and monitoring systems (WHO 2012). It is important to identify and know the outcomes of HIV positive pregnant women and their infants. This can happen through linkage of records where there is a gap and by actively tracking and tracing of mothers and infants who are LTFU and not only rely on available data of these mothers and their infants at the health facilities (Brinkhof, Pujadas-Rodriguez & Egger 2009; WHO 2012; Barron et al. 2013). Continuous monitoring or tracing of mothers and their infants provides the opportunity for programme planners to explore the outcomes of LFTU patients and inevitably measure the impact of the PMTCT programmes (WHO 2012). The lack of data to monitor the progress of the PMTCT programmes is one of the major challenges that progress throughout the cascade (National Department of Health 2013; Barron et al. 2013). There is insufficient mentoring in the PMTCT programmes including insufficient supervisory support systems that are influenced by policy changes (Doherty et al 2009). Banze et al. (2021) conducted an inquest in the southern region of Mozambique to evaluate the PMTCT national health information system for HIV/AIDS and found that the data completeness was 50%. A multi-country validation study by Shamba et al. (2021) conducted in five hospitals in Bangladesh, Nepal, and Tanzania regarding barriers to routine register data collection for mothers and new-borns found that complete data were more valued than correct data.

In the existing literature, there is insufficient monitoring of data in the PMTCT programmes. The studies found missing data (telephones numbers and home addresses), missing documentation (patients files) and poor record-keeping is associated with high rate of LTFU. Without proper data systems, especially where there are patterns of missing or incomplete data, it is difficult to track and trace patients who are LTFU which thereafter hinders the success of the PMTCT programmes (Kouassi et al. 2014; Cataldo et al. 2018; Etoori et al. 2020). Therefore, there are not enough qualitative studies conducted in rural settings of South Africa to understand social patterns that influence missing or incomplete data, and the challenges of tracking and tracing HIV positive mothers who are LTFU in the PMTCT post-natal programmes. There are fewer studies that focus on comparing the lived experiences of HIV positive mothers who are LTFU and the lived experiences of CHWs to understand the patterns of data monitoring, tracking and tracing HIV positive mothers who are LTFU in the PMTCT post-natal programmes. There is an opportunity to explore narratives from the lived experiences of the mothers and CHWs in the PMTCT post-natal programmes and the perceptions of nurses and lay counsellors in the ward-based PMTCT programmes. This study explores the relationship between community healthcare workers and HIV positive mothers and the extent to which implementation challenges of the PMTCT outreach programmes influence LTFU and non-adherence.

2.5.3. Societal/Publics policy factors

The PMTCT policies that are not communicated to the relevant healthcare workers delay the progress and scaling up PMTCT programmes (Chopra & Rollins 2008; Tearfund 2008). The USAID (2005) conducted research in South African on the prevention of MTCT and found that PMTCT policies are not communicated to the other healthcare workers in the PMTCT programmes. The results found that while government healthcare workers were informed about policies related to family planning and HIV/AIDS during workshops/training/meetings, the healthcare workers from the NGOs were not informed and that they learned about these policies on the internet or by accident, suggesting the exclusion of private sector or NGO from policy training programmes. Another problem with communication in the PMTCT programmes is that many PMTCT programmes focus merely on PMTCT interventions and only a few PMTCT programmes that focus entirely on the prevention of MTCT. This is caused by poor communication and guidance regarding the PMTCT policies (WHO & UNAIDS 2007).

Policies relating to PMTCT activities provide relevant guidance for project managers to successfully implement and operate the HIV programmes (Frizelle, Solomon & Rau 2009). The policies that are poorly constructed can hinder the success of the programmes and this can influence LTFU and non-adherence to treatment. The PMTCT policymakers and programme planners' goal is to implement successful and quality programmes to ensure that the mothers and their babies achieve desirable health objectives (Adedimeji et al. 2012). Communication between the programme planners, policymakers, and the overall government are important for future successes of the PMTCT programmes. Still, in many contexts, the communication between the stakeholders is poor, and the programmes are compromised (WHO & UNICEF 2016).

The quality-of-service delivery is compromised by poor communication between the parties involved. Poor policies and guidelines promote poor counselling and information sharing about important PMTCT activities (WHO & UNICEF 2016; Adedimeji et al. 2012). A South African exploration by Mnyani and McIntyre (2013) reveals that most of the respondents (80.0%) were satisfied with the PMTCT guidelines and the knowledge they obtained, 96.3% were confident about managing the PMTCT programmes and HIV positive women. Nevertheless, the exploration shows the clients and healthcare workers had low knowledge regarding the PMTCT interventions. A study in India by Suryavanshi et al. (2018) reveals that the CHWs complained about the lack of training/knowledge related to PMTCT infant feeding guidelines. Laar et al. (2018) show that healthcare providers were knowledgeable of the Option B+ guidelines.

Lack of support for healthcare workers hinders the success of the PMTCT programmes (Chopra & Rollins 2008). Inadequate information compromises the quality of the PMTCT services and due to poor advice and treatment from healthcare workers mothers will not take advantage of the important benefits of PMTCT services (Laar et al. 2018). Many healthcare workers report that they are not getting enough training or guidance on how to share relevant information, especially on exclusive breastfeeding, side effects and other practices in the programmes (Chopra & Rollins 2008; Laar et al. 2018). Mentorship and training provide education and psychological support for the healthcare workers and thereafter the mothers who are receiving PMTCT services (Frizelle, Solomon & Rau 2009). Furthermore, ineffective recording systems compromise PMTCT service and care in the health facilities and sometimes mothers just fail to report their health status to health personnel (Woldesenbet et al. 2010).

The existing literature shows that the PMTCT policies are not well communicated across all relevant healthcare workers in the programmes. There are patterns of poor communications and guidance that hinders the success of the programmes. Poor policies and guidelines promote poor counselling because healthcare workers will not getting relevant guidance on important PMTCT activities and recommendations (Suryavanshi et al. 2018; WHO & UNAIDS 2007). Therefore, there is an opportunity to explore narratives from the lived experiences of the mothers and healthcare workers to understand communications regarding relevant PMTCT activities. This study explores the integration of CHWs in the PMTCT post-natal to establish the extent of which the implementation challenges influence LTFU of HIV positive mothers. There is an opportunity to explore challenges related to PMTCT policies, guidelines and integrating of the programmes for effective eradication of non-adherence and LTFU of HIV positive mothers in the PMTCT post-natal programmes.

- Retention and interventions

Retention of patients in the health programmes refers to the patients who are on ART and continuing with their treatment at the clinic where they were initiated ART (Mutasa-Apollo et al. 2014). Fundamentally, the assumption is that the retention of patients as compared to patients who are LTFU is when patients who were LTFU are retained in care and continue with HIV treatment (Rollins et al. 2014). Retention of HIV positive mothers and their infants in the PMTCT programmes during the post-natal period is still a challenge for programme planners (Woelk et al. 2016). This is because HIV positive mothers and infants who are retained in the PMTCT programmes have better health outcomes and can prevent MTCT (UNAIDS 2017).

There are many HIV positive mothers and their infants who are LTFU in the PMTCT programmes and are not yet retained or integrated back into the HIV programmes (Kalembo & Zgambo 2012). In the rural setting of Zimbabwe, Vogt et al. (2015) analysed records of 1878 HIV-positive pregnant women between 2010 and 2013 and their new-borns in the PMTCT programmes. The study reveals that retention of HIV-positive pregnant women and their new-borns after the intervention was 496 (85.7%) and before the intervention was 1083 (87.3%) until the delivery. Retention of HIV-positive pregnant women was low until CTX initiation, 303 (52.3%) after the intervention, and 517 (41.7%) before the intervention. Retention of infant HIV testing after and before innervations was 272 (47.0%) and 427 (34.4%) respectively, and until HIV test result collection 172 (29.7%) and 405 (32.6%).

Full retention in the PMTCT programmes is equated with the attendance of HIV positive mothers at the health facilities in a period of 12-months after birth (Rollins et al. 2014). A study by Woelk et al. (2016) in Rwanda investigated the retention of HIV positive mothers and their infants in the PMTCT programme and found that from 348 of the study sample, 58% of the mothers and 81% of the infants were retained in care within a 12-months post-delivery period. Monitoring retention should continue throughout the antenatal and post-natal care with accurate follow-up systems (Rollins et al. 2014). Yotebieng et al. (2016) conducted a study with 433 patients in the Democratic Republic of Congo to investigate whether the provision of conditional cash transfers improves service use and retention in the PMTCT post-natal phase. The study found that the women who were provided with conditional cash transfers interventions were likely to be retained in care. Richter et al. (2014) conducted a study in KwaZulu-Natal, South Africa with HIV positive pregnant women and found that women in the intervention group were less likely to adhere to ARTs during pregnancy. Oyeledun et al. (2017) studied the effect of a continuous quality improvement intervention on retention in the PMTCT programmes and found 43% retention of the women at the six-month post-natal period.

An investigation in Malawi by Phiri et al. (2017) was done on the impact of the facility and community-based peer support models in the HIV PMTCT programmes on Option B+ to investigate uptake and retention. It found a 90% uptake of Option B+ in community-based models compared to 86% uptake of Option B+ in facility-based models. The study further found that retention of patients was higher (at 83%) in community-based models compared to 80% in facility-based models at 24 months. The findings reveal that uptake of Option B+ and retention of mothers can benefit from the facility and community-based peer support interventions. Similar findings were presented in a study in South African by Tomlinson et al. (2014) on the effectiveness of community-based packages for maternal and new-born care in the PMTCT programmes. The study found that interventions were effective at 12 months and the mothers who are benefiting from the interventions were more likely to bring their infant to the clinic in the first week of life (Tomlinson et al. 2014).

An exploration into Uganda by Igumbor et al. (2019) investigated the effect of mentor programmes on the retention of mother-baby pairs in the PMTCT programmes. It found that the Mothers2Mothers (m2m) intervention improved retention of HIV positive mothers. In addition, their HIV exposed infants and HIV positive women who are in the intervention group were less likely to be LTFU. A performance evaluation study in Tanzania by Sando et al. (2014) evaluated whether CHWs improve ANC and PMTCT uptake. They found that a large-scale CHW intervention was effective in identifying pregnant women in their homes early in pregnancy and before they had attended ANC. In the study, the CHWs conducted a total of 45,095 home visits to pregnant women in the first 16 months of implementation and the mean number of pregnant women visited per month was 2666. This finding shows the mean number of pregnant women who had not yet attended ANC at the time of the CHWs visit was 2036.

Yee et al. (2020) conducted semi-structured interviews with 23 caregivers in Myanmar to explore their experiences and perceived acceptability of a novel near point-of-care early infant HIV diagnostic test among mothers who are enrolled in the PMTCT programmes. The interviews found a lack of intergraded services for mothers and infants. The caregivers complained about the absence of combined services and that many mothers find it difficult to come to the clinic appointments that conflict with the appointments of their children. Dovel et al. (2021) conducted a study in Malawi with 29 mothers on the integrated interventions of Early Child Development (ECD) and PMTCT programmes and found that the mothers benefited from the integrated programmes. Despite benefiting from these interventions, over half of the women who were interviewed added concerning recommendations for improvements in the integrated programmes that need to be addressed. The mothers desired counselling sessions to help mothers cope with HIV (the study reveals that several of the mothers reported were sad and overwhelmed), the belief and addition of stress management and marital advice will be helpful services.

In the literature, retention of HIV positive mothers and their infants in the PMTCT programmes in the post-natal period is a challenge. There are mothers who are not yet retained or integrated back into the PMTCT programmes (Rollins et al. 2014; Woelk et al. 2016). The literature shows retention of infant improve after interventions as compared to before innervations, and community-based peer support models are highlighted as important interventions in the PMTCT post-natal programmes. However, there are lack of integrated services for mothers and their infants, the integrated programmes need to be improved (Richter et al. 2014; Yotebieng et al. 2016). There is not enough literature from South African studies on retention patterns in the PMTCT post-natal programmes. Most of the studies in the literature are quantitative in nature leaving a gap to understand social patterns related to retention of mothers who are LTFU in the post-natal programmes. Though quantitative studies offer generalized findings on retention patterns they do not incorporate the lived experiences of HIV positive mothers in the post-natal programmes. This study allows

HIV positive mothers who are LTFU to describe and narrate their experiences with healthcare workers in relation to returning back to the PMTCT post-natal programmes. Therefore, there is an opportunity to explore narratives from the lived experiences of community healthcare workers to understand communications regarding retention HIV positive mothers. This study explores the integration of community healthcare workers in the PMTCT post-natal to establish the extent of retention strategies and interventions are implemented and integrated in the post-natal programmes to eradicate non-adherence and LTFU of HIV positive mothers.

2.6. Strategies to Improve Care and Utilisation

The patterns of LTFU and non-adherence continue to affect the success of the PMTCT programmes every year (UNAIDS 2017). Urgent strategies have addressed the increasing rates of LTFU and non-adherence in PMTCT services (WHO 2009). The LTFU and non-adherences can be managed through multifaceted approaches that are either patient-related or health care related (WHO 2002; Department of Health 2016; WHO & UNICEF 2016). Patient-related strategies to improve LTFU and adherence include the responsibility of HIV positive mothers to take care of themselves, to actively engage in their health and that of their babies. They can further improve their health situation by developing healthy relationships with the health care providers and by following their instructions (WHO 2009). The health care provider strategizes to improve LTFU and adherence by having support groups and educational or awareness programmes that can help with a behavioural change that plays a vital role in the use of services and adherence (Department of Health 2016a/b; UNAIDS 2017). Educational programmes further support health care providers to deal with issues that HIV positive mothers face in the PMTCT programmes and at their homes or communities. Existing literature has suggested that programmes assist healthcare workers in establishing healthy relationships with patients and continuously engaging with patients between clinic visits (WHO 2009). Social support from family, partners, and healthcare workers can help mothers adhere to medication and follow-up visits. Peer-support programmes provide education and psychosocial support to mothers by assisting the mothers to understand the importance of HIV medication intake and utilizing PMTCT services. HIV positive mothers who participate in these activities are more likely to adhere to treatment, disclose their HIV status, and participate in HIV counselling and testing (WHO 2009; Department of Health 2016a/b; UNAIDS 2017).

Literature shows strategies to prevent or curb non-adherence in the HIV programmes that can be achieve through multifaceted approaches of either patient-related or health care related. Patient-related strategies include the responsibility of HIV positive mothers to take care of themselves and actively engage in their health and that of their babies. Health care provider strategies include provision of support groups and educational or awareness programmes. Strategies connected to family, partners, and healthcare workers involvements can improve adherence (WHO 2002; Department of Health 2016; WHO & UNICEF 2016). The studies can benefit by exploring strategies connected to family, partners, and healthcare workers involvements in the rural context of the Limpopo Province PMTCT post-natal programmes to improve adherence and service use. There is an opportunity to explore the establishment of healthy relationships between healthcare workers and HIV positive mothers in the PMTCT post-natal programmes. The studies can benefit from exploring strategies by contrasting narratives or lived experiences of HIV positive mothers who are LTFU with HIV positive mothers who are not LTFU, and with perceptions of healthcare workers in the PMTCT post-natal programmes.

2.7. Chapter Conclusion

The South African Government has increased the provision of PMTCT coverage and has shown tremendous effort in providing ART to the public for free. Nevertheless, the existing research suggests that social patterns of LTFU can play a critical role in fuelling LTFU and treatment non-adherence. Despite this, we lack detailed knowledge on what these factors are and how and why they impact adherence. The literature to date suggests that HIV positive mothers who fail to adhere to treatment encounter numerous setbacks such as financial problems, lack of social support, side effects, gender and family dynamics that influence LTFU and treatment non-adherence, impacting the PMTCT programmes. From existing research, it was possible to draw out broad social factors that might play a role in treatment adherence and required further investigation. These include patients' ability to make informed choices regarding their health, patient experiences of health care, stigma and socio-cultural factors. This broad reading informed the development of questions for this study as discussed in more detail in the next chapter.

CHAPTER 3

METHODOLOGY

3.1. Introduction

This chapter provides an overview of how the study was conducted, outlines the study settings, and designs that were adopted. The chapter details the processes that were followed when conducting the study, reflecting on the methodological frameworks that include the data collection, data analysis, study population, sampling procedures and sample size. This includes the quality criteria and the ethical considerations that were followed when conducting the study. The chapter provides clear descriptions and motivations to use the methods mentioned above including the challenges that I encountered when employing these methods.

3.2. Research Methodology

The research methodology is the strategies a researcher uses in a study, ranging from identifying the research problem to guiding the research process and conducting the final plans of the data collection and analysis (Burns & Grove 2005). This study applied a mixed-methods approach using both the qualitative and quantitative approaches. The qualitative approach focuses on subjective experiences and relies mainly on non-numerical data. This approach was adopted to collect data about the participants' lived experiences. The method helps in the understanding of the underlying reasons or motivations and gain insights, behaviours, lifestyles, and concerns from the participants (Christensen 2004; Neuman 2011). This method explores the in-depth data of individuals from a subjective point of view, the approach involves a socially constructed reality involving participants that deeply and clearly understand their lived experiences (Christensen 2004; Burns & Grove 2005). The approach is essential for this study to explore the lived experiences of HIV positive mothers and healthcare workers in the context of health beliefs, access, and other social experiences in the health care systems. Creswell (2013) argues that qualitative research involves gathering narrative data, mostly open-ended data. In a synopsis, the method captures raw data by delving deeper into the personal lives of the participants. This is done through interviews, focus group discussions, observation and other qualitative empirical methods used during data collection (Neuman 2011).

The quantitative method is applied to gather numerical information from a large population to develop a hypothesis that connects the study phenomena (Burns & Grove 2005). The method quantifies the problem understudied and reveals patterns of behaviour such as attitudes, beliefs, and other variables in the research. The method uses statistical or mathematical expressions of the data collected through methods such as questionnaire surveys, chart reviews and experimental research (Burns & Grove 2005; Polit & Beck 2012). With this method, I was able to underpin the connection between practical observation and the mathematical expression of the research problem or phenomena.

3.2.1. Why the use of a mixed method?

Mixed methods refer to “the use of multiple methods to collect and interpret data, to converge on an accurate representation of reality” (Polit & Beck 2009: 106). By clearer definition, Tashakkori and Creswell (2007:4) assert that a mixed method is “research in which the investigator collects and analyses data and draws inferences using both qualitative and quantitative approaches or methods in a single study”. The mixed method approach can be used for many reasons, this approach is used as either a complimentary, development, initiation, or expansion of a research phenomenon and the findings. The mixed methods of qualitative and quantitative approaches were used to assist with comprehensive validations and cross verifications of the research data and outcomes (Johnson & Onwuegbuzie 2004). Hence, in this study, the qualitative and quantitative approaches were intended to complement each other.

The data was collected concurrently to compare and search for congruent findings. The different research methods (qualitative and quantitative approaches) were incorporated, and the information was integrated to interpret the results. The qualitative findings of HIV positive mothers and the CHWs are presented concurrently with selected excerpts that reflect the participants' general view in every theme and sub-themes. Thereafter, quantitative findings of nurses and lay counsellors were presented at the end of each theme. The combination of different data sets from mixed method approach was benefiting in terms of providing qualitative data that is detailed, contextualised and insightful, and quantitative data that provide generalisable and valid insights. This is because quantitative studies struggle to incorporate the lived experiences of the participants, therefore, qualitative studies provided a deeper understanding of the research problem to enhance the quantitative findings. On the other hand, qualitative studies do not aim to generalise data because they reflect on the subjective experiences of the participants, therefore, the quantitative data provided validations of the qualitative findings. With quantitative methods, I achieved objectivity and with qualitative methods, I achieved subjectivity or explanation of a research phenomenon (Creswell & Plano Clark 2007; Cresswell & Garrett 2008).

The quantitative and qualitative data were analysed separately, and the results were compared to validate each other through side-by-side discussions and conclusions. I was able to explore social patterns of LTFU and non-adherence using mixed methods. With both qualitative and quantitative approaches, I explored the reasons why mothers were LTFU and failed to adhere to HIV treatment, and the extent to which LTFU and non-adherence affect the PMTCT post-natal programmes. The goal was to understand social patterns and motivations of LTFU and non-adherence to HIV treatment from different groups of HIV positive mothers and healthcare workers in the PMTCT post-natal programmes. By adopting different methods, I anticipated data that allows for a broader understanding of individuals and health care patterns the PMTCT post-natal programmes.

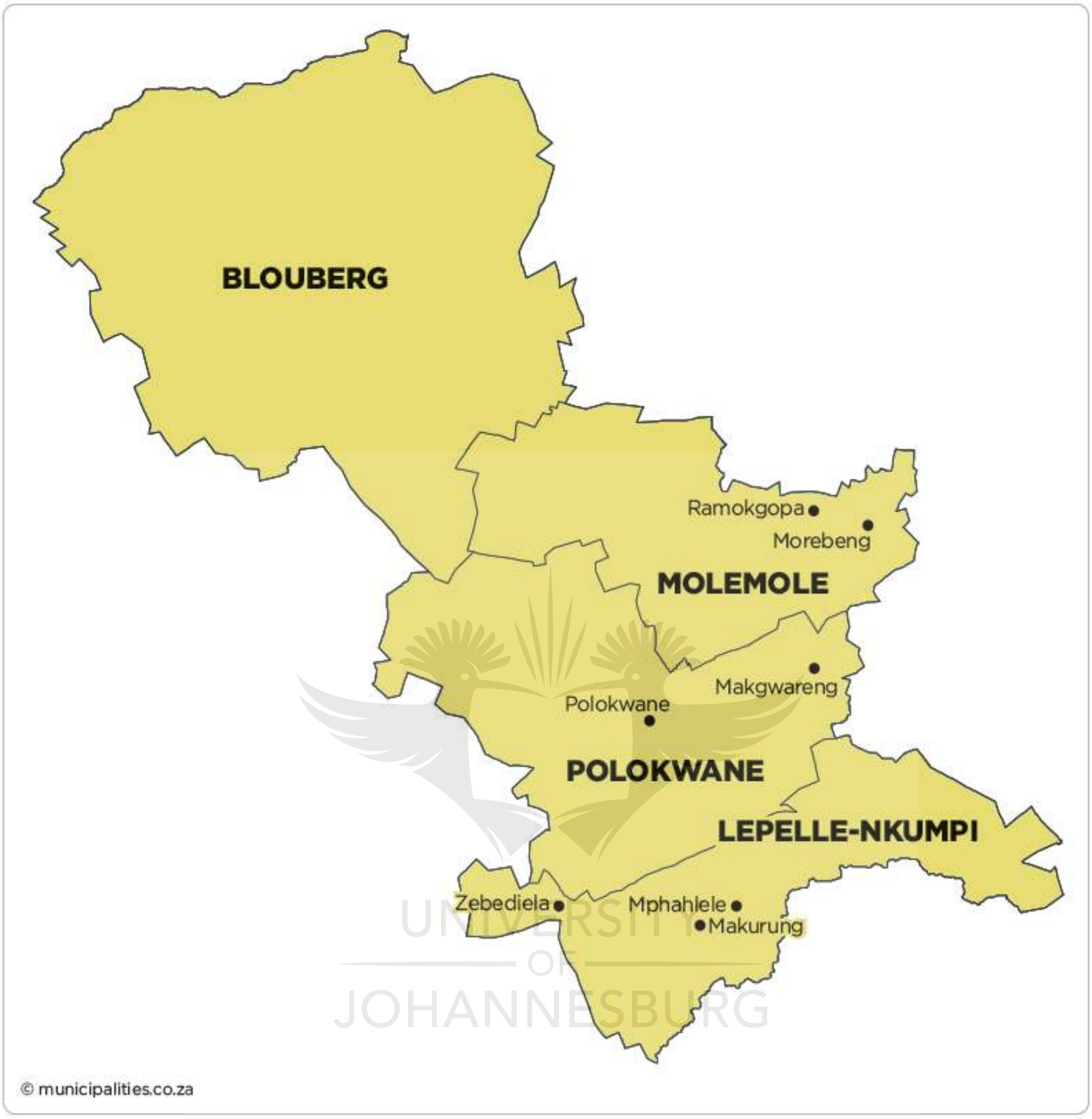
3.3. Description of the Study Settings

The physical region or a place where data is collected for research is referred to as the study setting (Burns & Grove 2005). The research data was collected in the Mopani and Capricorn Districts in the Limpopo Province of South Africa. The Mopani District is the largest district located within the north-eastern part of the Limpopo Province. It is bordered on the north side of the Limpopo province by Zimbabwe and the Vhembe District Municipality. Mopani district has a population of over one million and most of the population (97%) are Black Africans and speak the Sepedi language (45%), followed by the Tsonga language (44%). The Mopani district has four main towns Giyani, Hoedspruit, Phalaborwa, Modjadjiskloof, and Tzaneen (see figure 3.1). With a land size of 20 011km^2, the district has a total of 129 wards, with 16 urban areas, and 354 villages (Statistic South Africa 2018).

Figure 3. 1: Map of the Mopani District in the Limpopo Province

The Capricorn district is in the northern areas of Limpopo, and it is closest to the Gauteng Province. Named after the Tropic of Capricorn, the district is host to the capital city (Polokwane) of the Limpopo Province. It is home to a population of over one million people, 96% of the population are Black African. Approximately 84% of the population speak Sepedi. The Capricorn district has four main areas (see figure 3.2), Polokwane, Blouberg, Molemole, and Lepelle-Nkumpi (Statistic South Africa 2018). All the health facilities are in rural settings to explore and understand the socio-economic connections, geographical impact, and other social forces related to the study sites and service access or use.

Figure 3. 2: Map of the Capricorn District in the Limpopo Province



3.3.1. Description of the health facilities

The Mopani District has 131 health facilities, which consist of six district hospitals, one regional hospital, a specialized hospital, eight community health centres, 88 clinics, and 27 mobile clinics. The Capricorn district has 109 health facilities: these include one hundred clinics and nine district hospitals, of which two are tertiary hospitals. In this study, a total of five facilities were selected, two facilities from the Mopani district, and three from the Capricorn District. To ensure anonymity of the research participants, the selected health facilities are not mentioned by name. The facilities are given code names, for instance the Clinics in the Capricorn district are coded as Clinic

C1, C2 and C3 while those in the Mopani District are coded as Clinic M1 and M2 (see table 3.1). Clinic M1 is located in a township area of the Greater Letaba Local Municipality, in a lower-income area. Clinic M2 is located in the Greater Tzaneen Local Municipality, also in a lower-income township. The health facilities in the three clinics in the Capricorn District are located in the Polokwane Local Municipality, in the rural, low-economic outskirts. These five health facilities were selected to broaden the participants' recruitment process and were selected to explore the issues related to the geographic location and socio-economic status of the participants.

The clinics were selected because they offer PMTCT services for HIV exposed and infected infants and their mothers. This includes outreach services that are implemented or provided by the CHWs. Hence, using purposive sampling, only two health facilities were selected to sample CHWs. The proposed sample size was 30 CHWs, but data saturation was reached after the interviews of 20 CHWs. Therefore, data saturation determined the sample size of 20 CHWs as further interviews were not producing new information different from that generated from the previous interviews. The health facilities met the following criteria – the facilities were targeted on the basis that they have provided antenatal and post-natal PMTCT follow-up services for over five years (HIV positive mother were selected from all selected clinics); the facilities have HIV counsellors or lay counsellors and the nurses responsible for the implementation of the PMTCT programmes (nurses and lay counsellors were selected from all selected clinics).

Table 3. 1: Health Facilities selected for this study

Districts	**Health facilities**
Capricorn District	Clinic C1 Clinic C2 Clinic C3
Mopani District	Clinic M1 Clinic M2

3.4. Research Design, Population and Sampling

Research design is a strategy that guides the execution and purpose of the study, to achieve the proposed objectives and goals (Burns & Grove 2005). The research designs used in this study are qualitative: case-control study design and phenomenology design, and a quantitative cross-sectional survey.

3.4.1. Unmatched case-control design

The case-control design in this study compared patients with the outcome of interest (cases) and patients without the outcome of interest (controls). This design provides a retrospective comparison of how the exposure to a risk factor is recurrent to determine the relationship between the risk factor and the outcome. The risk factor to the outcome of interest is examined by comparing a group with the outcome of interest and a group without the outcome of interest, to determine how the frequency of the factor or attribute is present in each of the groups (Keogh & Cox 2014). For this study, the case group consists of HIV positive mothers who were LTFU, and the control group consists of HIV positive mothers who were not LTFU (control).

In South African health facilities, according to the country`s guidelines, a patient is declared LTFU when they discontinued clinic appointments for three consecutive months or more. The patients who are not LTFU and undergoing care are considered adhering to clinic appointments when they attend or adhere for 3 consecutive months and more (Department of Health 2010). The population attributes of all cases are within a defined geographic area at a specified period of time. This was achieved through the hospital registry network. The controls are individuals of the study without the exposure outcome in the same geographic area where the cases are determined. The controls in a matched case-control are selected to match case-by-case based on characteristics such as age, sex, and socioeconomic status. These characteristics and attributes are selected based on influence of the consequent outcomes (Keogh & Cox 2014).

This study used a novel qualitative unmatched case-control which was adopted to select number of participants in the case group that are not equal to the number of participants in the control group or vice versa. I initially planned to conduct a qualitative matched case-control study with the HIV mothers, to match the following demographics: age, marital status, socio-economic, and geographic location. However, I struggled with recruiting the participants in the control group that matched with the case group and had little or no time to reach that objective. I experienced difficulty in finding individuals of matching case and control due to the limited number of cases. As a result, a qualitative unmatched case-control study was opted for.

Deliberately, the unmatched case-control design was not framed in a conventional or traditional manner (quantitative nature). The motivation was to use certain qualities or traits of the design to frame a qualitative version that allowed comparative analyses of two different groups of HIV positive mothers in the PMTCT post-natal programmes. To support this, there are various published studies that used the qualitative case-control design in this manner or framing to enable comparative explorations of the research problem. For example, Kouassi et al. (2014) conducted face-to-face quantitative and qualitative interviews of a case-control study with a total of 632 cases and 632 controls (questionnaires interviews) and qualitative in-depths interviews of case-control subset of 23 cases and 23 controls on factors associated with LTFU status among ART patients in Cote d'Ivoire. Another study that explored a qualitative case-control is a study conducted by Rengerink et al. (2015) which invited 28 women for face-to-face interviews and 21 agreed to be interviewed (12 participants and 9 non-participants) for the qualitative case-control study. Similarly, another study that used qualitative case-control design is a study by Higgins et al. (2014) on the importance of relationship context in HIV transmission, using what they coined a novel qualitative case-control design they interviewed 30 newly HIV-positive cases with 30 HIV-negative controls.

The target population for this design comprised of two groups of HIV positive mothers: population A (HIV positive mothers who are LTFU), population B (HIV positive mothers who are not LTFU). The qualitative case-control study consists of a total of 38 participants, a subset of 18 HIV positive mothers in the case group (mothers who were LTFU) and 20 HIV positive mothers in the control group (mothers who were not LTFU) by the time of interviews.

The selection of mothers who were LTFU followed a quantitative approach. I used simple random sampling to select the mothers who are LTFU. Simple random sampling allowed each member of the targeted population an equal probability of being selected (Burns & Grove, 2005; Neumann, 2011). Therefore, all the respondents had equal probability of being selected. The HIV positive mothers who were LTFU were selected using the data from the health facilities database systems. Only participants who were not deceased and available or willing to be interviewed were included in the study. The list of HIV positive mothers who were LTFU was generated from the health facilities database systems. Using the database between the years 2017-2019, 143 participants were eligible for the study. Of the eligible participants, 96 either had missing residential and contacts information or non-existent number or voicemail calls, and only five were confirmed as deceased by tracking and tracing team. From the remaining 42 eligible participants, only 18 agreed to participate in the study. Thereafter, purposive sampling was to select the 20 HIV positive mothers who were not LTFU. These mothers were undergoing care at the time of interviews and were selected during their routine clinic appointments. Purposive sampling abetted in the selection of participants with a purpose that benefits the study (Neuman 2011).

The following eligibility criteria for inclusion of the mothers were met in the study: The mothers were HIV-positive and enrolled in the PMTCT programmes for HIV treatment and the Infants were born from HIV infected mothers. Patients who discontinued all the PMTCT services for three months and above were considered in the case group. Patients who continued with all PMTCT services for three months and above were considered in the control group. This design answered all the objectives listed in this study.

3.4.2. Phenomenology research design

The phenomenology research design helps understand people’s lived experiences by exploring the relationship with the research phenomena. In this design, the researcher collects data from persons who have experienced the phenomenon under investigation (Creswell & Creswell 2018). This helped me explore and uncover new ideas of the phenomenon under study. The researcher explores the attributes and the exposure to the research problem to gain more insights and familiarity for later investigations (Burns & Grove 2005; Neuman 2011). Therefore, this design provides the theoretical linkage of the research problem. Furthermore, interpretive phenomenology helps to understand and interpret participants' experiences (Finlay 2008). As such, the interpretative phenomenological design was used to gain insight on CHWs in the PMTCT programmes. I am aware that selecting CHWs for this design does not completely follow the tradition of phenomenological inquiry. The design was used in unconventional manner to make sense of the phenomenon that is LTFU and non-adherence from the perspective of CHWs.

Conventionally, the phenomenology design seeks to understand a phenomenon as it is understood by those who are experiencing it (Dowling & Cooney 2012; Teherani et al. 2015). Hence, my motivation to use CHWs for this design is that they experience LTFU as a challenge or barrier that affects their progress, hinders project goals and objectives. The CHWs are responsible for the implementation or provision of the PMTCT outreach services and for tracking and tracing of HIV positive mothers who are LTFU. This study explored the reasons for LTFU and non-adherence to treatment from the point of view of the CHWs. This includes the challenges they faced in the implementation and provisions of PMTCT services. This design was able to answer all the objectives listed in this study.

The target population for this design comprised of CHWs. I used purposive sampling to select the 20 CHWs to gain insights on LTFU and non-adherence in the PMTCT outreach programmes. They were sampled to complement the results from mothers and provide perceptions regarding LTFU and non-adherence to HIV treatment. The CHWs offered a description of the challenges that healthcare workers faced in the PMTCT outreach programmes and how the challenges affect service utilisation and retentions of HIV positive mothers in the programmes. The following eligibility criteria for the inclusion of CHWs were met in the study:

- The CHWs trained to provide outreach services (This is because the CHWs who are trained to provide outreach services are mandated or capable of tracking and tracing mothers who are LTFU or mothers who failed to adhere to the HIV treatment).
- The CHWs with one or more years of work experience in the PMTCT programmes (This is because the CHWs with work experience of one year or more in the PMTCT outreach programmes provided valuable input from their experiences or exposure to the conditions or issues in the PMTCT outreach programmes).

3.4.3. Cross-sectional survey

The cross-sectional survey is a design that provides a snapshot of the variables included in the study at one point in time. Cross-sectional studies are conducted in a short period and collect data on the characteristics of a population, including potential risk factors (Burns & Grove 2005; Neuman 2011). I collected information on the characteristics of the individuals and potential risk factors to determine how respondents are affected by the conditions of LTFU and adherence to the PMTCT programmes. This design answers all the objectives listed in this study. A census population of professional healthcare workers (nurses and lay counsellors) in the PMTCT programmes was included in the study from five health facilities. About 44 respondents were included and agreed to participate in the census, and only four withdrew later due to workload and there was no replacement as there were no other respondents to select. The size for the quantitative surveys with healthcare workers was small (a total of 44 nurses and lay counsellors) due to a limited population, only 40 participated in the study. Therefore, unexpectedly, a census was opted for because of the limited number of professional healthcare workers who qualify and work directly with HIV positive mothers in the PMTCT programmes.

Although nurses and lay counsellors have different demographics that potentially affect how patients view them as well as their responsibilities to the women, the combination of nurses and lay counsellors in this study was motivated by their direct involvement in the PMTCT programmes. The nurses and lay counsellors have qualifications to work in the HIV programmes including the PMTCT programmes. These individuals also share challenges and responsibilities in HIV programmes and work alongside to ensure the effectiveness of the PMTCT programmes.

The professional healthcare workers provided responses on the challenges that healthcare workers faced when implementing the PMTCT programmes, this includes the reasons and associated factors that influenced the LTFU of mothers and why mothers failed to adhere to HIV treatment. To be eligible for inclusion, the nurses and lay counsellors were registered as nurses or lay counsellors and were qualified to provide PMTCT services; the nurses and lay counsellors had at least one year or more of work experience in implementing the PMTCT programmes. This design complemented the data of HIV positive mothers and the CHWs. The nurses and lay counsellors provided perceptions regarding the reasons HIV positive mothers were LTFU or failed to adhere to HIV treatment; and offered insights on the implementation challenges that healthcare workers faced in the PMTCT post-natal programmes.

3.5. Data Collection

Data collection is a process of gathering information to answer research questions and achieve research objectives (Burns & Grove 2005). Qualitative and quantitative data collection on social patterns of loss to follow up and non-adherence in the PMTCT programmes were conducted using mixed methods of semi-structured interviews, in-depth interviews, and questionnaire surveys. Data were collected in the five selected health facilities between 2019 and 2020. The interviews and questionnaires were conducted in English and were also available in the participants' Indigenous Sepedi language constructed with the help of a professional Sepedi translator.

3.5.1. Semi-structured interviews

Semi-structured interviews are the kind of interviews where the researcher asks a series of predetermined and open-ended questions or topic to the participants. The open-ended questions provide opportunity for the interviewer or interviewee to discuss or probe some topics in detail. The semi-structured interviews were used to cover a variety of topics to ensure that important information is not missed. They were used in this study to provide reliable and comparative data from different participants and groups. This helped in drawing objective comparison from two groups of HIV positive mothers (Wengraf 2001). This provided the opportunity to ask for clarification on answers.

A total of 38 semi-structured interviews were conducted with HIV positive mothers, subsets of 18 cases, and 20 controls. The LTFU participants were identified as mothers who were enrolled in the PMTCT programmes and had gone for a period of three or more consecutive months without returning to the health facility for their appointments. The CHWs assisted in the identification and tracking patients who were LTFU through telephone calls and home visits. The CHWs are trained to track patients and have experiences with tracking patients who are LTFU and understand the ethical issues involved. They invited the participants to the facility and when the participants agreed, they were referred and accompanied to my temporary office at the health facilities. I was also able to explain the purpose of the study and ask the mothers to participate in the study. The participants were welcomed by a professional member of staff at the clinic instead of limiting the involvement of other patients and healthcare workers.

The tracking and tracing of LTFU participants were challenging because most of the health facilities had incomplete data on the patients' addresses or contact information. Another challenge was that the other patients who were LTFU declined to come to the health facilities or refused to participate in the study, most citing that they had moved to another location or area. One of the facilities (Clinic M2) had a small record number of patients who were LTFU at the time of data collection, there were only three patients who were LTFU at the time of data collection. In this clinic, I was unable to track or trace two patients due to missing contact information while the other patient refused to participate in the study. I initially planned to conduct a matched case-control study with the mothers, to match the following demographics: age, marital status, socio-economic, and geographic location. I have mentioned that I struggled with recruiting the participants in the control group that matched with the participants in the case group and had little or no time to reach that objective, and a result, an unmatched case-control study was opted for.

Moreover, the 20 HIV positive mothers who were included in the control group were selected during their routine clinic appointments (these are mothers who were not LTFU). The mothers selected had been on treatment for at least three consecutive months. These participants were approached with the assistance of the facility managers and nurses working directly with the mothers in the PMTCT programmes. Voice recording tapes and direct note-taking tools were used to collect data. Interviews of the selected participants were held at the clinics, and due to the number of the questions and follow up questions, the interviews lasted approximately 45 minutes for each participant. That allowed me to gather more data and to ensure the accuracy of information from the participants. Interviewees were encouraged to talk freely about events, behaviour, and beliefs related to LTFU and non-adherence in the PMTCT programmes. The following examples of questions were asked in the in-depth interviews with the HIV positive mothers: 'How can a mother transmit HIV to her child after she gives birth? What are challenges did you encountered that contributed to or influenced your decision not to go back to the health facility for HIV treatment or services?’ (See Appendix I) Most of the participants preferred to communicate in their home or native language which is Sepedi. Therefore, the interviews were conducted in Sepedi, which is also my home language.

3.5.2. In-depth interviews

In-depth interviews seek to gain more information from the participants, allowing the participants to engage freely in the study and give clear descriptions of their experiences. A total of 20 CHWs were interviewed using in-depth interviews. The CHWs were introduced to the study through the help of the facility managers and the CHWs operation leaders. These were arranged through a planned meeting with the CHWs at the health facilities. In the meeting, I introduced the purpose of the study, the research procedures to be followed, which included the ethical procedures (adhering to privacy, confidentiality, and anonymity). The participants who were willing to participate were given informed consent forms to fill in before the interviews commenced. Voice recording tapes and direct note-taking tools were used to collect the data, and the interviews lasted approximately 45 minutes (see Appendix H). Most of the CHWs were interviewed in Sepedi which is also the language that they preferred.

3.5.3. Questionnaire surveys

Questionnaire surveys are a method of asking structured questions to gather information from the respondents in a study. The surveys were conducted with 40 healthcare workers (nurses, lay counsellors) who have been working in the PMTCT programmes for over a year. The healthcare workers provided relevant information on non-adherence and LTFU of the HIV positive mothers and the challenges that they face in implementing the PMTCT programmes. These respondents were approached in a planned meeting through their health facility managers. The questionnaire took approximately 15 minutes to fill out. The following are sample questions for the quantitative survey with the healthcare workers: ‘Do you have a formal system in place to monitor clients receiving PMTCT services? Does the system monitor whether clients receiving PMTCT services attend scheduled appointments or not? If a client does not attend a scheduled visit, do you have a way of knowing if they are ill, have died, or have LTFU? (See Appendix L). I expected a reasonable number of nurses and lay counsellors that work in the PMTCT programmes during data collection. However, there was a limited number of nurses at the health facilities that qualify to works in the PMTCT programmes. This reduced the number of eligible respondents that met the criteria of the study. Consequently, due to the reduced population of the study, I opted to include the total population of 44 healthcare workers who were eligible for inclusion in the study, and the population was relatively small to allow sampling.

3.6. Data Analysis

During the analysis of the research data, patterns, and familiarity of the data is spotted, organized and given meaning (Burns & Groves 2005). The thematic data analysis method was used to analyse qualitative findings. Microsoft Excel and Statistical Package for the Social Sciences (SPSS) software were used to analyse quantitative data.

3.6.1 Qualitative data analysis

The thematic data analysis method analysed qualitative data from the unmatched case-control study with HIV positive mothers, and the qualitative data with the CHWs. The data of HIV positive mothers and data of CHWs were analysed separately. During thematic analysis of semi-structured interviews with HIV positive mothers, I have listened to the audio, transcribed it into readable data. The transcripts are read and reread to search for patterns in the data. During data analysis, I transcribed the interviews as soon as data collection was completed. This allowed immediate recall of verbal and non-verbal behaviours, and to the transcription of data in such a way that the original meaning of the language was retained. Firstly, the recorded interviews were transcribed in the original native language (Sepedi) and then later translated into English. Transcription and translation took place concurrently in order to stay as close as possible to the original meaning. The English transcripts were cleaned and checked for errors. The patterns in the data were highlighted, and codes were then generated to identify the data that have a similarity. Labelled data were then categorised for more efficient analysis, this enhanced the understanding and meaning of the data. The categories and sub-categories were initially generated by coding the participants` answers into different groups. This coding patterns involved transforming raw data from the participants to form an idea. A descriptive coding method was used to summarise a word or short phrase of the topic, data was summarised into interpretive categories without reducing the original meaning of the data. The main themes and sub-themes were generated to represent the data. The data was reviewed to see how it data supported the important themes. In cases where there was incomplete analysis, I returned to the transcripts to search for the missing data. Intra-thematic analysis was done to consider the themes identified for a particular participant and inter-thematic analysis was done by comparing themes emerging from different groups of participants. Moreover, important aspects of data that made up the themes were captured and themes that make meaningful contributions to the study were selected to represent the research findings.

Thematic analysis of in-depth interviews with CHWs, audio recordings were translated from Sepedi to English and transcribed it into readable data. After cleaning and checking the transcripts for errors, patterns in the data were highlighted, and codes were generated to identify the data that have a similarity. The codes were inspired by the data from HIV positive mothers and were labelled and categorised for more efficient analysis to enhance the understanding and meaning of the data. The themes and sub-themes were generated to represent the data. The themes that supported or similar to the themes from semi-structured interviews with HIV positive mothers were identified and presented concurrently. Moreover, important and new aspects of data that make up the themes were captured and themes that make meaningful contributions to the study were selected to represent the research findings.

The data analysis software such as NVivo could have been helpful to analyse the data, but I benefited from manual data analysis where I was able to put careful thoughts to the analysis and discussions, and to reject and accept some coded themes. I was able to interpret meaning because in other instance, computerised method may interpret certain excepts as to be both positive and negative. Manual analysis may interpret certain excerpts to be two separate ideas. Qualitative analysis is a difficult and complex method. Coding through texts provides meaning which data is interpreted and analysed to develop outcomes and conclusions. This ensures codes are an accurate interpretation of any given text to judge the validity, reliability, trustworthiness. Using an independent coder would have been beneficial to this study, especially to ensure credibility and avoid investigator bias. Additionally, coding requires an understanding of context, and qualitative coding decisions often evolved and repeated over time while I developed and increased sensitivity to the context and the data. However, a new coder who does not have the same knowledge could not be expected to code the data in the same way or pattern.

3.6.2. Quantitative data analysis

The quantitative data were analysed Statistical Package for the Social Sciences (SPSS) analysis software. Data was entered or captured on a Microsoft Excel spreadsheet. The data was explored for errors and the missing values were added before the analysis. The data was entered on SPSS analysis software to analyse the data. Descriptive frequencies and percentages were obtained to describe the socio-demographic and clinical characteristics of the participants at the baseline. Microsoft Excel was used to compose frequency tables, pie, and bar graphs. The quantitative analysis was used to offer statistical expressions for the reasons why HIV positive mothers were LTFU at their primary health care facilities. The data was used to express the lived experiences of healthcare workers in the PMTCT programmes, and the healthcare workers added their perceptions regarding their experiences with the mothers in the programme.

3.7. Quality Criteria

Triangulation was used to ensure validity and reliability of the research results. Triangulation is a method used to establish the credibility, validity, and reliability of research findings (Polit & Beck 2009). This increases the trustworthiness, credibility, and validity of the research results (Christensen 2004; Neuman 2011). Triangulation was used to explore complex human behaviour from different datasets or methods to explain the different aspects of the research phenomenon. Data triangulation was employed to collect the information from four types of samples: Professional healthcare workers (nurses and lay counsellors), CHWs and HIV positive mothers who were LTFU, and HIV positive mothers who were not LTFU (continuing with PMTCT services). The data was collected at different times and was checked daily making sure it was completed, edited, and coded before entry in the spreadsheets. Methodological triangulation of in-depth and semi-structured interviews and questionnaire surveys were used for the collection of reliable and valid data. The data collection tools were developed and submitted to the supervisors for approval before fieldwork. The research tools were well structured with sentences that were well constructed and easy to read.

3.7.1. The quality criteria or methods to ensure trustworthiness

Trustworthiness in the research is the quality value of the results of a research study and the conclusions that are achieved address the research questions and objectives (Burns & Grove 2005; Neuman 2011). Trustworthiness has several methods that ensure the quality of research. These methods are credibility, transferability, dependability, and confirmability. The credibility of the research data implies the assurance in the truth of the data, the integrity, and interpretation (Christensen 2004; Neuman 2011). In order to determine credibility of the findings, the study employed multiple data collection methods (in-depth interviews and semi-structured interviews) and multiple data collection sources (HIV positive women, community health workers, nurses and lay counsellors). The participants were able to openly express themselves in their home languages.

Transferability implies that the findings of a study are transferrable to another context of the study or with other participants (Neuman 2011). Triangulation ensures the transferability of the study through multiple informants and methods of gathering data. I compared the emerging themes between the different sources of information and used in-depth detailed descriptions to present the findings by ensuring that the categories and themes identified during data analysis were direct quotations from participants' interviews. The participants' characteristics, culture and context were clearly described, and these included descriptions of the data. The in-depth detailed descriptions of the findings enabled transferability of the study information to other settings. The triangulation methods used to collect data are semi-structured interviews, in-depth interviews, and questionnaire surveys; this created the diversity of the research findings and allowed the transferability of the information to other contexts.

Confirmability was ensured through the support of the research data by using audio recorders as accessible evidence (Burns & Grove 2005; Jafran and Buchan 2013). As a point of reference, written field notes and tape recorders were used to support in-depth and semi-structured interviews and ensure confirmability. The scientific methods and procedures employed in this study were described in detail during data collection.

Questionnaire surveys and excerpts from the qualitative data were verified with existing literature control to determine whether similar findings were identified in other studies. Another method to prove the trustworthiness of a study is dependability, and Neuman (2011) contends that dependability in research is the consistency of the research findings. In this present study, this was ensured through a clear outline of the research by describing in detail the methods, reviewing, and tracking of the research process.

3.8. Bias of the Study

Bias in a research study is a systematic error that influences or favours one outcome over the other and can occur at any phase of the research process (Neuman, 2011). The instruments or data collection tools in this research were given to participants who met the criteria for minimizing selection bias. The participants in the case group were asked retrospective questions and selected HIV positive mothers were LTFU for less than four years. The interviews and questionnaires were indirect to minimize structured responses. I maintained a neutral and impartial stance on everything from the start to the end of the study. Non-response bias was minimised by expressing the importance of the study and taking less time during interviews. I conducted the interviews in their home language (Sepedi) which is the language they understand and preferred over the English language.

- Researcher positionality

The positioning as a researcher comes with prior involvement or work involving the implementation of the PMTCT programmes. I have also conducted a similar study for my Masters' Degree. Greater familiarity and understanding of the participants' perceptions regarding health care and service use were understood. The following similar characteristics were shared with the participants: language, race, and ethnic background and I resides in the region (Limpopo Province) where the study was conducted. Consequently, there was no language or cultural differences as the participants speak Sepedi which is a language that provided the participants with the opportunity to communicate their experiences freely and with ease. During the recruitment process, I shared my biography with the participants and the respondents gained trust to explore similarities. In most cases, I shared my original place of birth, age, marital status, and current residence with the participants.

Also, sharing the information about academic and ethical responsibilities helped them trust the interviewer with their personal information. The mothers were interested in my ethnic background and environment for them to be more comfortable about their personal information. Fontana and Frey (1994) indicate that the gender difference of the researcher might have a significant impact on the outcome of the interview. Despite the gender difference, the participants were able to speak and express their personal feelings. The HIV positive mothers and CHWs were all women and seemed to be impressed with the ethical process before the research process, and that I was there in a professional capacity to understand their plight.

3.9. Ethical Considerations

The research proposal was submitted to University of Johannesburg Faculty of Humanities Research Ethics Committee to obtain ethical clearance. After receiving the ethical clearance on 2 October 2018 (see Appendix A), I obtained permission from the Limpopo provincial Department of Health (see Appendix B) and the Limpopo district Department of Health (Appendix C and Appendix D). The letters were presented to the health facility managers before the study commenced.

3.9.1. Informed consent

The participants and/or respondents who were interested in participating in the study signed the consent forms before they participated in the study. Informed consent is an ethical procedure where the participants give consent to the researcher to participate in the study, and they are given the opportunity before the study commences to decide on whether to participate or not to participate in the study, Neuman (2011) states. This implies disclosure of the research purpose including how the participants will be affected by the study. The researcher is obliged to explain the risks and the benefits of participating and to inform the participants of an option to decline participation at any stage of the research (Christensen 2004). The participants were approached through the health facility managers to discuss with them the research procedures to be followed in the study. The HIV positive mothers and healthcare workers who were willing to participate were interviewed and respondents were given questionnaires to fill out. The purpose of the study and the objectives were explained to the participants, thereafter, the participants willing to participate signed the informed consent forms.

The participants were again informed that they could withdraw at any stage if they are uncomfortable with the study or the research process.

3.9.2. Confidentiality and anonymity

This is a sensitive study that involves vulnerable individuals. To ensure confidentiality and anonymity, the participants were not mentioned by name in the entire research process. A coding system was used to identify the participants' data and ensure that the information obtained from the study will be for scientific use only. Additionally, data collection took place at the health facilities where I was provided with a temporary office by the health officials at the health facilities to ensure that the confidentiality and anonymity ethics had been followed. The data collected was archived in a secure area, in a filing cabinet at my home that includes all recordings and other fieldwork tools or resources, this data will be stored for at least five years. The research soft copies were stored in a password-protected and secured computer and backed in my password-protected external hard drive.

3.9.3. No harm to respondents

During the research, I was welcomed into the participants' lived experiences on sensitive topics, like HIV. HIV has proven to carry or potentially lead to emotional and even physical harm from stigma and discrimination. I was careful to ensure that the participants were not subjected to any kind of harm. The participants' involvements were confidential and anonymous. The interviews and questionnaires were conducted in a secure office at the health facilities to ensure that the information from the participants was safe.

3.9.4. Debriefing

Debriefing is a process in research where a participant is given counselling support from a professional counsellor while he/she experiences stressful and anxious feelings during the research process, Neuman (2011) expresses. The research investigates sensitive health issues that provoke negative memories or experiences (Christensen 2004). This research had debriefing available for all the participants. I took the necessary steps and responsibility to ensure that the participants are comfortable by minimizing the negative feelings that the participants might experience in the study. The participants were encouraged to speak freely and honestly and those who experienced discomfort were to be referred to a qualified professional social worker for debriefing. I made plans and arrangements for a professional social worker to assist with the debriefing when needed. All the participants in this study completed their sessions without any need for debriefing.

3.10. Chapter Conclusion

This chapter offered a description of the research methodology methods - the study applied a mix-method approach (qualitative and quantitative methods). The study highlighted multiple research designs, applied a novel unmatched qualitative case-control design to better understand social patterns of LTFU and treatment non-adherence from mothers who were LTFU and the mothers who continued with the PMTCT services. The study setting and the description of the health facilities that were used to collect data were clearly described. The study outlined the study sampling procedures and the data collection, data analysis, and ethical considerations that were followed. The next chapter presents the data analysis of the finding from the semi-structured interviews with mothers, the in-depth interviews with the CHWs, and questionnaire surveys with nurses and lay counsellors.

CHAPTER 4

UNDERLYING REASONS FOR LTFU AND HIV TREATMENT NON-ADHERENCE

4.1. Introduction

This chapter presents the findings from the semi-structured interviews with HIV positive mothers, in-depth interviews with CHWs and questionnaire surveys with nurses and lay counsellors. The chapter analyses HIV positive mothers' experiences in the PMTCT programmes in the rural context of the Limpopo Province, South Africa. This analysis traced the lives of HIV positive mothers who were LTFU and HIV positive mothers who were not LTFU to explore the social patterns leading to LTFU and non-adherence to HIV treatment in the PMTCT programmes. The analysis considers the experiences of the CHWs in the PMTCT outreach programmes and the experiences of the nurses and lay counsellors in the ward-based PMTCT programmes. The findings in this chapter address the first objective of the study:

- To explore the reasons for LTFU and non-adherence of HIV positive mothers in the PMTCT programmes from the perspective of mothers and healthcare workers (CHWs, nurses, and lay counsellors).

This chapter is divided into two sections, the first section presents the study demographics of HIV positive mothers, CHWs, nurses, and lay counsellors. The second section presents the qualitative findings of the HIV positive mothers and CHWs, and the quantitative findings from the questionnaire surveys with nurses and lay counsellors. The second section provides a detailed presentation of the social patterns of LTFU and draws initial connections to the risk of LTFU and treatment non-adherence.

4.2. Demographic Information

Drawing on data generated from the novel qualitative unmatched case-control study, this section presents the demographic information of HIV positive mothers who were LTFU (cases) and HIV positive mothers who are not LTFU (control). This includes demographic information of the CHWs who are responsible for the implementation of the HIV outreach programmes and professional healthcare workers (nurses and lay counsellors) who are responsible for the implementation of the PMTCT ward-based programmes.

4.2.1. Demographic information of HIV positive mothers

Table 4.1 below shows that the ages of the participants ranged from 18-45 years. Most of the mothers in both the case and control group were between 31-35 {case (n=5) & control (n=7)} and the age group between 26-30 {case (n=6) & control (n=5)}. This is followed by the age group between 22-25 {case (n=3) & control (n=4)} and 18-21 {case (n=3) & control (n=2)}, the lowest age group was between 41-45 {case (n=1) & control (n=1)}. The sample of HIV positive mothers in both the case and control group was relatively youthful. Many studies in South Africa have shown that young women are at high risk of HIV infection (Muula 2008; Pettifor et al. 2009; SANAC 2016). Regarding marital status, most of the mothers in both the case group and control group were not married {case (n=10) & control (n=17)}, most of these mothers were not in any intimate relationship and were living with either their family or extended family. This is followed by the mothers who were married {case (n=3) & control (n=2)}, these mothers were living with their husbands. Four mothers, all of whom were in the case group were cohabitating (living with their sexual partner in a single household). This is significant because existing evidence suggests that mothers who are cohabitating or married may struggle with treatment adherence, especially when they fear disclosing their HIV status to their partners (Frizelle, Solomom & Rau 2009; Muchedzi et al. 2010; Mitiku et al. 2016). This is because they fear negative reactions from their partners and that the male partners may influence the decisions to use HIV services (Muchedzi et al. 2010).

The employment status shows that most of the mothers in both the case group and control group were unemployed {case (n=13) & control (n=18)} and only a few of the mothers from both groups were employed {case (n=5) & control (n=2)}. The unemployment rate in South Africa is high, many people especially youth experience financial difficulties (Yacobson et al. 2016; Statistic SA 2019). The mothers with similar financial status struggle with the costs of transportation to access PMTCT services (Kalembo & Zgambo 2012; Anígilájé, Ageda & Nweke 2016). The education level in both groups shows that most of the mothers acquired secondary level education {case (n=14) & control (n=13)}, followed by tertiary education {case (n=3) & (n=5)} and primary level education {case (n=1) & control (n=2)}. This suggests that most of the mothers would be literate enough to understand and read the PMTCT information during counselling. Most of the mothers in both the case and control group followed and practiced the Christianity religion {case (n=15) & control (n=15)}, this is followed by those practicing both Christianity and African traditions {case (n=2) & (n=3)}. The churches and African traditional organisations are often involved in the fight against HIV infection by redirecting people with symptoms of HIV or those living with HIV to use HIV services at the health facilities (Frizelle, Solomon & Rau 2009). Nevertheless, there have been examples where the church promotes false information and stigma regarding HIV infection and treatments. The church leaders or traditional healers often advise HIV patients that a prayer or traditional or church medicines can cure HIV (Zou et al. 2009). Wanyama et al. (2007) conducted a study in Uganda and found that beliefs can be a barrier to ARV adherence. The study found that six out of 558 (1.2%) patients discontinued their treatment because they believed that their pastors' prayers had cured them of HIV. Doherty (2009) attests those beliefs affect the PMTCT programme when patients fail to follow the instructions from healthcare workers.

Most of the mothers had one child {case (n=7) & control (n=5)}, followed by mothers with three children {case (n=4) & control (n=7)}, mothers with 2 children {case (n=5) & control (n=5)} and the mothers with more than four children {case (n=2) & control (n=3)}. The findings show that most of the participants were first-time mothers with a single child. Wubneh et al. (2021) conducted a study in Ethiopia from charts of 423 child-mother pairs to investigate LTFU of HIV-Exposed Infants. The study found that infants who were LTFU were unable to access full HIV diagnosis and care services. The study further found that the mothers who have more than three children were independent predictors of LTFU of HIV-exposed infants. In this study, most of the mothers in both the case and control group were aware of the HIV status of their children. The mothers who did not know the HIV status of their babies were 18 in total {case (n=9) & control (n=9)}. The mothers whose children had negative HIV status were 18 in total {case (n=8) & control (n=10)}. Only two mothers indicated that their babies were HIV positive, one in each group {case (n=1) & control (n=1)}. The HIV results for HIV exposed babies are important to ensure that the mothers adhere to early feeding and HIV treatment instructions provided by healthcare workers. HIV positive mothers are initiated early in the ART programmes and adhere to treatment during pregnancy and delivery. However, the mothers become LTFU after giving birth, risking MTCT (UNAIDS 2017).

Table 4. 1: Demographic information of HIV positive mothers

Characteristics	**HIV positive mothers**	
	Case group (n=18)	**Control group (n=20)**
Age		
18-21	3	2
22-25	3	4
26-30	6	5
31-35	5	7
36-40	-	1
41-45	1	1
Marital status		
Never married	10	17
Married	3	2
Divorced	1	-
Separated	-	1
Co-habiting	4	-
Education		
Primary	1	2
Secondary (not completed)	-	-
Secondary (Matric)	14	13
FET/collage	-	-
University	3	5
Employment status		
Unemployed	12	18
Employed	6	2
Religious Affiliation		
Christianity	15	15
African tradition	-	1
Christianity & African tr	2	3
No beliefs	1	1
No. of children		
One child	6	5
Two children	5	5
Three children	4	7
Four plus children	3	3
HIV status(child)		
Negative	8	10
Positive	1	1
Do not know	9	9

4.2.2. Demographic information of CHWs

This section presents the demographic information of the CHWs who work in the PMTCT outreach programmes. Table 4.2 below shows the demographic characteristics of in-depth interviews with the CHWs (N=40). All the CHWs who participated in this study were females. The CHW professions are mostly dominated by females, the selections of female CHWs are prioritized due to their capability to work with infants or other maternal issues in the community (Feldhaus et al. 2015; Najafizada, Bourgeault & Labonté 2018). Most of the CHWs were between the age of 46-50 (n=7), followed by 50+ (n=6). The CHWs who are older can provide experience and understanding that can encourage clients and ensure the reliability of anonymity or confidentiality of clients' personal information (Oliver et al. 2015). However, other healthcare workers often judge the lifestyle of their patients (Dageid, Sliep & Akintol 2011), which can thereafter influence LTFU and non-adherence to treatment.

The educational level of the CHWs in this study shows that most have completed secondary school (matric) education (n=13), followed by those who have been to secondary school but have not completed matric (n=4), those with primary level education (n=2), and only one with a diploma. The findings show the CHWs can read and write, therefore, they can understand the basics from the PMTCT guidelines. Most of the CHW programmes in South Africa offer various workshops and training. Moreover, most of the CHWs in this study had between 6-10 years of work experience (n=9) followed by 11-16 years (n=9) of work experience and only two had 1-2 years of work experience. In this study, work experience as a CHWs is the criteria for the respondents to be participants in the study. This reflects on the level of experience or exposure to the challenges or conditions in the PMTCT programmes.

Table 4. 2: Demographic information of CHWs

Characteristics	**Healthcare workers**
	Community Health Workers (n=20)
Age	
26-30	-
31-35	-
36-40	3
41-45	4
46-50	7
51 +	6
Gender	
Male	-
Female	20
Education	
Primary	2
Secondary (not completed)	4
Secondary (Matric)	13
FET certificate	-
Diploma	1
University degree	-
Work experience	
1-5 years	2
6-10 years	9
11-15 years	9
16yrs-20yrs	-
30yrs-35yrs	-
36yrs-40yrs	-

4.2.3. Demographic information of nurses and counsellors

This section presents the demographic information of the nurses and lay counsellors who work directly with HIV positive mothers in the ward-based PMTCT programmes. All the respondents (n=40) answered the questions, most of the respondents were females (n=35), only five of the respondents were males. The findings in this study show that the nursing and lay counselling professions are predominantly female as is evident in table 4.3 below. The nursing and lay counselling profession involve caring for patients by endorsing the feminine traits of caring and gentleness. The profession is surrounded by stigma given the overall feminisation of nursing (Ross 2017). The nurses and lay counsellors play a vital role in ensuring that HIV positive mothers are well counselled or informed about PMTCT activities, adhere to treatment, and involve their partners in the PMTCT programmes (Mpinganjira et al. 2020). Most of the respondents were between 41-45 (n=10), this was followed by the age group between

46-50 (n=9) and 50 plus (n=9). The lowest age group was between the age of 31-35 (n=5), 26-30 (n=4) and 36-35 (n=3). The findings show older healthcare workers as the main providers in the PMTCT programmes. A research study by London, Orner and Myer (2008) reveals that there is a poor relationship between healthcare workers and patients. The study found that HIV positive mothers were at risk of being judged by the healthcare workers. Similarly, Jonas et al. (2017) conducted a systematic review of the Sub-Saharan Africa region on healthcare workers' behaviours and personal determinants associated with providing adequate sexual and reproductive healthcare services. The study found that healthcare workers have negative attitudes towards young people who want to access contraceptives. Thus, the age difference between mothers and nurses was followed up in this research.

Most of the respondents (n=28) were nurses and only 12 were lay counsellors. Health promotions at the health facilities are the responsibility of both the nurses and lay counsellors. However, the nurses are often occupied with influxes of patients in the clinics and lack time to properly complete face-to-face counselling with the patients (Fayorsey et al. 2019). The lay counsellors are expected to cover detailed and more effective counselling in the PMTCT programmes. Most of the respondents (n=19) hold a Nursing Diploma. This was followed by 10 respondents who graduated with a Bachelors' Degree. The respondents with the lowest qualifications hold a matric certificate (n=7) followed by those with a diploma (n=4). Table 4.3 shows that most of the respondents have diploma qualifications. Moreover, the respondents' work experiences in the PMTCT programmes show that most of the nurses and lay counsellors have between 6-10 years of work experience (n=14). This was followed by 1-5 years (n=13) and 11-15 years (n=6). The other respondents have work experience between 16-20 years (n=3), 30-35 years (n=1) and 36-40 years (n=1). These findings are summarised in Table 4.3 below.

Table 4. 3: Demographic information nurses and lay counsellors

Characteristics	**Healthcare workers**
	Professional Nurses & lay counsellors (N=40)
Age	
26-30	4
31-35	5
36-40	3
41-45	10
46-50	9
51 +	9
Gender	
Male	5
Female	35
Education	
Primary	-
Secondary (not completed)	-
Secondary (Matric)	7
FET certificate	4
Diploma	19
University degree	10
Employment status	
Nurse	28
Lay counsellor	12
Work experience	
1-5 years	13
6-10 years	14
11-15 years	6
16yrs-20yrs	2
30yrs-35yrs	1
36yrs-40yrs	1

4.3. The Reasons Why HIV Positive Mothers are Loss to Follow-up

This section draws on the thematic analysis of qualitative and quantitative data. This theme focused primarily on the reasons why HIV positive mothers are LTFU and fail to adhere to HIV treatment. The mothers in the control group and the healthcare workers were also asked to provide their inputs or perceptions on why HIV positive mothers are LTFU and fail to adhere to HIV treatment. The following are the underlying reasons, according to HIV positive mothers and the CHWs, as to why mothers were LTFU and failed to adhere to HIV treatment: Guilt, fear and struggles to disclose HIV, mobility or self-transfers to other health facilities, HIV medication barriers, delays, and interruptions of ART and Health system barriers. The qualitative findings from the mothers and the CHWs are presented concurrently with selected excerpts that reflect the participants' general views on the issues of LTFU in the PMTCT programmes. Hereafter, the reasons for LTFU from the perceptions of the nurses and lay counsellors (quantitative findings) are presented at end of this theme. Below is the detailed presentation of why HIV positive mothers are loss to follow-up in the PMTCT programmes.

4.3.1. Guilt, fear and struggles of HIV disclosure

The reason the mothers in the case group were LTFU is that they struggled to disclose their HIV status. The mothers experienced guilt and fears as they struggled with HIV disclosure to their sexual partners, fears of disclosing HIV status to family/parents, and fears of inadvertent HIV disclosure to neighbours/community members at the health facilities.

Guilt, fears and struggles with HIV disclosure to sexual partners: Disclosure of HIV is a process of telling or revealing HIV status often voluntary to other people. One of the reasons the mothers in this study were LTFU is they have not disclosed their HIV status to their partners, and they were worried about the reactions of their partners if they were to disclose their HIV status. They feared that their partners might blame or judge them. The mothers delayed HIV disclosure and struggled with ways or methods of disclosing their HIV status. For instance, a mother who was LTFU feared inadvertent disclosure of her HIV status to her sexual partner and feared being blamed. The mother struggled with the methods or ways to disclose her HIV status. This is what she said:

> My problem is that when I want to come to the clinic the father of my child does not know my HIV status, I do not have the reason to tell him that I'm going to the clinic, he still doesn't know now and I don't know how to tell him, I am afraid that he might blame me (LTFU M8, age 26).

The excerpt above shows that the mother was afraid to disclose her HIV status to her sexual partner. Thereafter, the fear has influenced her to be LTFU and fail to adhere to HIV treatment. The mother is LTFU to avoid suspicions from her partner as she struggles to provide the reasons to attend her clinic appointments. Fear of blame was a common feature that influenced the mothers' decision to not disclose their status. Another mother who feared inadvertent disclosure of her HIV status to her partner was worried about the aftermath of HIV disclosure. The mother spoke of feeling guilty that her partner was not on treatment and that she was taking the medication secretly. Although the mother was LTFU, she was aware of the importance of HIV treatment for her partner. Nonetheless, she struggled with strategies to disclose her HIV status to her partner. This is what she said:

> I have a problem, I have not disclosed to my partner about my status, you see, when I take treatment and he is not taking treatment it does not sit well with me, I would love to come with him here for testing so that we take treatment together; it is not nice for me to take treatment alone in hiding if he finds out what will I say the pills are for? I do not have a problem coming to the clinic I just have a problem that I have not disclosed to my partner, I don't have a problem with the treatment I know it helps, I am waiting for the right chance to tell him, I will just accept the aftermath (LTFU M2, age 42).

The above quote shows how a mother struggles with ways to disclose her HIV status to her partner and her guilt about non-disclosure. The mother was aware of the importance of HIV treatment and show concerns about both her health and that of her partner. She describes the ideal scenario where she and her partner could receive treatment together and support one another in the process. However, the mother halted ART to find the courage and a strategy to disclose her HIV status to her partner. Additionally, the findings from the CHWs support the mothers' narratives. The study found that the CHWs believe that HIV positive mothers are LTFU in the PMTCT programmes because they fear disclosing their HIV status to their partners: The CHWs had this to say:

> It's become hard because they don't tell their partners, they are afraid of the partners' reactions, so when patients have a problem disclosing to their partners - we tell them to bring their partners to the clinic together with them and pretend as

> if it’s the first time they come to the clinic so that they can get tested together at the same time (CHW P10).
>
> It results in fights between partners, they say that it starts fights, some are already broken up, they have divorced already, with LTFU patients, when we go to their households, we don’t tell them why we are there, we just refer them to the clinic, even if we find the partner, we do not tell the reason we are there, most of the HIV positive mothers who come to the clinic they don't disclose their status to their partners (CHW P8).

Though the CHWs advise mothers to convince their partners to come to the clinic for HIV testing and counselling, the mothers still face challenges of involving their partners. The first quote shows the willingness on the part of CHWs to develop strategies with the mothers that can mitigate the negative consequences of disclosure. The CHWs were aware of the need to avoid inadvertently disclosing the mother’s HIV status. The CHWs ask mothers to bring their partners for HIV testing and counselling as if it is the first time they test for HIV. The second quote shows that the CHWs believe that HIV positive mothers endure negative reactions that lead to fights, break-ups, or divorces in the relationships. The CHWs avoid accidentally disclosing the HIV status of the mothers to the partners during household visits by referring the mothers to the health facilities. They also avoid inadvertent disclosure of their HIV status during household visits by adhering to confidentiality and privacy practices or pretending to be unaware of the mothers’ HIV status.

Fear of disclosing HIV status to family/parent*:* Family is an important factor that influences service use in the PMTCT programmes. This study found family dynamics related to HIV disclosure and explored the communications between family or parents and their children (Madiba, Ralebona & Lowane 2021). The findings show that HIV positive mothers were LTFU as they fear disclosing HIV to their families. They fear negative reactions from their elders/parents. For example, a 25-year-old young mother who was LTFU fears her mother’s reaction if she discloses her HIV status. This is what she said: *“I am afraid of my mom, she doesn’t know, my mom is impatient, I will find a time to tell her”* (LTFU P9, age 25). The quote shows that the mother is afraid of disclosing her HIV status to her mother because her mother is impatient. Though the respondent fears negative reactions she plans to disclose her HIV status when she finds time. Some family members lack the understanding or support for their children and could easily expose their children to the vulnerability of unkind or judgemental treatment. This is the reason why most young mothers delay HIV disclosure to their parents/family and are then LTFU to avoid disclosure. For instance, a 23-year-old, young mother who has been LTFU for 10 months, did not disclose her HIV status to her family, fearing their judgemental reactions to her status:

> They are judgmental at my home, I did not tell anyone at home because they are judgmental, I am afraid that they will judge me. It took almost a year, close to ten months of not coming to the clinic, the I am not coming to the clinic is because of my family at home, I am afraid that they will be judgmental. Since my biological parent passed away, they have been treating me badly. They do not treat me badly now, but I can feel it by the way they talk to me, that it is not right. I do not trust anyone at home, if I had both parents, I would sit down with them and tell them. I have siblings, but our relationship is not good, so I did not tell them. (LTFU M17, age 23).

The excerpt shows that this mother is an orphan and is not comfortable with disclosing her HIV status to family members. The mother was afraid that her family members might treat her badly. The mother further states that she does not trust her family members as she recalls that since her biological parents passed away her family treated her badly. She would have disclosed her HIV status to her biological parents if they were alive. She did not disclose to her siblings because their relationship was not on good terms. Additionally, a 28-year-old mother in the control group believes that HIV positive mothers do not disclose their HIV status to their parents and believe that is the reason they are LTFU. This is what she said:

> Some are just ignorant, some they just fear, they do not share with their parents, they don't share their status with their children.

The mother in the control group believes that the mother who are LTFU experience fear of disclosing their HIV status to their parents. Besides, the other mother in this study did not struggle with disclosing their HIV status to their family. The quote shows that the mother in the case and control group disclosed their HIV status to their family for the sake of social support. They believe it is important for their family to know their status. This is confirmed by a mother who said: *"I told my mother so that she can come and collect medication for me when I cannot."* Furthermore, the CHWs believe that HIV positive mothers are not well supported by their families because they have not disclosed their HIV status to them. This is confirmed by a CHW who said:

> They do not have support, but if they disclosed their statuses to their families, they will be offered support, they (family) can remind them about the date to collect medication but if they do not disclose it's difficult (CHW P16).

The excerpt above highlights the importance of HIV disclosure to family members or parents as they act as treatment supporters, improving adherence to treatments. HIV positive mothers miss their clinic appointments as it deprives them of a possible source of support for treatment adherence.

Fear of inadvertent HIV disclosure to the neighbours/community members: The mothers in the case group presented fear of HIV disclosure to the neighbours or the people who know them at the clinics as the reason they were LTFU. A young mother who was LTFU feared people/community members who are using the same health facility. This is what she said:

> I feared what people will say, there are people from my place who use this clinic, they will be looking at me, asking the wrong questions (LTFU, age 19).

The mother fears inadvertent HIV disclosure to the neighbours/community members at the health facility. This shows that the mother is afraid that the people from her community might ask her uncomfortable questions and discover her HIV status. There is still fear of stigma and discrimination 40 years since the first case of HIV was recorded even with high coverage of prevention and education programmes. An unemployed mother from the control group with a similar response had this to say: *"They fear that if they go to the clinic other people will see them."* Likewise, a mother in the control group is convinced that HIV positive mothers who are LTFU have not accepted their HIV statuses and are worried about other people:

> It could be work or school, but I will come the following day I will come if I get a chance, some of these mothers have not accepted and they worry about what other people will say, they think of death when they talk about HIV, I don't know about others, but I always come, I don't miss my appointments (CIC P3, age 23).

The excerpt above highlights the perceptions of a mother in the control group regarding why HIV positive mothers are LTFU. The mother believes that HIV positive mothers in the PMTCT programmes are concerned about other people's judgements and struggle to accept their HIV status. The quote shows that there are still misconceptions about HIV and that HIV infection inevitably leads to death. Hence, the quote shows that the mothers in the control group will continue with their HIV treatment. The mother shows commitment to her treatment regime and will not miss her appointments even if she experiences obstacles on her appointment dates, she comes to the health facility the following day. The CHWs agree that HIV positive mothers fear disclosing their status to their neighbours or other people at the clinic. This is what the CHWs had to say:

> The reason is that they believe that when they come to the clinic the people will suspect that they have HIV, and they then miss their appointments. When they go to clinics to collect medications and they see their neighbours they get worried because they think the neighbours know that they are there to take HIV medications (CHW P11).
>
> Let me just say it is not this clinic, it is like they still have a problem with what people will say if you trace them and then if they see someone they know at the clinic, they will not come back (CHW P3).

The excerpts imply that HIV positive mothers fear inadvertent disclosure of their HIV status at the health facilities. Similar to the previous excerpts from the mothers, the CHWs believe that when mothers attend their clinic appointments at the health facilities, they fear that people from their neighbourhood will know their HIV status. The mothers fear inadvertent disclosure of their HIV status and they will not return to the health facilities if they see someone they know from their community or neighbourhood.

4.3.2. Mobility or self-transfers to other health facilities

Another reason why HIV positive mothers were LTFU is because they self-transferred to other health facilities. Self-transfers are a major setback for the health facilities' ability to record the actual numbers of LTFU patients. The reasons for self-transfers are not recorded or known by health personnel in most cases, creating LTFU status. Understanding the reasons why a mother self-transfers is important and there is a need to understand the motivation for self-transfers and if the mothers have transferred to reputable and sustainable health facilities. In this study, the mothers who self-transferred failed to apply for transfer letters and blamed a lack of awareness or prior knowledge of clinic processes. One of the mothers was completely unaware of the transfer letters: *"I did not know that I have to take a transfer letter."* Another mother who self-transferred was aware of the transfer letter applications but did not come to a point of alerting the clinic personnel that she is moving to another clinic: "*I knew that I have to take a transfer letter, but it was not in my mind to do so."* These show mothers' lack of knowledge and awareness of the importance of alerting health providers of their intentions to move to other health facilities. Therefore, the healthcare systems place a burden on mothers to do administration for healthcare workers regarding the application for transfer letters.

Self-transferring to health facilities closer to home: Self-transfers are outcomes that show patterns of health-seeking behaviours, and this is an important contribution to this study. This brings the need to bridge the social meaning, patterns, and reasons why mothers' self-transfer to other health facilities. As an example, a mother who was LTFU also failed to apply for a transfer and decided to move to another province to live with her spouse. This is what she said:

> It is because I was in Gauteng Province and could not come here every month, I now moved to Gauteng Province with my husband, and I am using another clinic in Gauteng. I did not take the transfer letter, I left because my husband stays in Gauteng. I only came to the clinic because of the Zion Christian Church. I think I do not have access to take medication here in Gauteng, I don't think I will be able to take medication. Now I am home in Tzaneen, and I have to take treatment, I do not know if it's possible they can transfer me (LTFU M15 age 27).

Some of the mothers who self-transfer did so because they experienced problems with the distance or/and travelling costs to the health facilities. The findings show that the mother moved from one health facility to another and that the facilities that used to be convenient were no longer available. The excerpt above shows that the mother initially enrolled for ART at a clinic while attending a church event at the Zion Christian Church (ZCC) headquarter in Moria, Boyne, which is far from her home. This shows that the mother selected a health facility that is not sustainable or is far from the place which she resides, this influenced her to later self-transfer to health facilities that are closer to her home or health facilities that were convenient. The excerpt shows patterns of mobility where the mother moves from one health facility to another in different areas. The mother wants to continue with her HIV treatment, but she is not sure whether the health facility in her current area will allow it because she does not have a transfer letter. This highlights the complexities of moving from one area to another without transfer letters. One of the mothers who was using a facility from another community self-transferred to a private practitioner in town and complains about the distance of the facility and that her initial attempt to register in her local clinic failed due to lack of recording books:

> The distance from this clinic is a problem for me because I am studying, I am not around. I am studying in Lebowakgomo. I have never come back to this clinic after giving birth to my baby. I came here while I was pregnant, and then I stopped and started going to a private doctor, at the hospital, they asked which clinic I will be attending, and I told them I am going to Mothiba clinic because I am from Ga-Mothiba village. When I started going to this clinic for treatment, I went to Mothiba clinic, and they told me that they do not have books (record books), so I have to go and try at this clinic (Clinic C2). I was planning to go to Mothiba all along because when I come back home the clinic is close to home, even when I leave my child behind it is a close distance for the person who will take my baby to the clinic on my behalf. I did not know that I have to take a transfer letter (LTFU M1, age 21).

The mother initially moved and registered ART with a clinic that is far from home because the clinic that is closer to her community could not register her due to the unavailability of recording books. She describes how she was forced to move again to another health facility that is further from her home due to school commitment. Similar to the previous excerpt, there are patterns of mobility where the mothers are forced to move from one area to another. The mother was unable to register with a health facility that is closer to her home or her community and had to select a facility that is far from her community, then she had to move again to another health facility because of school obligation and was not aware that she has to apply for a transfer letter. In addition, she has moved in and out of the public health sector at different times based on her health needs. The recording systems from her previous clinic failed to record this making it look like she was LTFU, and programmes are less effective. Another mother who has immediate regret for selecting a clinic that far explained how the travelling costs affected her, that thereafter coerced her to move to a clinic closer to her home:

> I have left the clinic before my baby’s birth; it was very far so I went to another clinic, and I was afraid of transport costs to this clinic (Clinic C2). It was far and I was not okay, and I went home, so I use a nearby clinic [Ga-Mothapo village] because this clinic is far. So, I started taking treatment at Ga-Mothapo village, I have not been here since 2017 (LTFU M5, age 31).

Most of the participants from both the case and control groups stay close to the clinic they use. Accessible PMTCT services allow mothers to participate in PMTCT activities, which includes the continuous collection of HIV medication. This is confirmed by a mother who said: *"It is far but it's not that far, I can walk on foot if I do not have money for transport."* Another mother with similar responses had this to say: *"I don't have a problem the distance is not far from this clinic."* The excerpts show that most of the mothers did not experience issues related to distance of the health facilities, they walk to the facilities. This eliminates the need for transportation or travelling money to attend health care services. Though many of the mothers did not experience challenges with accessing PMTCT services, the CHWs believe that the distance and travelling costs are the reasons mothers are LTFU. This is what they said:

> They tell us that they do not have money for transportation that if they don't have money for transportation they cannot come to the clinic, they don't have money to come and collect medication. There are those who are complaining about transport costs and that the clinic is far, they complain about the money for transportation so that is why they are LTFU (CHW P13).
>
> Sometimes when we go to their household, they remind us that we should have brought the medication with us for them because they complain about the issue of transportation costs (CHW P1).
>
> Some are complaining about transport costs, that it is far, they complain about the money for transportation so that is why they are loss to follow-up (CHW P13).

The CHWs confirms that HIV positive mothers struggle with the distance to health facilities and lack of transportation money to the clinics. For these reasons, a few HIV positive mothers were LFTU when they cannot travel to the health facilities because of the distance and travelling costs. The second quote shows that the mothers seek assistance from CHWs to collect medications for them to avoid the distance and travelling costs.

Self-transfers due to poor or rigid healthcare systems: Some mothers who self-transferred blame poor communications and the attitude from healthcare workers during negotiation for clinic appointments that do not clash with their school or work schedules. Mothers who experience poor communication or treatment from healthcare workers may lose interest in the services or treatments. This was experienced by one of the mothers who self-transferred to another clinic due to poor communications and services from the healthcare workers. The clinic personnel refused to change her clinic appointment schedules when the appointment dates overlapped with her work schedules. This is what she said:

> The service here was moderate because at the time I started here I did not know the instruction regarding the time to come here for my appointments, like the days or dates to collect medications etc. They did not give me counselling but the dates that they gave me for clinic appointments clashed with my work schedule so when I explained my situation, they did not help me. I have asked them if they can give me different dates that do not clash with my work because where I am working, they do not allow me to take leave so many times, so I cannot just take a day off. I did not have anyone to collect my medication, I do not know anyone I trust this side. They said either I come and collect treatment on Monday or Friday and these days/dates at the shop where I work is very busy. When I explain to them, they said if I cannot come on the dates they gave me, they cannot give me other dates. So, I decided to go to another clinic, when I called my sister and explained and she recommended that I go to a clinic in zone one (Mankweng Township) and I was able to be helped with my problem, I am not afraid of what other people will say, I self-transferred because at the clinic they refused to give me the appointments dates that do not clash with my work, the clinic I transferred to was able to help me (LTFU M6, age 33).

The mother needed appointments schedules that accommodate her daily life activities or work schedules. The mother explains how lack of communication and failed negotiations to collect HIV medications at the time or dates that do not overlap with her work schedule motivated her to move to another health facility. This shows that the healthcare workers sometimes fail to accommodate mothers' needs in the healthcare process. As a consequence, the mother showed a great deal of resourcefulness in finding a place that can accommodate her needs. The quote also shows less flexible working conditions that make the mother unable to take a day off to fetch her medication. The quote also shows the challenge of rigid health providers as other health care facilities were able to be flexible with their services. In addition to poor services from the healthcare workers, the mother was not provided with counselling regarding the appointment dates. Another mother who experienced similar treatments from the healthcare workers left the clinic when the nurses refused to understand that her school schedule clashes with the dates that she collects her medications. This is what she said:

> The healthcare workers wanted me to take treatment at their time. Their conduct was not good, when I came here, I was attending school and I told them I will be able to collect treatment after school and they refused and told me I must come at the right time (the time provided by healthcare workers) to collect treatment, and that treatment is only collected in the morning. I was going to be able to collect treatment after school, but they refused. I take my baby to a mobile clinic; I do not mind bringing my baby here, but I will take him

> to the mobile clinic. I will rather go to another clinic, but I can bring him [baby] here if the mobile clinic does not come (LTFU M14, age 23).

The excerpt demonstrates a culture of rigid health practices by healthcare providers where mothers are forced to accommodate healthcare workers' needs rather than the health system accommodating the mothers' multiple daily life responsibilities. This excerpt shows similarities with the previous one where both mothers experience daily life responsibilities that they could not postpone. Their daily life responsibilities clashes with clinic appointments. The mother also showed a great deal of resourcefulness and found a clinic that accommodate her needs, which does not clash with her schooling. Consequently, the mother chose to use a mobile clinic as her primary healthcare, and for her baby, which is risky because mobile clinics are not sustainable. Mobile clinics provide access to healthcare for patients who are unable to access health facilities. The rigid health system forces the mother and her baby to move to a health facility that is not sustainable and may risk the health of both the mother and the baby.

4.3.3. Delays and interruptions of ART

The mothers in both the cases and groups delayed or interrupted ART as they struggled with the acceptance of their HIV statuses. The theme shows that the mothers were not ready or were unwilling to initiate ART, they were in denial of HIV or beliefs that HIV is cured, and others interrupted ART because of work obligations/responsibilities. The sub-themes are discussed in detail below.

Unreadiness and unwillingness to initiate or continue with ART: Mothers' unwillingness and unreadiness to initiate ART was a major challenge that has influenced LTFU and non-adherence of HIV treatment. In one instance, a mother intentionally delayed ART and states that she was not ready and that she will take her HIV treatment when she is ready. This is what she said:

> I was just delaying, I know the importance of coming here but I was not ready, I was ignorant, I do see the importance of taking HIV treatment. I said to myself I will take them when I am ready, I was not ready. I can see that the treatment is working. When I first found out after giving birth, I came to the clinic with my baby for the first time and since I realized that I was not in any sexual activities at that moment I decided to take a break to raise my baby until I can gather enough information and understand. I do not have any real reasons is just that I wanted to raise my baby. I was taking treatment and then it finished and when it was finished, I started losing interest (LTFU M18, age 32).

The mother in the above excerpt is aware of the importance of taking HIV medications and that the HIV treatment works. Although, she was intentionally delaying treatment at least until she was ready. The excerpt highlights the importance of readiness to initiate ART or take HIV treatment. The excerpt shows that the mother was initially on HIV treatment but lost interest when her medication ran out. The mother's unreadiness was influenced by her desire to focus on her motherhood duties and to gather enough information and understand her treatment. Likewise, an HIV positive mother who was delaying ART claims that she was not aware of her next appointment date, and she did not do anything to find out about it. At the time of tracing and interview the mother was very weak and struggled to speak. Her responses were short. This is what she said: "*I was just saying I will come, and I did not come, I did not know about my appointments, and I did not do anything about them*" (LTFU M7). This extract also shows the importance of readiness and willingness to initiate ART and to understand the importance of attending clinic appointments. The mother was delayed or unwilling to acquire information about her next clinic appointment. The extract shows the mother was not ready to initiate ART as she made no effort to find out the dates of her next appointment.

Denial of HIV and Beliefs that HIV is cured: The news of contracting HIV can be a heavy burden to bear for many patients. Consequently, other patients chose to deny that they have contracted the virus. For instance, one of the mothers admits that she has not accepted that she has HIV. A mother who was LTFU and failed to adhere to HIV treatment for about four months could not understand the importance of taking HIV treatment. The mother only takes her medication because the HIV test results read that she is HIV positive and claims to be feeling well. This is what she said:

> This year I did not take it [medication], I was four months without taking them, I just take them because the test results came and they said, I am positive. I do not see the importance of taking it because I do not feel anything on my body, I take them because they said I am positive, the results say, I am positive. I do not see the importance because I don't feel anything even when I started taking treatment, I was not sick (LTFU M5, age 31*).*

In the excerpt above, the mother who was LTFU believed that she was not sick, that she was feeling well. As a result, she did not see the importance of taking treatment. The excerpt highlights the mother's lack of knowledge about HIV and the importance of taking HIV treatment. Comparably, a mother in the control group was denial that she has contracted HIV and that she was only taking the treatment for the sake of her children. This is what the mother said:

> I was in denial you know; I have not yet accepted my status up to now, right now I am doing this for my children, I am not doing this for me. I do believe that I have HIV, but I have doubt, I do not know but there is something inside of me that is telling me otherwise. I am not influenced by someone else because I know someone whose been sick and I was the one who guided that person to take treatment, for myself I just have this thing inside of me I don't know what to call it, it tells me that, I just don't believe (CIC M9, age 28).

The excerpt above shows that the mother is yet to come to terms with her HIV status. The mother is aware of the importance of HIV treatment, but she doubts that she contracted the virus, and explains how she guided someone into taking HIV treatment. However, the mother has not accepted or believed that she has contracted HIV. The mother continues to take her HIV treatment for her children highlighting motherhood as a factor that influenced her to continue with the HIV treatment. The belief that HIV is cured is common among patients who have HIV. Every HIV patient wants to be relieved from the burden of HIV at some point. Unfortunately, there is currently no cure for the virus. Mothers are often in shock and manifest beliefs and myths about HIV. In one instance, a mother who defaulted for five months believes that she felt well, and that the virus does not affect her and that is why she stopped taking treatment:

> No, maybe it is because I see that I am well now, that the virus is not affecting me, I stopped taking medication in October 2018, they told me to come back, it is just that I failed to go back (LTFU M2, age 42).

The mother is under the impression that she is well, and that the virus is not affecting her and she, therefore, decided to stop treatment. The extract shows that the mother lacks awareness and knowledge regarding HIV and the importance of the Option B+ treatment regimen. Option B+ is recommended as an immediate provision of lifelong treatment regardless of CD4 count (Department of Health 2020). One of the mothers in the control group believes that HIV positive mothers who are LTFU are under the impression that they are healed after they get tested and the virus is suppressed or untraceable. This is what she said:

> The problem is that when they come back to the clinic and get tested and then the result reads a false-negative- they think they have been healed, they do not come to the clinic but that is not how it works. It is because they feel like they are not sick anymore, it is like they've been healed. As for me, I have never had

> any intention of stopping I will keep coming to the clinic I do not have any problem that will stop me from coming back to the clinic (CIC P7, age 30).

A mother from the control group believes that HIV positive mothers are LTFU because they believe that they are healed when they retest for HIV. The excerpt implies a lack of awareness and knowledge regarding the nature of HIV and testing for HIV. The mother states that her intentions are to always honour her clinic appointments regardless of what the retest says. This shows awareness of the danger of false-negatives and the importance of adhering to clinic appointments. The extract shows the commitment of the mother to continue with treatment. Additionally, the CHWs hold that when HIV positive mothers come to the health facilities to get tested for HIV again and find that the virus is not detectable, they misunderstand or interpret the results as negative HIV results. The CHWs believe that the mothers are under the impression that they are healed when they receive false-negatives, and this makes them believe that their HIV is cured and thereafter decide to not come back to the clinic. This is what the CHW said:

> Some have a problem when they're taking medication well and it happens that the virus becomes suppressed, so when they get tested again and the test result reads a false-negative they think that they are healed because the virus is no longer detectable, they don't know that they have to take this medication for life, for example, today if a pregnant woman tests positive, when she gives birth she will think she has been positive because she was pregnant and others get tested and find that they are positive; when they are supposed to start treatment they don't come back. How we find out that we have a lot of loss to follow up is when they do not come because they are denial, they don't believe that they can be HIV positive, they lack the knowledge and some they just tell themselves that they will never be positive (CHW P9).

The CHWs believe that HIV positive mothers lack awareness and knowledge about Option B+ which is a lifelong treatment regimen. They imply that the mothers who are LTFU have certain beliefs and understanding about HIV and believe HIV can be healed especially after they receive false-negative HIV test results due to viral suppression. False-negative tests is a term used to describe an error made by the testing devise, the test fails to detect the virus even though the patients are HIV positive. False-negative test results can occur due misinterpretation of a test, specimen mix-up, mislabelling and improper handling technical issues (Centre for Disease Control and Prevention (CDC) and Association of Public Health Laboratories 2016). In the quote, the CHWs further explains that the mothers lack knowledge because they are in denial of HIV, and they do not believe that they can be HIV positive.

Work obligations/responsibilities: The patients are affected or influenced by daily life activities like work obligations, survival. This sub-theme was slightly addressed in the previous sub-theme about self-transfers due to poor or rigid healthcare systems, where one of the mothers complained that the dates that they gave her to collect HIV medication clashed with her work schedule. This sub-theme addresses the behaviour patterns of mothers in relation to their work responsibility, that directly led to LTFU and non-adherence to HIV treatment. In this research, an HIV positive mother missed her appointments quoting that *"I found a piece job"* and to fulfil those obligations she became LTFU. Work responsibility prevents mothers from adhering to clinic appointments and HIV treatment, the mothers find little or no time to attend their clinic appointments because of work responsibilities. As an example, a mother who works as a care worker had to miss a clinic appointment due to work obligations in another country: "*I was out of the country because of work"* (LTFU P10, age 27). Similar responses were expressed by other mothers who were LTFU. This is what these mothers said:

> I was at work, I was not able to come because of work, I worked throughout my pregnancy until delivery, even when I went to labour, I was at work. I told my boss that I want to take a leave, he refused, it has been long since I went on leave (LTFU M6, age 33).
>
> When I started a new job, it was very difficult for me because the people I work for were very difficult, If I asked for leave from work, they didn't pay for that day, even if I showed a letter, they would not pay me for the days that I missed work and I cannot afford that because I need the money. I need money to buy formula milk, so I have to come to work even when I have an emergency (LTFU P18, age 32).
>
> The reason I did not come to the clinic is personal, it is not the clinic's problem, the day I was supposed to go I was at work, and I was not in the mood, I got irritated (LTFU M11, age 26).

The excerpts above highlight the impact of a work schedule on adherence to clinic appointments. The first and the second excerpts show that the mothers barely find time to commit to clinic appointments considering the harsh work schedule and their employers refusing leave of work. The first mother struggled to apply for leave from her work, her employer refused to approve her leave requests and made her work throughout her pregnancy. In the second excerpt, the mother could not afford to miss work because of unpaid leave as she needed the money to buy formula milk. This highlights the importance of work as an important daily activity that provides financial security and allows HIV positive mothers to provide for their families. In the third excerpt, the mother failed to come to her clinic appointment because she had to attend to her work responsibilities and was not in the mood to attend her clinic appointments as she had moved to another province and could not go to the clinic.

4.3.4. HIV medication barriers

The HIV medication barriers influence LTFU and non-adherences. The theme discusses the mothers' fear of getting sicker from the HIV medication side effects and the lack of support to cope with the medication side effects, taking alternative medicines to treat HIV, and lack of food to take with the medication. The sub-themes are discussed in detail below.

Fear of getting sicker from the side effects*:* The medication used to treat HIV helps mothers to live longer and prevents new infections especially from MTCT (UNAIDS 2017). Nevertheless, the medication often comes with side effects that influence mothers to stop the treatment and become LTFU. One of the mothers failed to adhere to her HIV treatment after feeling weak at work because of taking her HIV medication. This mother decided to only take the pills on the days she was not going to work, to avoid the side effects from interfering with her work. This is what she said:

> I last took it on Tuesday, the reason for not taking it the following day is that most of the time when I take it is when I go to work and I do not feel good, they make me feel weak. So, I take them when I am not going to work and when I go to work, I don't take them. I sweat too much, and they make me dizzy, and I am afraid that I will be dizzy at work. I received counselling about the side effects, they told me to make them aware when I am getting the side effects, that If I feel like they not sitting well with me I should come back. I did go back and tell them, and they explained to me that the pills are like this in the beginning when I start taking them (LTFU P11, age 26).

The mother explains how she would be comfortable with taking the HIV medication as long as the medication does not affect her during work responsibilities, considering the impact of the side effects. In the previous sub-theme, I presented the findings on the impact of work responsibility on adherence to HIV treatment and clinic appointments. This quote highlights the complexities involving the side effects and the work responsibility including the time to take the HIV medication. It is more than just taking the medication because there are other factors, for example, choosing the right time to take the medication considering the side effects and how they impact daily life activities and responsibilities. At the facilities, HIV patients are told to take their medication in the afternoon during counselling. However, other patients may have other obligations at that time, which brings the question about the best time to take the medication considering the side effects to accommodate the patients’ daily life obligations. Also, a mother who was LTFU experienced challenges with adhering to treatment because of the side effects. The mother previously admitted to having been LTFU due to fear of disclosing HIV to her mother. She has not been taking her medication for six months and complains that the HIV medication makes her even sicker. This is what she said:

> I do not feel okay when I take them, I am not free when I take them, I think too much, I think that taking the pills make people even sicker, that is the way I think. I took them once in January and I did not feel well after taking them, I do not feel comfortable when I take them. I have not mentioned this to the nurses, at this clinic I took them twice, I just took one and then started feeling bad and then I stopped taking it (LTFU M9, age 25).

The excerpt highlights the fear and beliefs about the medication and its side effects. This shows how other people react differently to medication side effects. The mother explains the discomforts that come with taking the medication which she immediately responded and believed that the medication makes her even sicker. The CHWs, on the other hand, support that HIV positive mothers complain about the side effects of HIV medication during tracing. The mothers who were successfully traced have already stopped taking their medication because of the severity of the side effects. In consequence, the CHWs convinced the mothers to continue with their treatment and assured them that the side effects are just temporary. This was confirmed by a CHW who said:

> Yes, some will have side effects, some tell us that when they are sleeping the bed moves on its own, some have pimples on their face, we tell them that they will pass because it’s the first time they're using the medication. Someone decided to stop taking their medication, but we convinced them not to stop (CHW P2).

The CHW confirms that HIV positive mothers stop or halt HIV treatment after experiencing severe side effects. The CHWs make efforts to convince mothers to continue with the treatment. The extract highlights the importance of the outreach team in terms of support for HIV positive mothers on how to cope with the side effects of the HIV medication.

Lack of support to cope with the side effects: Mothers who struggled with the side effects complain about lack of support from nurses. This is supported by a mother who admits to being LTFU due to the poor support regarding the medication side effects and has stopped taking HIV treatment after birth. The mother complains about the poor attitude from the healthcare workers, that they did not give her valuable attention on how to cope with the side effects when she consulted:

> I just gave birth, and I decided not to come because of the side effects from the pills, when I take it [medication] they come back, and I kept trying to take them and they come back. I told a nurse at the clinic that the treatment gives me problems and she told me that she is busy and ask me if I want to live or not and I responded that I want to live. She did not assist me well. I did not do anything, I just kept saying I will go to the clinic but I was afraid of getting those side effects again and I was going to talk to my sister so I can go and take them somewhere else, at the doctor. I wanted to ask what to do when they come back, but she told me she is going to lunch (LTFU M16, age 31).

The above excerpt shows that healthcare workers were less supportive to the mother regarding ways to cope with the side effects of the medication. The poor treatment from the healthcare worker influenced the mother to discontinue her treatment because she was not supported or assisted regarding ways to cope with the side effects. The excerpt shows that the mother was seeking information about the side effects, but she was treated as if she was not serious about taking treatment. Consequently, the mother showed concern and even opted to see a doctor for clarity regarding the reason why the medication keeps coming back when she takes them. This highlights the importance of social support and professionalism from the healthcare workers to ensure that mothers return to the health facilities for treatment. Another mother was worried that the side effects were making her lose weight and explained how the nurses failed to provide valuable advice on how to cope with the side effects. This is what she said:

> When I am taking treatment, I'm not gaining weight I'm losing weight, it makes me think so much because I'm taking the treatment and it's making me lose weight. I spoke to the nurse and the nurse told me that I have not accepted my HIV status, it makes me feel like there is something wrong (CIC M9, age 28).

Though the mother is taking her medication the lack of clarity or support regarding the side effects can influence her non-adherence to the medication in the future. The mother is concerned about weight loss, and this can easily influence non-adherence. Another mother who experienced the side effects expresses her complaints to the healthcare workers who take long during counselling (to explain what causes the side effects and how to cope). She was afraid to ask the healthcare workers about the side effects because of the poor treatment she received from her previous visits:

> I was satisfied with the information; they also explained the side effects - that if I come across the side effects I should come to the clinic and maybe they can change the medication. Maybe they should have taken time to explain to me about the medication not making me feel well and what could cause it. I did not understand well. The reason I did not tell them about the side effects was that I was afraid of the way they treated me before (LTFU M9, age 31).

This extract shows a mother who is unsure about the information regarding the side effects and feels the need for more detailed discussions about the effect of side effects during counselling, on what causes the side effects and how to cope with the severity of them. The mother highlighted the importance of time during counselling that the healthcare workers could have taken their time to explain so that she can understand. This is a hint that detailed counselling sessions for mothers are important rather than healthcare workers explaining selectively about adherence and other PMTCT activities. There is a lack of support for mothers to help them cope with the side effects during consultations at the health facilities. HIV medication often has severe side effects that can be scary or unbearable. This results in many patients stopping ART altogether when they experience severe side effects. It becomes easier for patients to stop ART when health personnel fail to support or provide relevant information on how to cope with the side effects.

Taking alternative medicines: The use of untested alternative medicines to treat or manage HIV can impact negatively on the success of the PMTCT programmes. In one case, a mother intentionally delays initiating ART and trusts alternative remedies to treat HIV by believing in the use of protein supplements as an effective immune booster: *"I was taking proteins so for me I think they are helping, so I've never had any problem or illness that can make me very sick"* (LTFU M18). The mother believes in alternative medicine as a treatment for HIV. The mother believes the protein supplements are a substitute for HIV treatment because in her understanding the supplements are working after all as she never had a problem with illness or been severely ill. This shows a lack of awareness and knowledge about HIV and the treatment of HIV. Similarly, church and traditional medicine have been highlighted by the CHWs as common alternative methods for treating HIV. The CHWs said:

> Yes, they do not take treatment or return to the clinic because of their beliefs, they just tell us that right now they are still busy with their traditional medicines, and they will come to the clinic after they go through the process of using traditional medicines. Some come to the clinic afterwards and are still busy taking the traditional medicines, they say traditional medicines help them, they think that they have been bewitched. They [mothers] are taking traditional medicines but they cannot cure the virus, someone who was lost to follow up told me she is no longer taking HIV treatment because they are taking traditional medicines. So, we talk to them, we show them the importance of taking HIV treatment even if they stop coming to the clinic, we have been given them counselling (CHW P11).

> Some have church beliefs, you find someone saying that I went to a church and at the church, they told me to follow instructions and now she could not choose between following the instructions and taking medication from the clinic or following both instructions from the churches and the clinic, the church medicines or African traditional medicines are very strong and make it hard for the HIV medication to work very well. We do talk to them about taking treatment and the danger of beliefs, sometimes you can convince them, but you will not convince them at the same time, its take time (CHW P6).

> We find that they are taking traditional medicines, the reason being that they think they will get healed, so because they do not believe that it is HIV, they believe that they can be healed from whatever they are suffering because they believe that this is what they got from other people. So, they have been told that they are sleeping at night with people and with animals and these animals are the ones that are giving them this kind of diseases, they tell them that they can heal from the disease, that's why some they more concentrated in the traditional medicine, at the church they just say it's bad spirits (CHW P1).

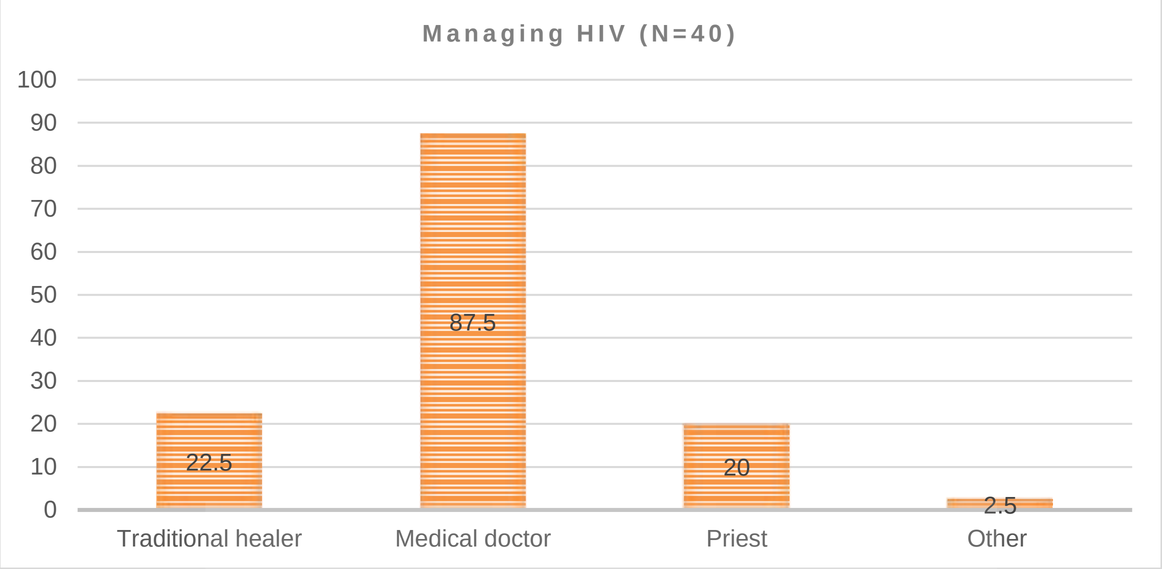
The CHWs believe that mothers fail to adhere to HIV treatment they have opted for alternative medicines. They believe that the mothers are using church or African traditional medicines to treat HIV. In the first excerpt, the CHW explains how during tracking and tracing of mothers they experience challenges of initiating the mothers back into the ART programmes. They find the mothers use alternative medicines and ask to finish the medication course before they can return to the clinics for treatment. Mothers are perceived to be using traditional medicines because they are helpful and believe that HIV is witchcraft. The second excerpt emphasises the use of multiple health systems (medical pluralism) to treat HIV. Yet, the mothers are not sure of which system to follow or whether they can use both health systems. The excerpt shows that the CHWs do not support the use of alternative medication, especially the church and African traditional medicines as they believe that these medicines are strong and that they reduce the effectiveness of Western HIV medication. The CHW also explains how difficult it is and take time to convince mothers to adhere only to Western HIV treatment.

Though the CHWs believe that HIV positive mothers are LTFU because they use the church or traditional medicine as an alternative to treat and manage HIV, most of the mothers in the case and control group were not using church or traditional medicines. The mothers in this study tended to believe in the healthcare workers (nurses and doctors) and Western medicine (ARVs), to treat HIV. This is confirmed by a mother who is LTFU: *"The doctors know better about the life of a person."* Other mothers with similar responses that support the use of medical doctors and nurses' services to treat HIV have this to say:

> I only use HIV medications, it is the only treatment that I use to treat HIV, doctors can give pills that I am supposed to take to get better, alternative medicines are not good for treating the virus (LTFU P14, age 23).
>
> I pray but I use ARVs to treat HIV, as instructed, the nurses and doctors can manage HIV because they were able to treat me well and give me treatment (LTFU P8, age 26).

The mothers were aware of the importance of HIV treatment and trust the doctors and nurses to provide effective treatment for HIV. The nurses and lay counsellors in the quantitative approach believe that patients trust medical doctors/nurses (87.5%) to manage HIV, followed by traditional healers (22.5%), priests (20%) and others (2.5%). The findings show that healthcare workers think clients trust medical doctors/nurses to better manage HIV (see figure 4.1).

Figure 4. 1: Healthcare workers` perceptions on whom mothers trust to manage HIV better



The findings from the case-control approach with HIV positive mothers support the claims of the CHWs that HIV positive mothers use multiple health systems to treat HIV. One of the mothers from the control group use both doctors and African traditional healers to treat HIV and believes that traditional medicine works. This is what she said:

> I used doctors because their treatment regime does not end, they don’t run out of treatment. Traditional healers give us medication to drink, and they work so that you can have power so that we can have strength, they work the same way as Western medicines (CIC P4, age 31).

The mother, therefore, uses both traditional and Western medicines, the mother claims that traditional medicines work and that they assist with strength or power. Medicine pluralism is used widely used as a way to tackle the impact of HIV.

Lack of food to take with the HIV medication: Poverty is widespread in South Africa. This results in many having no money to afford basic needs like food to eat. Food is important for any patient as they are advised to take medication before or after eating. Patients follow these instructions and often lack food to take the medications. For instance, an unemployed mother failed to adhere to the medication towards the end of every month due to lack of food to take with the medication:

> I cannot take the medication without food, every month at end of the month, I ran out of food, so I do not take my medication because I do not have food. I could go two days without taking my medication because there is no food at home. Sometimes I ask my neighbour if they can just give me a little so that I can cook porridge at least, and they help sometimes (CIC M10, age 23).

The findings show that poverty or lack of food is one of the barriers to treatment adherence. The excerpt shows a mother who collects her medication every month but fails to adhere to her medication when she runs out of food to take the medication with. Every month the mother runs out of food, and she is under the impression that the HIV medication can only be taken with food. This shows that not all the mothers in the control group (mothers who were not LTFU and adhere to their clinic appointment and collect their medication) adhere to HIV treatment according to the instructions from the healthcare workers. Also, the CHWs confirm that the mothers struggle with money to buy food to take with the medication. The mothers believe that the medication is only taken with food. One of the CHWs has this to say:

> Yes, most of the patients did not take treatment but some of them live in poverty. They find that the grant money is not enough for them to buy food but most of them are taking treatment but those who are not taking treatment do not have food and cannot take medication without food (CHW P7).
>
> Some struggle to take their medication and say that they cannot take medication if they do not have food, they cannot take the medication if they have not eaten (CHW P1).

The CHWs believe that mothers fail to adhere to treatment because they lack food, and they cannot take their medication if they have not eaten. The first excerpt implies that the mother lacks the money to buy food even with the assistance of social grants from the government.

4.3.5. Health system barriers

This theme addresses the health care system barriers that influence LTFU and non-adherence. The themes discuss long waiting periods at the health facilities and poor treatment from healthcare workers and medication runs-out. These sub-themes are discussed in detail below.

Long waiting periods at the health facilities: The finding from CHWs shows that long waiting hours led to LTFU of HIV positive mothers. The mothers in the case group show that long waiting hours at the clinics are the reason they are LTFU. The CHWs believe HIV positive mothers are not satisfied with the waiting periods at the clinic. This is confirmed by a CHW who said: *"Some say that when they go to the clinic they wait for long, that they find long queues and end up going back home"* (CHW P10). The other CHWs with a similar response had this to say:

> They are afraid of the long waiting hours, you find that when they come to the clinic they wait for a long time before they can be attended to, the reason for not coming to the clinic they are not telling us (CHW P1).
>
> Some are not satisfied because they are saying that they wait for long, we tell them about the adherence club where they will not wait for long, so I encourage them that if they're taking medication well for at least a year and their viral load is low they can join adherence club, it helps them because there are no queues. There are long waiting hours at the clinic because the clinic gets full because it supports many people in the community and surrounding villages (CHW P3).

The excerpts show that the CHWs believe that HIV positive are LTFU because of the long waiting hour before they receive HIV treatment. The CHWs imply that the health facilities experience long waiting hours because of the influx of people attending to the health of their families in the community. They further highlight the importance of adherence clubs as a tool to curb the issue of long waiting periods at the clinics and suggest the idea that the mothers should join adherence clubs because there are not as long queues or long waiting hours. Though the CHWs believe that long waiting hours is the reason why HIV positive mothers are LTFU, none of the mothers in the case group (LTFU) reported long waiting periods as the reason they are LTFU. Still, the mothers in both the case and control group have experienced long waiting hours at their respective health facilities. This is confirmed by the mothers who said:

> Sometimes they take long, the maternity section is slow sometimes I do not know why but sometimes they are faster (LTFU P8, age 26).
>
> I am not satisfied, the first time I came to the clinic here I came at 7 am in the morning and I left at 5 pm in the afternoon (LTFU P5, age 31).

Waiting to receive treatment can be frustrating sometimes because most public health clinics struggle with an increasing number of patients. The excerpt above shows how the mothers are frustrated by the waiting periods, especially when they are one of the earliest to arrive at the clinics: The long waiting hours at the healthcare facilities can influence mothers to be LTFU. This is confirmed by a mother who said: *“What will make me not go to the clinic is when I go to the clinic for help and do not get help but so far, they are helpful here.”* The excerpt shows that the mother will not return to the health facilities where services are either delayed or she leaves the health facility without receiving services.

Poor treatment from healthcare workers and medication runs-out: Negative treatment from the healthcare workers impact negatively on HIV treatment adherence and the success of the PMTCT programmes. There are sub-themes that have already addressed the poor attitude, communications, and lack of support from the healthcare workers at the health facilities. This sub-theme addresses the behaviour of healthcare workers that displayed poor treatment of HIV positive mothers, that directly led to LTFU and non-adherence to HIV treatment. Some of the mothers decided to leave the clinic when the nurses treated them poorly. In particular, mothers complained that the nurses were not confidential about their HIV status in the public spaces of the health facility. This is what the mother said:

> I was not treated well by the nurses, so, after being treated badly by the healthcare workers I did not feel the need to come back. When I come to collect treatment here, they always remind me of the pills, so this was bothering me, they were telling me I am sick, it felt like I am the only one who is sick. The last time I was here the person who was helping us was going to a meeting. I was the first one, she took my file and say she was in a hurry and told us (those who are sick) to go that way in front of other people, I did not feel comfortable with what she did (LTFU M14, age 23).
>
> Nurses have an attitude, I always come here every month when I bring my baby to look for my baby's HIV test results, but I do not get them. They do not treat me well and even when I come looking for the treatment, they yell at me (LTFU M3, age 27).

The above quotes show that the mothers felt badly treated by the healthcare workers. The mother in the first quote complained about a lack of confidentiality regarding her HIV status. The second quote shows a mother who was not impressed with the attitudes of the nurses. She claims that the nurses yelled at her when enquiring about her baby's HIV results. In the third quote, the mother was LTFU because she was not sure whether the healthcare worker will assist her considering that they threatened her badly the last time she was at the health facility. Additionally, a mother in the control group believes that mothers who are LTFU are recipients of negative treatment from the clinic staff, the mother further emphasises that when she would leave the clinic the health personnel treated her poorly. This is what she said:

> Maybe they are not treated well here, I do not know, if they don't treat me well, I will go somewhere where they will treat me well. I will go to another clinic with my baby (CIC P8, age 21).

There are mothers received poor treatment and support from the healthcare workers when the medication runs out at the health facilities. In the PMTCT programme, it is important for mothers to collect their medication every month and for the medication to be available at the health facilities. Sometimes mothers run out of medication and sometimes it happens that the health facilities experience shortages of medication supply. This results in the issue where HIV patients interrupt treatment schedules. Another example is of a mother who previously admitted having been LTFU by self-transferring to another clinic expresses her anger related to lack of medication every time she attends her appointments and that the healthcare workers shouted at her when she shared her grievance:

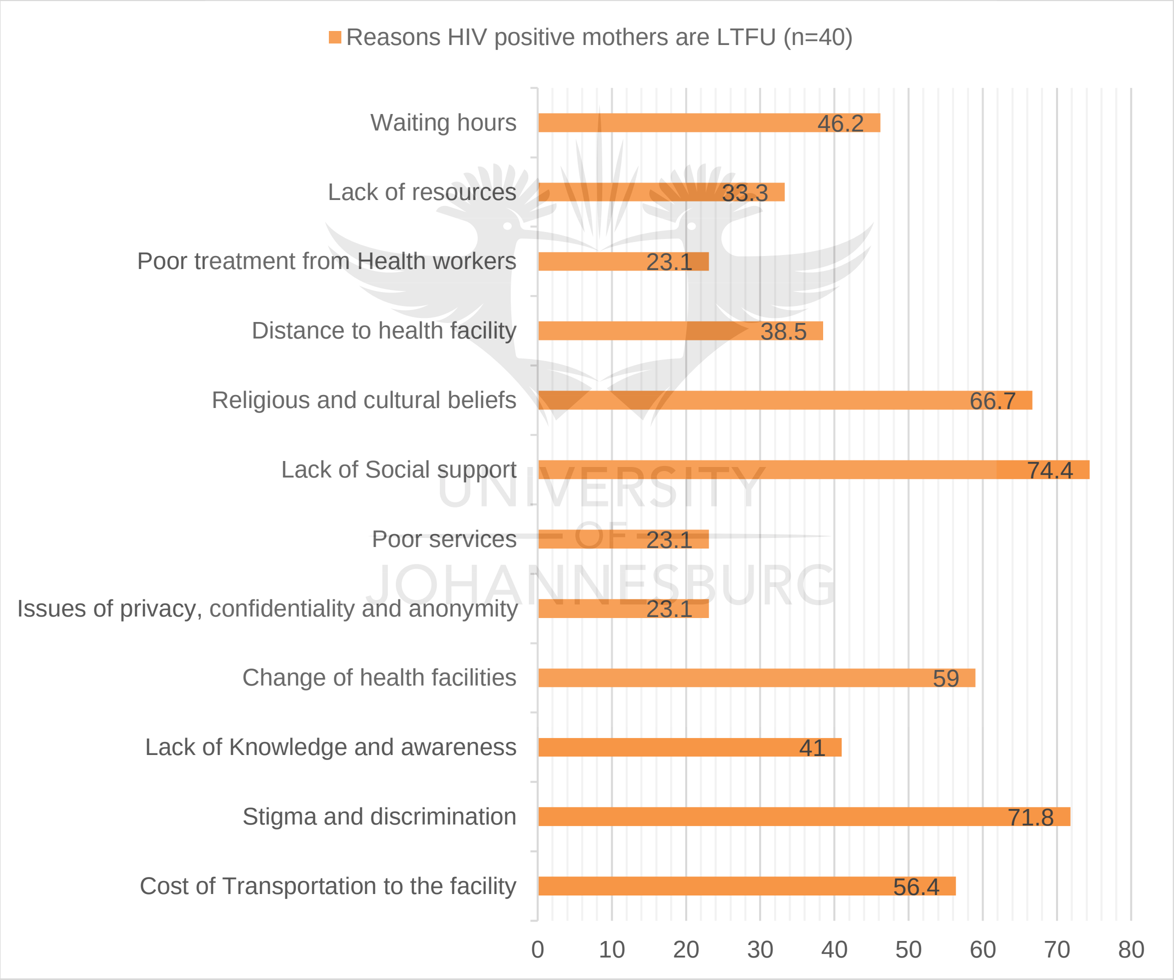
> This year I did not take them, I took four months not to take them. I was angry and did not want to go to the clinic anymore because of the way they treated me when I go there to collect treatment, they say that the pills are not available, and I did not have other pills when I came back to the clinic and explained that. They gave me a date to come but they told me there are no pills, they shouted at me telling me that I do not want to take treatment (LTFU P5, age 27).
>
> I always come here, and they say they do not have medication and they don't explain why *(*LTFU P4, age 34)

The mother in the control group shows that HIV positive mothers who are LTFU experience poor treatment from the healthcare workers. The mother emphasises that she will transfer to another health facility if she experiences the poor treatment of the healthcare workers. This poor treatment from the healthcare workers influences service use. The last excerpt shows that the mother attended her clinic appointments but experienced poor treatment from healthcare workers and shortages of medication at the health facilities. The problem is not only the shortages of the medication but also the poor treatment from the healthcare workers.

Findings from the nurses and lay counsellors: The quantitative findings reveal the perceptions of the nurses and lay counsellors regarding the reasons why HIV positive mothers are LTFU (see figure 4.2 below). The findings show that most of the nurses and lay counsellors believe that lack of social support (74.4%) is the reason HIV positive mothers are LTFU. This is followed by stigma and discrimination (71.8%), religious beliefs (66.7%), cost of transportation (56.4%), change of health facility (59%), waiting hours (46. 2%), lack of knowledge and awareness (41%), the distance of health facility (38.5%), lack of resources (33.3%), poor services (23.1%) and issues of privacy, confidentiality, and anonymity (23.1%).

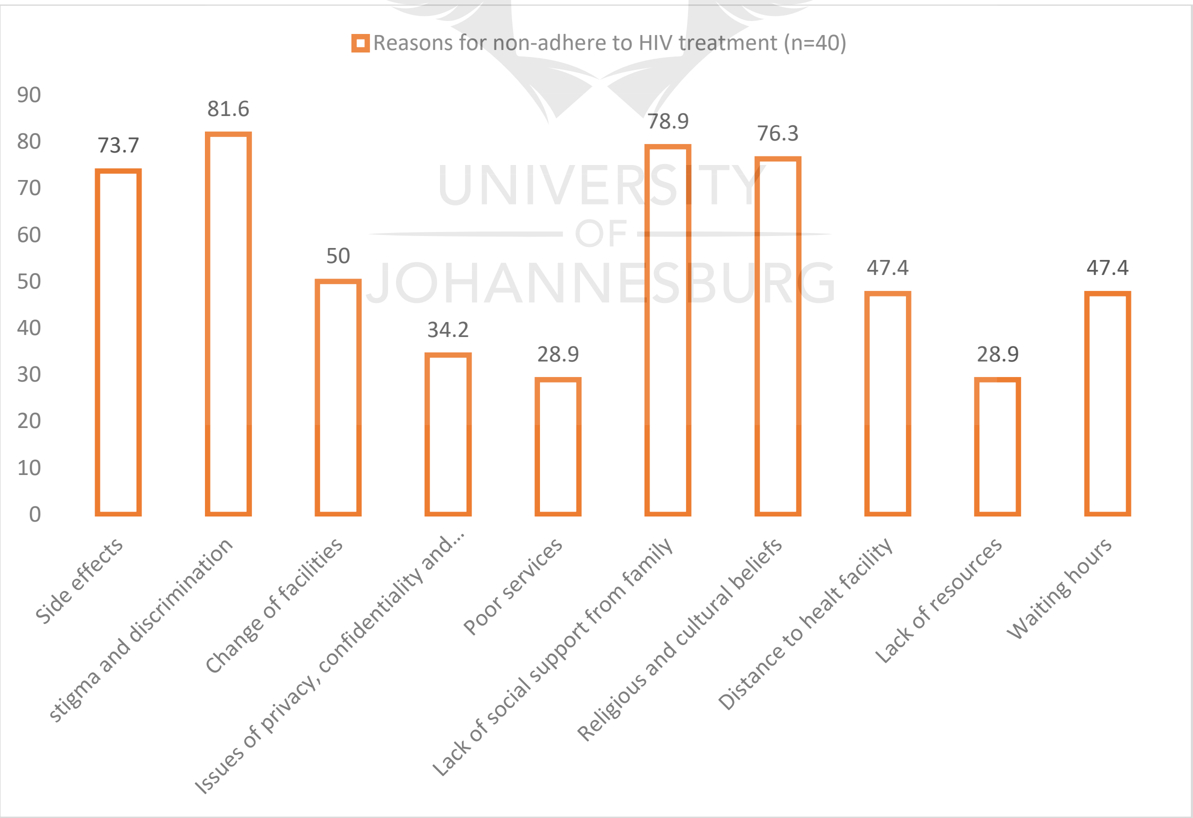
The findings show that the nurses and lay counsellors think lack of social support is the reason HIV positive mothers are LTFU, followed by stigma and discrimination. The findings with HIV positive mothers show fear of disclosure to their sexual partners and family. The fear of negative reactions from partners or family exposes the issue of social support and fear of stigma and discrimination. The finding from mothers also presents a lack of support from the healthcare workers on how to cope with the medication and support regarding flexible appointments. The nurses and lay counsellors also indicated religious beliefs, cost of transportation, change of health facility, waiting hours, the distance of health facility, lack of resources, poor services, issues of privacy, confidentiality and anonymity, and the lack of knowledge and awareness which are similar findings from HIV positive mothers and CHWs.

Figure 4. 2: The reasons HIV positive mothers are LTFU



The nurses and lay counsellors were further asked to indicate the reasons HIV positive mothers fail to use or adhere to HIV treatments. In figure 4.3 below, most of the respondents (81.6%) show that the reason HIV positive mothers fail to adhere to HIV treatment is that they fear stigma and discrimination. This is followed by the lack of social support from the family (78.9 %), religious beliefs (76.3%), medication side effects, (73.7) and change of facility (50%). The other reasons that HIV positive mothers fail to use or adhere to HIV treatments are the distance of the health facility (47.4%), confidentiality and anonymity (34.2 %), lack of resources (28.9%), poor service (28.9%), and long waiting hours (4.5%). The findings show that healthcare workers think HIV positive mothers who fail to adhere to HIV medication fear stigma, discrimination, and lack of support from family. The findings of the mothers have not mentioned the experiences of stigma and discrimination as a reason they failed to adhere to treatment. However, the mothers have confirmed that they fear disclosing their HIV status to partners/family/community members. Similar to the findings from HIV positive mothers and CHWs, the nurses and lay counsellors indicated religious beliefs, cost of transportation, change of health facility, waiting hours, the distance of health facility, lack of resources, poor services, issues of privacy, confidentiality and anonymity, and lack of knowledge and awareness.

Figure 4. 3: Healthcare workers’ perceptions of the reasons why HIV positive mothers fail to adhere to HIV medication.



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4.4. Chapter Conclusion

The chapter presented complementary findings of HIV positive mothers and healthcare workers (CHWs, nurses, and lay counsellors). This chapter presented the underlying reasons of LTFU that are rooted in the family and gender dynamics of HIV disclosure. The findings presented the reasons for LTFU and non-adherence to HIV medication from mothers who were LTFU and mothers who were not LTFU. Though the majority of the mothers who were not LTFU and were adhering well to their HIV treatment, others experienced challenges with adherence. The majority of the mothers who were LTFU had stopped their HIV treatment by the time of the study and provided the reasons which influenced their decisions not to come back to their respective health facilities. Hence, the mothers provided details into their experiences of adhering to the HIV medication, exposing other factors that contributed to their non-adherence to treatment.

The findings demonstrated that not every mother who was LTFU has stopped attending health facilities as some self-transferred to other health facilities. Though, not every mother who self-transferred to other health facilities was adhering to treatment. Some mothers decided to self-transfer to other health facilities closer to home while others self-transferred due to poor health systems. Other mothers experienced negative attitudes or poor treatment from healthcare workers when they used PMTCT services, while other mothers feared the side effects from the HIV medication or delay the start of ART. The healthcare workers (nurses and lay counsellors) believed that a lack of social support is the main reason HIV positive mothers were LTFU. The CHWs added that mothers were not satisfied with the waiting periods at the clinic. The nurses and lay counsellors believe that HIV positive mothers who failed to adhere to HIV medication fear stigma and discrimination. The next chapter addresses the associated barriers of LTFU and non-adherence to HIV medication. The chapter also revisits themes on gender dynamics of HIV disclosure, religious organisations, mothers' guilt and self-blame and health systems barriers to address the associated factors and barriers that influence service utilisation from all the mothers in each group. The chapter incorporates experiences of all the mothers even those who were not LTFU to explore social patterns on non-adherence to HIV treatment and LTFU.

CHAPTER 5

THE ASSOCIATED BARRIERS OF LTFU AND NON-ADHERENCE TO HIV TREATMENT

5.1. Introduction

The previous chapter presented the findings on the reasons why HIV positive mothers are LTFU and why the mothers failed to adhere to HIV treatment. This chapter presents the factors that are associated with LTFU and treatment non-adherence or the barriers that influence the use of PMTCT services. The chapter addresses the following objective of the study:

- To determine accompanying intrapersonal (knowledge and beliefs) and interpersonal factors (gender and family dynamics) of treatment non-adherences and LTFU of HIV positive mothers.
- To explore community, systems, and the organisational barriers associated with LTFU and treatment non-adherences in the PMTCT programmes.

This chapter consists of five themes that address the barriers that are associated with LTFU and HIV medication non-adherence. The following are the main themes of discussion: mothers' knowledge awareness and attitude, information access, sharing and networks, motherhood and infant feeding patterns, gender dynamics, stigma and discrimination, health care systems, and community barriers. This chapter complements the findings from the previous chapter to understand the barriers that played a role in non-adherence to treatment and clinic appointments. Similar to the previous chapter, the findings are drawn from the thematic analysis of qualitative and quantitative data. The chapter incorporates the findings of HIV positive mothers with the findings of CHWs, nurses, and lay counsellors. The findings are presented concurrently with selected excerpts that reflect the participants' general views on the issues related to non-adherence to treatment and LTFU in the PMTCT programmes. Below is a detailed presentation of the findings.

5.1. Knowledge, Awareness, and Attitude

This theme presents a discussion of the knowledge, awareness, and attitudes towards MTCT. Also, the theme presents healthcare workers' knowledge and training on PMTCT activities, and mothers' attitudes towards PMTCT services. Below is the detailed presentation of these sub-themes.

5.1.1. Dearth of knowledge about MTCT

MTCT during pregnancy: The findings show that the mothers in the case and control group did not always know that a mother can transmit HIV to her child during pregnancy. One of the mothers in the control group confirms this: *"I don't know, I am not sure, is it when I am not attending clinic appointments early?"* (CIC P3, age 26). Another mother in the control group believes that MTCT does not occur during pregnancy but occurs during labour: *"It does not transmit according to me, it transmits during labour*" (CIC P19, age 23). Other mothers in the case group do not know how a mother can transmit HIV during pregnancy. Yet, they were aware of HIV treatment as a prevention measure. This is confirmed by a mother who said: *"I will infect my baby if I am not taking my medication, I don't know the process, it is the way they explain to us when we come here"* (LTFU P1, age 18). Yet another with a similar response said: *"If a mother doesn't take her medication, there is a certain medication that a mother is given during pregnancy, I don't know the process, I just know how it prevented"* (LTFU P10, age 27). The excerpts show that the mothers are not aware that they can transmit HIV to their babies during pregnancy, they failed to explain how MTCT occur during this stage. Some mothers have extrapolated that a mother could transmit HIV to her child if she is not using HIV treatment. Though the mothers failed to explain the process of MTCT during pregnancy they are aware of MTCT preventive measures. In addition, the findings show that the CHWs lack the knowledge or understanding of how the virus is transmitted to the baby from the mother during pregnancy. This is confirmed by the CHWs who said:

> It can be transmitted because they are not using condoms, I don't know the process of how the virus gets into their baby during pregnancy (CHW P7).
>
> It can transmit to the baby, I do not know how it can transmit to the baby but when mothers are not taking treatment, we tell them to take it while pregnant or they can transmit the virus to their baby (CHW P6).

> No, it cannot be transmitted, the baby is inside the mother's stomach when the mother is pregnant, the baby is protected inside the mother's stomach, so the baby it is safe. Where the baby it is not safe it is during labour when the mother is delivering the baby but at the hospital, but they will give the baby nevirapine during labour (CHW P5).

The CHWs need to understand how MTCT occurs because they must share the information or knowledge with mothers who are LTFU or those [mothers] who are not adhering to the HIV treatment. The extracts show that the CHWs lack knowledge and awareness on how HIV transmits from a mother to her baby during pregnancy. One of the CHW maintained that MTCT cannot happen during pregnancy and believed that the baby is protected inside the mother during pregnancy. In the second extract, though the CHW does not know the process of MTCT during pregnancy, she was aware of the importance of treatment during pregnancy to prevent MTCT.

MTCT during labour/delivery: The findings show that most of the mothers were not aware that a mother can transmit HIV to her baby during labour/delivery. A mother who was LTFU said *"I don't know if it can be transmitted"* (LTFU P7, age 29), and this is supported by a mother who asked: *"During delivery? I do not know"* (LTFU P8, age 26). Similarly, the mothers in the control group were not aware that a mother can transmit HIV to her baby during her labour/delivery. This is supported by a mother who was not sure if it is possible at this stage: "*I heard that is possible, but I am not sure"* (CIC P20, age 31). One of the mothers in the case group was aware that a mother can transmit HIV during delivery if the mother forgets to take her medication. This is what she said:

> It is possible that the baby can be infected with HIV but when you deliver or in labour, it depends on whether you took your treatment or not, sometimes it happens that I forget to take treatment, HIV can transmit to my baby, so it depends on how you take treatment and what time (LTFU P6, age 33).

The excerpts show that the mothers from both the case and control group lack awareness and knowledge about MTCT during labour. The mother who was aware of MTCT at this stage emphasises the importance of taking treatment at the right time to prevent MTCT. In addition, the findings show that the CHWs were aware that HIV can be transmitted from a mother to her child during delivery or labour and that it can be transmitted through blood contamination. One of the CHWs had this to say: *"You find that the baby can be crying or just opened its mouth if the mother was not taking* *treatment the blood will get in through the mouth and infect the baby"* (CHW P5). The CHWs were aware that a mother can transmit HIV to her child during labour or delivery. The CHWs were aware that the mothers can risk MTCT through blood contamination, and they were aware of the importance of HIV treatment in reducing the risk of MTCT during labour/delivery.

MTCT during breastfeeding: According to the health promoters, breastfeeding is important for the development of a baby and exclusive breastfeeding is an important HIV prevention measure for mothers in the PMTCT programmes. HIV positive mothers can exclusively breastfeed their babies as long as they are on treatment (UNAIDS 2017; WHO 2020). The findings in this study show that the mothers in both the case and control groups were aware that a mother can transmit HIV to her baby during breastfeeding. Nonetheless, they failed to explain how a mother transmits the virus to her baby during this phase. This was confirmed by the mothers who were LTFU:

> When I am breastfeeding and not taking treatment, doesn't breastmilk come from me? And I am positive. I am not sure whether breastmilk has HIV or what, but where will the child get the virus? So, when I am not taking the treatment I will infect the baby, they [healthcare workers] instructed me that when I am not taking treatment, I will infect my baby and even the baby gets treatment. Why do they give the baby HIV treatment/medication? (LTFU P6, age 33)
>
> I think it can transmit to the baby but how? I do not know. HIV is transmitted during sexual intercourse and through blood, but I do not know how it's transmitted to the baby (LTFU P5, age 31).
>
> It does not transmit because I am breastfeeding, when you come from the hospital and they checked, they helped so that I do not infect my baby (LTFU P7, age 29).

The first and second quotes show that the mothers were aware that a mother can transmit HIV to her baby during breastfeeding and emphasise the importance of HIV treatment as a prevention measure. However, they failed to explain the process of MTCT during this stage. The last excerpt shows that the mother is not knowledgeable about MTCT preventions after birth and the mother believes that HIV does not transmit to her baby during breastfeeding. She argues that this is because the healthcare workers undertook some prevention measures against MTCT at this stage.

Comparably, the mothers in the control group could not clearly explain the virus transmission to the baby during breastfeeding. The mothers in both the case and control groups believe that breastmilk does not have HIV. One of the mothers believes that MTCT takes place through blood contamination and not through breastmilk. This is what she said: *“A baby is infected when there is a cut during breastfeeding, breastmilk does not have HIV”* (CIC P16, age 29). Other mothers with similar responses had this to say:

> No, the child cannot get infected through breastmilk, breastmilk does not have the virus. If the CD4 count is right and I am taking treatment, I think MTCT occurs through a cut or bleeding (CIC P15, age 37).
>
> Breastmilk does not have the virus, the virus gets transmitted when the child starts to bite, and it can be transmitted through blood (CIC P14, age 32).

Mothers understand the importance of taking treatment while breastfeeding to prevent MTCT. Yet, they do not believe that breastmilk can be a carrier of HIV. The mother believes that the mode of HIV transition during breastfeeding is through blood contamination when the mother’s breast has a cut or a scratch. Additionally, the findings show that the CHWs were aware that HIV can be transmitted from a mother to her child during breastfeeding through blood contamination, through a mother’s breast if the baby bites or scratches. This is confirmed by a CHW who said:

> During breastfeeding when their baby is given breast milk, they bite the mother’s breast and when the breast bleeds and you find that the baby has pimples or have a scratch in the mouth the virus can be transmitted through the blood (CHW P6).

Besides, the CHWs believe that HIV positive mothers are not knowledgeable about MTCT. This is confirmed by a participant who said:

> No, they do not know because if they know, they will know immediately when they get pregnant that they have to come to the clinic, when we trace them, they say ‘no they didn’t know so we give them health talks (MCHW 6).
>
> They do not have the knowledge they have to be educated because they’re not doing things according to the instructions, they’re not following the instructions well, they’re not taking treatment (MCHW 4).

The CHWs believe that the HIV positive mothers lack knowledge of MTCT, that they are not following the instructions to prevent MTCT. This implies that if the mothers were knowledgeable about the risk of MTCT they would follow instructions from the healthcare workers – to prevent MTCT.

The nurses and lay counsellors were also assessed on their knowledge about MTCT. Table 5.1 below shows that 92.5% (n=37) of the respondents had knowledge that

MTCT can occur during labour and only 7.5% (n=3) lacked knowledge that MTCT can occur during labour. Most of the respondents 90% (n=36) also showed knowledge that a mother can transmit HIV to her baby during breastfeeding while 10% (n=4) of the respondents disagreed with this assertion. The respondents were aware of the different stages that a woman can transmit HIV to her baby. The findings show a concerning number of healthcare workers who were not knowledgeable of MTCT during pregnancy, labour, and breastfeeding.

Table 5. 1: Healthcare worker'` knowledge about MTCT

Variables	**Category**	**F(N)**	**%**	**Total (N)**	**Total (%)**
During pregnancy	Yes	36	90	40	100
	No	4	10	40	100
During Labour	Yes	37	92.5	40	100
	No	3	7.5	40	100
During Breastfeeding	Yes	36	90	40	100
	No	4	10	40	100

5.1.2. Healthcare workers' knowledge and training on PMTCT activities

In this sub-theme, HIV positive mothers provided their perceptions regarding the knowledge of health care personnel in the PMTCT programmes. The findings show that HIV positive mothers believe that health care personnel were knowledgeable about PMTCT activities. This was confirmed by a mother who was LTFU:

> Yes, sometimes when we come here in the morning there are those [healthcare workers] that come and educate us about HIV, how to prevent it, and if I am pregnant how we can get help (LTFU P8, age 26).

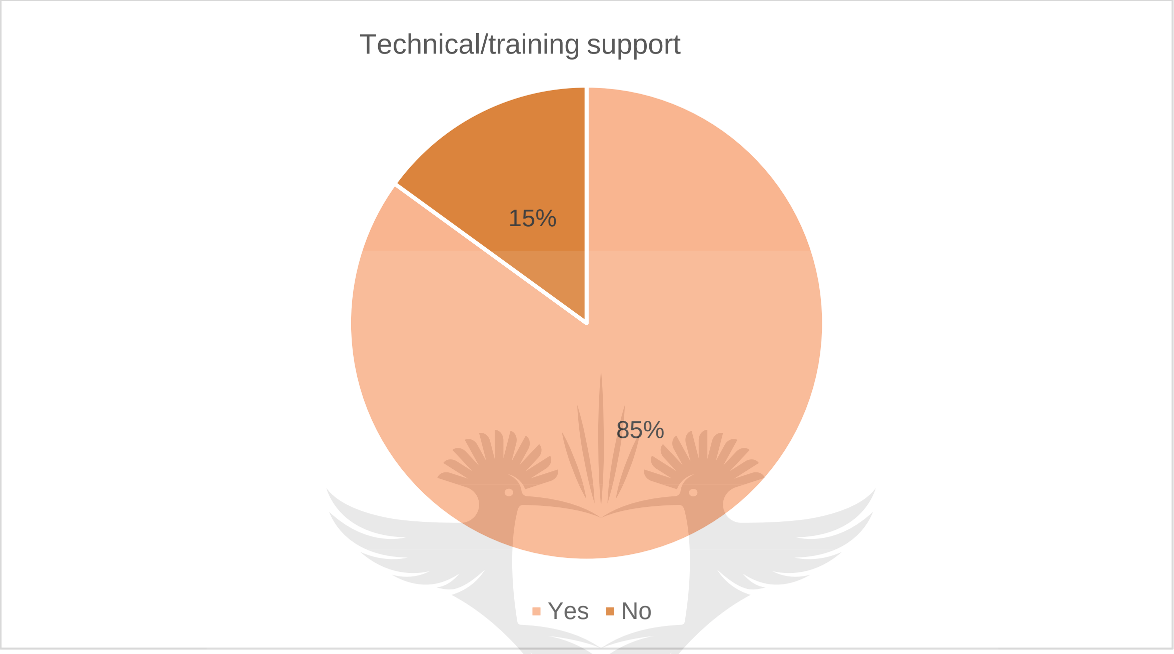
The mothers who are currently in care say that health care personnel are knowledgeable as *“they provide health talk regarding PMTCT activities”* (CIC P20, age 31). It is important to educate patients about the use of treatment, patients who are not well counselled are at risk of not adhering to the treatment and LTFU. Even so, one of the mothers complained about the lack of counselling on how to prevent MTCT: *“I don’t know, they have never explained to me (when I take treatment) how it helps me not to transmit the virus to my baby”* (LTFU P5, age 31). Though most of the mothers in the case-control study were satisfied that the healthcare workers were knowledgeable about MTCT and other PMTCT activities, some mothers felt that the HIV counselling from healthcare workers was insufficient or lacked details. In addition, the findings with the CHWs shows that the CHWs need more training on PMTCT activities.

Though this theme provided perceptions from HIV positive mothers regarding healthcare workers` training and knowledge about PMTCT activities, the CHWs added their experiences regarding their training on PMTCT activities and the knowledge they acquired on the PMTCT activities. The CHWs expressed that they lack knowledge about MTCT and other PMTCT activities. This is confirmed by the CHWs who said:

> No, I want more information about how long a baby is supposed to be breastfed and how HIV can be transmitted to the baby so that I can explain this information when I go to the households, so that when they asked me a question, I am able to answer (CHW P4).
>
> I understand a little, I know a little so we need more training about it [PMTCT], about what is HIV and how it can be infectious (CHW P2).
>
> Not well enough but they do explain to us, but we do not understand, for me, I do not understand it, I need more training on it [PMTCT], about how HIV is transmitted during pregnancy because sometimes we have to explain to the patients about getting tested, we need that information. (CHW P3)

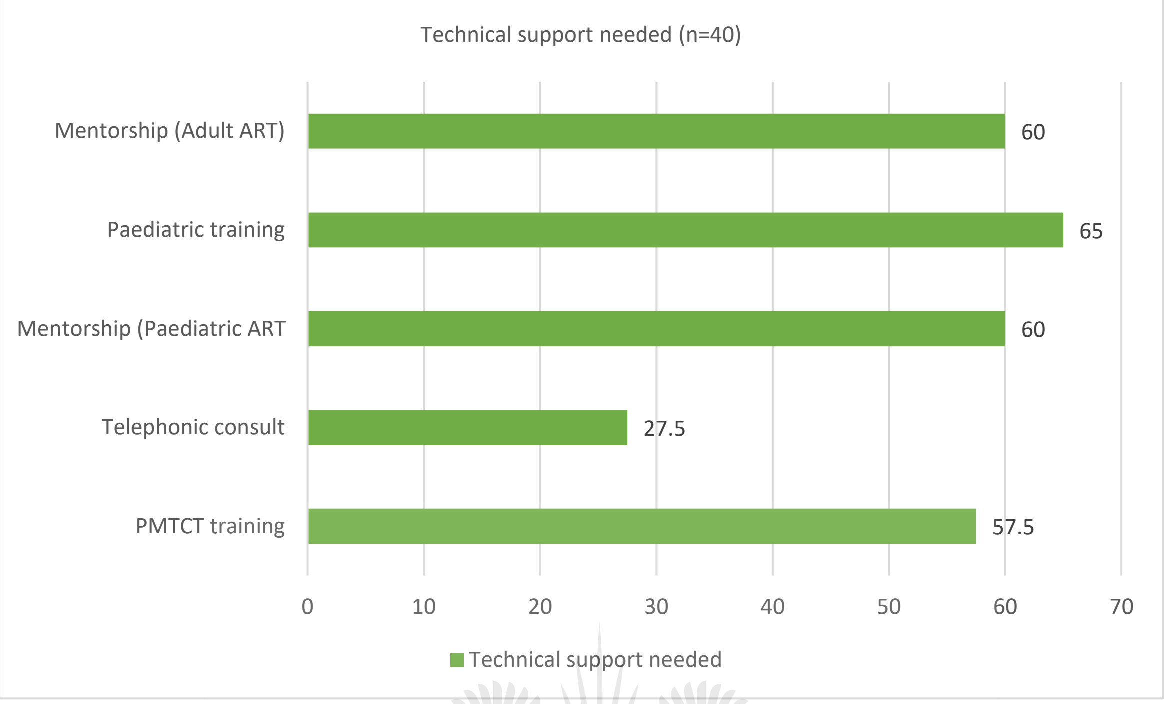
The CHWs need more information on how a baby is infected during pregnancy and information on what HIV is and the process of MTCT. They need information on feeding recommendations and emphasise that the information will be helpful to them and the mothers during household visits or counselling processes. The third quote shows that the CHW received training on the PMTCT activities. Consequently, However, she did not understand and needed more training about MTCT during pregnancy. Moreover, the nurses and lay counsellors were asked if they need any specific training. Most of the respondents (85%) need technical/training support, only 15% of the respondents do not need technical/training support (see figure 5.1). The findings show that most healthcare workers need technical/training support. More training on MTCT

Figure 5. 1: Healthcare workers in need of training/workshop on PMTCT activities



As well as the 85% of respondents who indicated that they needed training support on MTCT, the findings show that the main areas of technical support or training needed are paediatric training/workshops (65%), mentorship on adult ART (60%), mentorship on Paediatric ART (60%), PMTCT training (57.5%), and telephonic consults (27.5%). The findings show that nurses and lay counsellors felt they need paediatric training the most (see figure 5.2 below).

Figure 5. 2: The training/workshop that healthcare workers need



The nurses and lay counsellors were further asked to demonstrate how much other nurses and lay counsellors know about PMTCT activities. Table 5.2 below shows that most of the respondents 38 (97.4%) felt that their colleagues in the PMTCT programmes were knowledgeable on how to deal with non-adherence to ART by HIV positive mothers and their babies. In contrast, only 2.6% of the respondents disagree. Most of the respondents show that their colleagues were knowledgeable about how to deal with LTFU of HIV positive mothers.

The table further shows that other health care personnel know enough about PMTCT follow-up activities (77.5%) as only 22.5% of the respondents do not agree that other health care personnel (nurses and lay counsellors) at their facilities know enough about PMTCT follow-up activities. The findings show that the respondents' feel their colleagues are knowledgeable about PMTCT activities and how to deal with LTFU of HIV positive mothers and non-adherence to treatment. Similarly, the findings show the healthcare workers feel that their colleagues (other nurses and lay counsellors) were knowledgeable enough regarding PMTCT follow-up activities.

Table 5. 2: Healthcare workers perceptions on their colleagues` knowledge of PMTCT activities

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Other health care personnel knowledge about PMTCT follow-up activities	Yes	31	77.5	40	100
	No	9	22.5	40	100
Colleagues' knowledge on how to deal with non-adherences of ART by HIV positive mothers and their babies	Yes	38	97.4	39	100
	No	1	2.6	39	100
Colleagues' knowledge on how to deal with loss to follow-up of HIV positive mothers and their babies	Yes	39	100	39	100
	No	-	-	39	100

5.1.3. Mothers' attitudes towards PMTCT post-natal services

The PMTCT post-natal services are important in reducing the spread of HIV. In this study, the mothers in both the cases and control groups were aware that PMTCT post-natal services are important in reducing the spread of HIV. They were able to express how the service assisted their babies. This is confirmed by some of the mothers who said:

> Yes, it is important because children are vulnerable to diseases, they can be infected, so by bringing my baby here for treatment after giving birth I can know my child's status (LTFU P8, age 26).

The excerpt shows that mothers were aware of the importance of PMTCT programmes, in helping their babies. Their attitude towards the programmes is motivated by the ability of the programmes to protect their babies against diseases. The CHWs were asked if HIV positive mothers see the need to use PMTCT post-natal services and adhere to HIV treatment. The findings show that CHWs believe that HIV positive mothers understand the importance of HIV treatment. This is supported by a CHW who said*:*

> Yes, they see the importance but maybe they struggle because when the baby's growing and they take them to the clinic, we ask for the baby's card and we check their cards, maybe it is because of that (CHW P3).

The CHW implies that mothers understand the importance of the PMTCT programmes but worry about the confidentiality of their baby at the clinic as they are required to provide identification cards, the mothers show concern about their HIV status and that of their babies.

The quantitative findings show that the nurses and lay counsellors think that HIV positive mothers understand the importance of PMTCT follow-up services (n=39) and only one respondent disagrees. Table 5.3 below shows that most of the respondents 95% (n=38) indicates that HIV positive mothers have faith in the PMTCT post-natal services. All the respondents 97.5% (n=40) show think HIV positive mothers believe that the PMTCT services are important in reducing the spread of HIV. The findings show that the nurses and lay counsellors think HIV positive mothers understand the need to use PMTCT follow-up services and understand the importance of bringing babies for PMTCT post-natal follow-up visits. HIV positive mothers have faith in PMTCT post-natal services and believe that PMTCT services are important in reducing the spread of HIV.

Table 5. 3: Healthcare workers' perceptions on mothers' attitude towards PMTCT services

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
HIV positive mothers' need for PMTCT services	Yes	39	97.5	40	100
	No	1	2.5	40	100
HIV positive mothers believe that PMTCT post-natal follow-up visits are important	Yes	39	97.5	40	100
	No	1	2.5	40	100
Faith in PMTCT post-natal services	Yes	38	95	40	100
	No	2	5	40	100
HIV positive mothers believe that PMTCT services reduce the spread of HIV	Yes	40	100	40	100
	No	0	0	40	100

5.2. Information Access, Sharing, and Networks

The previous theme presented the knowledge and awareness of MTCT. So, this theme presents the discussions on how HIV positive mothers access information and how the information is shared throughout the different health systems. Such as churches, African traditional organisations and healthcare systems. The sub-themes are discussed in detail below.

5.2.1. Churches and African traditional organisations as referrals

The church leaders and traditional healers often advise HIV patients that a prayer or traditional or church medicines can cure HIV (Zou et al. 2009). The previous chapter mentioned the use of church and African traditional medicines as the reason HIV positive mothers delay the use of western HIV medications or delays in initiating ART. In this chapter, the themes highlight the influence of church and African traditional organisations survive use. These themes highlight the roles of the religious organisations as promoters and referrals in the PMTCT cascade. The mothers in both the case and control groups were not affected or influenced by their religious or traditional beliefs and felt that they are supported and are advised to use HIV treatment and follow instructions from the healthcare workers. The mothers had this to say:

> They just discuss all chronic diseases, I go to ZCC, so they never discourage anyone. There is a time in the Church where there are programmes or awareness regarding chronic diseases because our Bishop discovered that most churchgoers stop taking their treatment the moment, they know they are HIV (LTFU P10, age 27).
>
> I am a Zion Christian Church member, they always tell us to not leave medication behind and when we go to church, they are supportive (CIC P3, age 26).

The mothers in the case and control group show that the religious organisations remind people living with HIV about the treatment, adherence and compliance. The HIV positive mothers were not affected or negatively influenced by religious organisations. The religious organisations were able to refer HIV positive mothers to utilise PMTCT services to prevent MTCT and educate mothers not to stop the treatment.

5.2.2. Safety of using church or traditional medicines

Traditional methods are often exposed as unreliable and even dangerous (Peltzer et al. 2008). The use of traditional medicines as HIV treatment is not safe according to various studies (Varga & Brooks 2008). The beliefs can be very dangerous when HIV patients continue to use only the traditional healthcare methods than the Western methods (Frizelle, Solomon, & Rau 2009). Most of the mothers (from both the case and control groups) in this study were not using traditional medicines as HIV treatment. The mothers maintain that traditional healers are unqualified to treat HIV. This is confirmed by the mothers who said:

> I have never taken it, they told me when taking the treatment, I should not take traditional medicines because they will affect the ARVs' performance (LTFU P5, age 31).
>
> I do not use traditional medicines; they are very strong, and they told us ARVs do not need strong medicines. If traditional medicines worked many people would have been cured by now, I do not trust them to cure HIV. For in the church, I drink only church tea and it is not strong, but it does not treat HIV (LTFU P8, age 26).

One of the mothers believes that traditional medicines are very strong and could affect the patient's HIV treatment process negatively. The mothers do not believe in the use of traditional medicines as HIV treatment and question their use. They do not trust traditional medicines as a treatment for HIV and believe that they do not work.

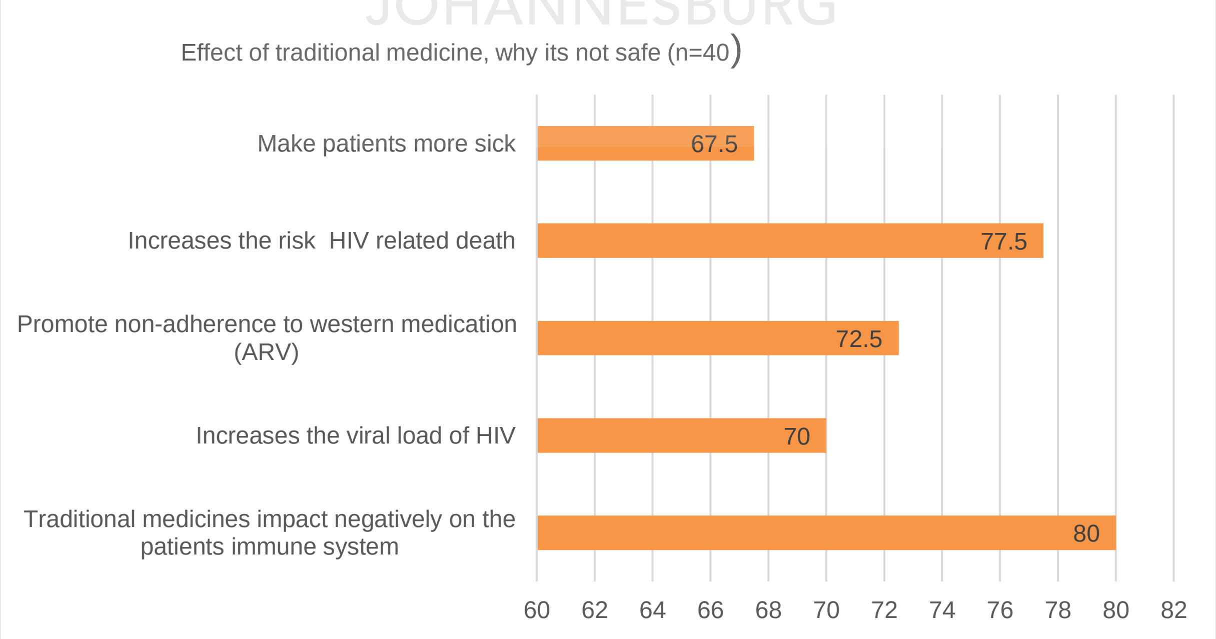
In table 5.4, most of the nurses and lay counsellors in the quantitative study show that 37 (92.5%) believe that it is not safe for HIV positive mothers to use traditional medicines over Western HIV medicines (ARVs). However, three respondents (7.5%) claimed that it is safe. The respondents were further asked if clients who follow religious or cultural beliefs adhere to the Western HIV treatment provided by healthcare workers. The majority of the respondents 22 (55%) show that clients adhere to the Western HIV treatment provided by healthcare workers even when following religious beliefs (see table 5.4). The majority of the nurses and lay counsellors believe that HIV positive mothers who follow religious medicines adhere to the Western HIV treatment provided by healthcare workers.

Table 5. 4: Healthcare workers' views on the issue of using traditional medicines

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
If it is safe for HIV positive mothers to use traditional medicines	Yes	3	7.5	40	100
	No	37	92.5	40	100
HIV positive mothers' use of church/African traditional medicines	Yes	22	55	40	100
	No	18	45	40	100

The respondents who believe that traditional medicines are not safe were asked to indicate why they believe that they are not safe for HIV positive mothers. In figure 5.3 below, the majority of the respondents claimed that traditional medicines impact negatively on the patient humane system (80%), increase the risk of HIV-related deaths (77.5%), promote non-adherence to ARVs, increase the viral load of HIV (70%), and make patients sicker (67.5%). The findings show that nurses and lay counsellors believe that it is not safe for HIV positive mothers to use traditional medicines and disregard ARVs and that traditional medicines impact negatively on the patient immune system.

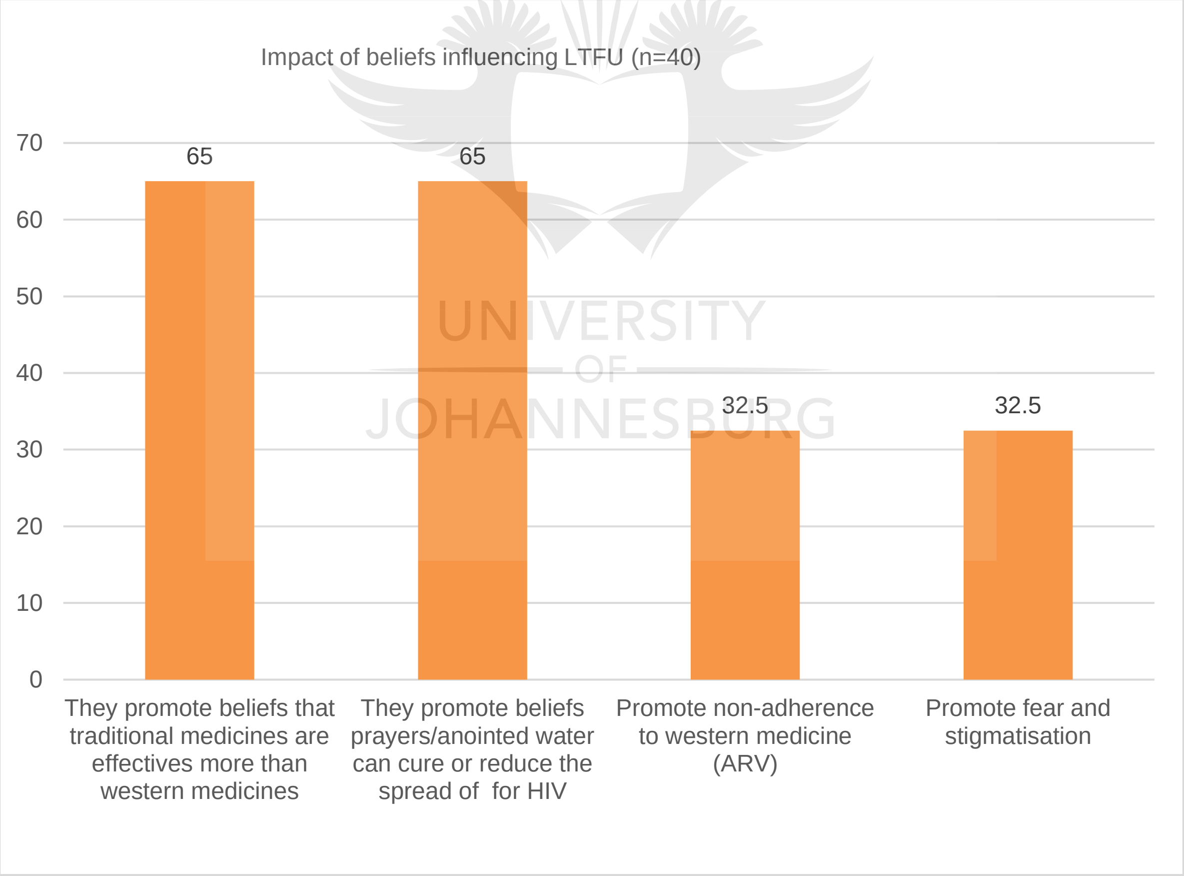
Figure 5. 3: Perceptions of nurses and lay counsellors regarding the effect of traditional medicine, why it is not safe to use



5.2.3. Healthcare workers' views on what religious beliefs promote

The nurses and lay counsellors were asked to indicate whether they think religious beliefs are harmful or beneficial. Most of the respondents (65%) indicated that religious organisations promote the belief that traditional medicines are more effective than Western medicines. Similarly, 65% of the healthcare workers believed that prayers/anointed water can cure or reduce the spread of HIV (see figure 5.9). The chart further shows that religious beliefs promote fear of stigma (32.5%), and 32.2% of the respondents show that religious beliefs promote non-adherence to Western medicine ARVs (see figure 5.4). The findings show that nurses and lay counsellors believe that one's beliefs promote that prayers/anointed water can cure or reduce the spread of HIV, as well as beliefs that traditional medicines are more effective than Western medicines.

Figure 5. 4: Healthcare workers' view on what churches/African traditional beliefs promote



5.3. Motherhood and Infant Feeding patterns

This theme presents discussions on motherhood practices that shape the behaviours of mothers in the PMTCT programmes. The theme covers motherhood protectiveness of their infants' health and mothers' guilt, regrets, and self-blame. This theme also presents mothers' infant feeding patterns and explores the practices, knowledge, awareness, attitude, and information networks regarding infant feeding. These are further discussed below.

5.3.1. Motherhood protectiveness

When HIV positive mothers are LTFU it impacts negatively on infants/babies who are exposed to HIV. Every health facility that provides PMTCT services includes PCR testing, paediatric ART, and other immunisation treatments for HIV exposed and infected infants/babies. The health facility provides scheduled appointments for mothers or caregivers to bring their babies. The findings show maternal protectiveness of infants and how this affects women's experiences of mothering in the PMTCT post-natal phase. The mothers in the case and control groups prioritized their infants` health and adherence by bringing their babies to the clinic for HIV treatment. This is what they said:

> My baby was coming to the clinic and has never missed an appointment because I want to get him the treatment, I started post-natal early (LTFU M8, age 26).
>
> I have not missed a chance to bring my baby for clinic appointments and I will never miss an appointment. I will come even when it is raining, you can even check that I have not. (LTFU M7, age 30).
>
> I do not want my baby to miss the HIV treatment and if I am at work, I will find someone to bring my baby for me (CIC M4, age 31).

The mothers in both the case and control groups were very protective of their infant/baby's adherence to clinic appointments and treatment. They answered the question with confidence that their babies were adhering to schedule clinic appointments. They see the benefits to bring their babies for clinic appointments as an important measure to protect their infants against other illnesses or diseases. They are supported by their family members. The third excerpt shows the mother does not want her babies to miss appointments and rely on the assistance of other people to take their babies to the clinic when they are unable to do so themselves.

5.3.2. Mothers' guilt, regrets, and self-blame

Mothers commonly blamed themselves for infecting their children. They expressed guilt over delaying or being hesitant to use ART. In the previous chapter, I have mentioned that the mother experienced guilt of not disclosing their HIV status. In this chapter, the sub-themes address the guilt and self-blame of not initiating ART early, which led their babies been HIV infected through MTCT. In the case of infants who were HIV positive, their mothers experienced the guilt of failing to protect their babies from HIV through MTCT, they blame themselves. This is what they said:

> They told me to take the pills in time when it is 8 pm, they told me about the side effects that they will take a few weeks but for me, they took a month. That is why I stopped taking them, but if the side effects come back again this time, I will continue taking the pills, I will stay put. I have made a big mistake that I will never repeat in my life, my baby is positive now, I blame myself for this. At that time, I did not know how HIV can be transmitted to the baby but now I know because they explained it to me (LTFU M8 age 26).

> The thought of my baby taking the pills while still so young, even when I take the pills and I do not feel well, I can't blame anyone for my baby being positive, I am the one at fault. I am the one at fault for not coming to the clinic early, I came here when I was six months pregnant and then they found that my baby was HIV positive. They asked why I did not come early to the clinic, and I told them that I was not aware that I was HIV positive, after the birth they confirmed that my baby is HIV positive and was placed on ART. I didn't know that I was HIV positive if I knew I would come to the clinic earlier (CIC P7, age 30).

The mothers' self-blame for infecting their babies with HIV propelled them to commit to the PMTCT programmes in the future. The negative situation where the babies were infected with HIV filled the mothers with regrets and they maintain that they will not repeat the same mistake in the future (as above in the quote). The quote emphasises that it is important for pregnant women to test for HIV early and for HIV positive mothers to bring their infants early in the PMTCT for HIV treatments. The delays of bringing infants to the health facility risk MTCT. The mother in the second excerpt blames herself for not attending PMTCT appointments at an earlier point of her pregnancy. The mother delayed treatment during her pregnancy and now blames herself for not acting sooner. These excerpts further expose the mother's knowledge and awareness about the risk of MTCT at an earlier stage of pregnancy and the importance of early initiation of ART.

5.3.3. Mothers’ infant feeding patterns

In this section, the mothers were asked to explain their infant feeding patterns. The case-control approach shows most of the mothers in the control group were following exclusive breastfeeding as a recommended feeding method by the healthcare workers. This is confirmed by a mother who was following instructions from the healthcare workers to exclusively breastfeed her infant:

> The doctor told me to not give the baby food and water and only breastfeed, that breastmilk has water in it (CIC M16, age 29).

Though most of the mothers in the case group were mixed feeding, that includes a few of the mothers in the control group. Their feeding patterns include breastfeeding, formula feeding, water or/and solid food such as porridge and purity. These patterns were influenced by the desire to help the baby’s growth or to follow traditional feeding patterns or unavailability due to school and work responsibilities. This includes moments like “the babies do not get enough breastmilk and get hungry or thirsty and cries” and some added that their *“breasts do not produce enough milk”* and opt for alternative feeding methods. A mother from the control group has this to say:

> I am mix feeding so that he can grow, he was crying so much though he was not getting enough food (CIC M14, age 32).

Another mother in the control group gives her baby water when he is thirsty: *“I am mix feeding, sometimes I give my baby water because he gets thirsty”* (CIC M4, age 31). A similar response was expressed by a participant who said: *“When I am not around, they can give my baby formula milk”* (CIC M12, age 22). In the case group, the mothers who provided similar responses said:

> I breastfed for a month so I saw that if I stopped breastfeeding him before the time comes it will be hard for him, so I gave him a bottle (formula milk). I started giving him formula milk when he was three weeks, I do not remember how long I breastfed him. I started breastfeeding him at first, he has now stopped, and he is now using formula milk. I was also giving him water and porridge; they say he must drink water. I give him food because he gets hungry but not a lot, at the clinic they told me to give him food after six months but the reason I am giving him food now is that he is problematic at home and they [at home] say I must give him food. The reason for mix feeding is that I don't want him to suffer because he was going to stop before time. At the hospital, after I gave birth, I asked if it is possible to breastfeed and formula feed and they told me to choose one method, so because I was going to school and when I go - he will have to take formula milk (LTFU M14, age 23).

> I started mixing at first for two months with breastmilk and formula milk because I was not producing enough breastmilk and the child was not getting full and cries a lot, at the Clinic they explained how I should feed my baby, when I came to the clinic they immediately noticed that I'm mix feeding, when a child is mixing they notice by checking inside the child`s mouth and they asked me and I told them that I am mixing, I can afford the formula milk but now I'm breastfeeding my breast are now producing milk (LTFU P8, age 26).

> I am breastfeeding and use formula milk and solid food because, in my family, all the children have lived like this, we were raised by our grandmother. I gave my child formula milk when I went to school (LTFU P7, age 29).

The first excerpt shows a mother from the case group who understood the recommended feeding instructions but mixed to stop the baby from crying. The excerpt shows motherhood patterns where a mother mix feeds her baby to ensure her baby does not suffer. The excerpts also show the complexities involving daily activities or obligations that mothers encounter that often force them to ignore feeding instructions from the healthcare workers. Family members often pressure mothers to introduce solid food to ensure that the baby is well-fed. The mother faces pressure to mix feed their babies. One of the mothers had mixed feed her baby by following the way her grandmother raised her when she was a child, she mix-fed her baby with breastmilk, formula milk, and solid food. Following African traditional and other religious ways of feeding infants often goes against instructions from healthcare workers that a baby should exclusively breastfeed. The other mothers who were mix feeding complain about the challenges they experience with their breasts, that their breasts are painful and not producing breastmilk. This is what they said:

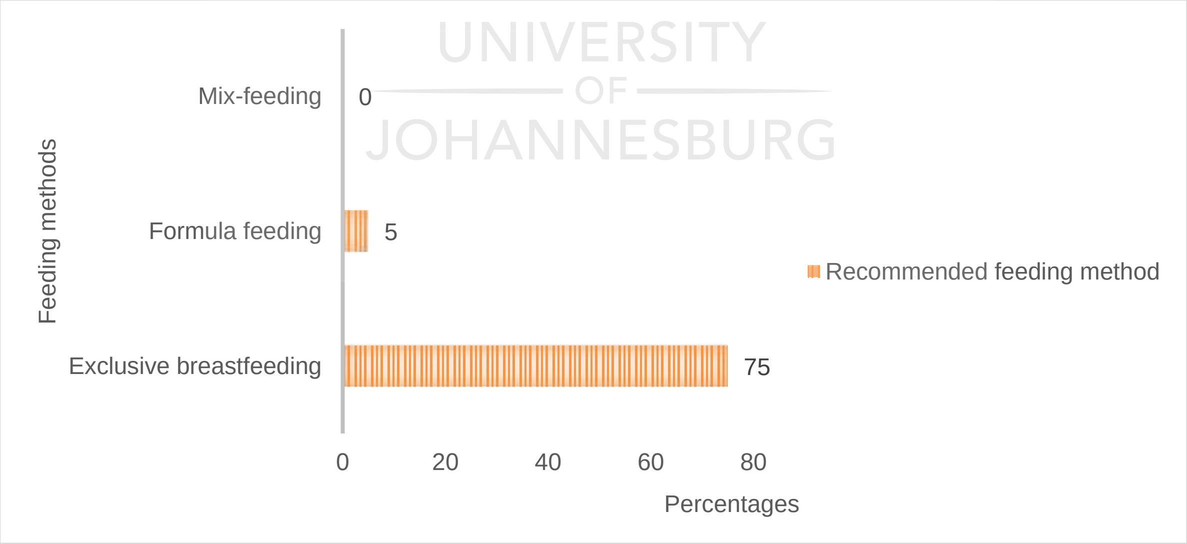
> I was giving my baby formula milk and water, the reason is that my breast had pimples and was painful, breastmilk was coming out but sometimes water comes out (LTFU P5, age 31).

The mothers experienced challenges and as a result, opted for alternatives and mix feed their baby. This highlights the complexities related to motherhood expectations and judgements. Mothers are faced with demands and expectations, there are many expectations for a mother to be responsible and ensure their babies are well fed and grow, and at the same time neglect the instructions from the healthcare workers to accommodate the need of their babies, to fulfil their role as mothers. Additionally, the CHWs were asked which feeding methods HIV positive mothers use to feed their infants: the findings show that the CHWs believe that HIV positive mothers mix feed their infants. One of the CHWs said:

> They are mix feeding, some give their babies porridge, some mixed breast milk and formula milk. We tell them that the baby has to be exclusively breastfed for six months, but most give them formula milk. The reason is that the baby bites them on their breasts when they breastfeed, they also cannot afford formula milk, you will find that they have to wait until they get money to buy formula milk. When the formula milk runs out, they will start to prepare formula milk with a lot of water but here we tell them they should breastfeed their babies for six months without any other food sources. Then after six months they can introduce other food, but we are not sure if they are following these instructions, we do not see them at home" (CHW P13).

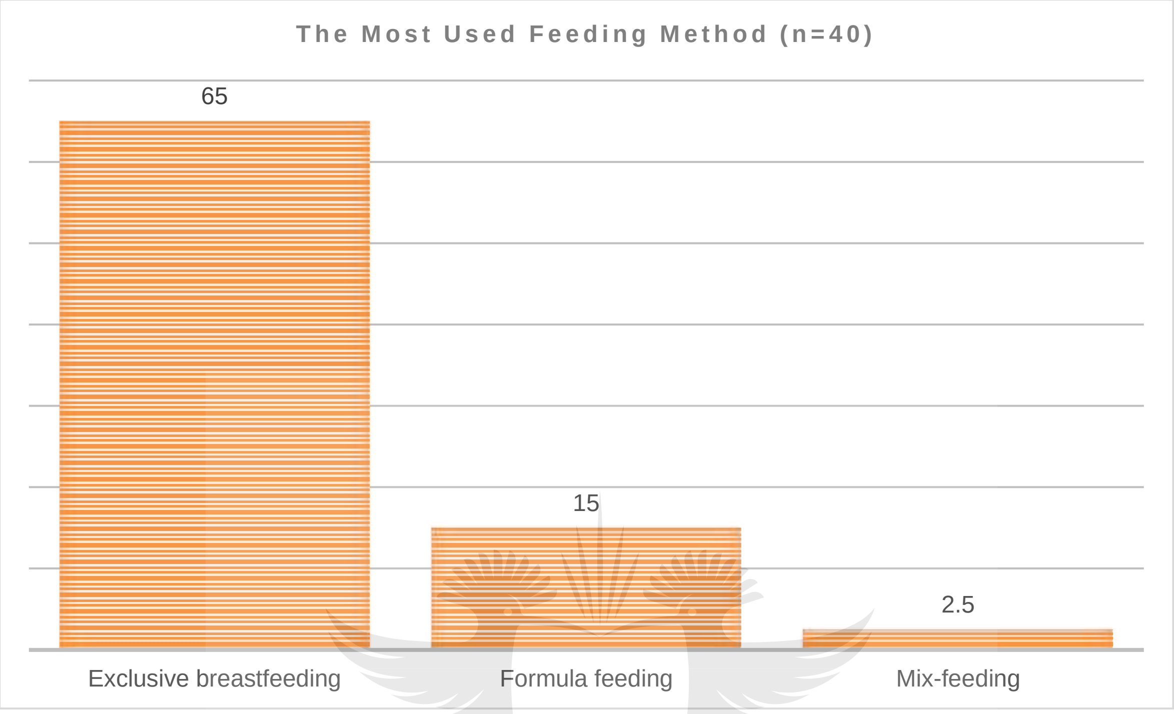
The CHW believe that the mothers are mix feeding their babies and they provide health talk for mothers to exclusively breastfeed for six months after birth. They believe that the mothers mix feed breastmilk with solid food and formula milk and that sometimes they do not follow the proper methods to prepare the formula milk. The extract shows that the CHWs struggle to monitor if mothers are following the recommended feeding methods at their homes. The nurses and lay counsellors were asked to indicate the feeding method that they recommend for mothers. Figure 5.5 below show that most of the respondents (75%) recommend exclusive breastfeeding for HIV positive mothers, followed by formula feeding (5%). The findings show that nurses and lay counsellors promote the use of exclusive breastfeeding for HIV positive mothers.

Figure 5. 5: Feeding methods recommended for HIV positive mothers by healthcare workers



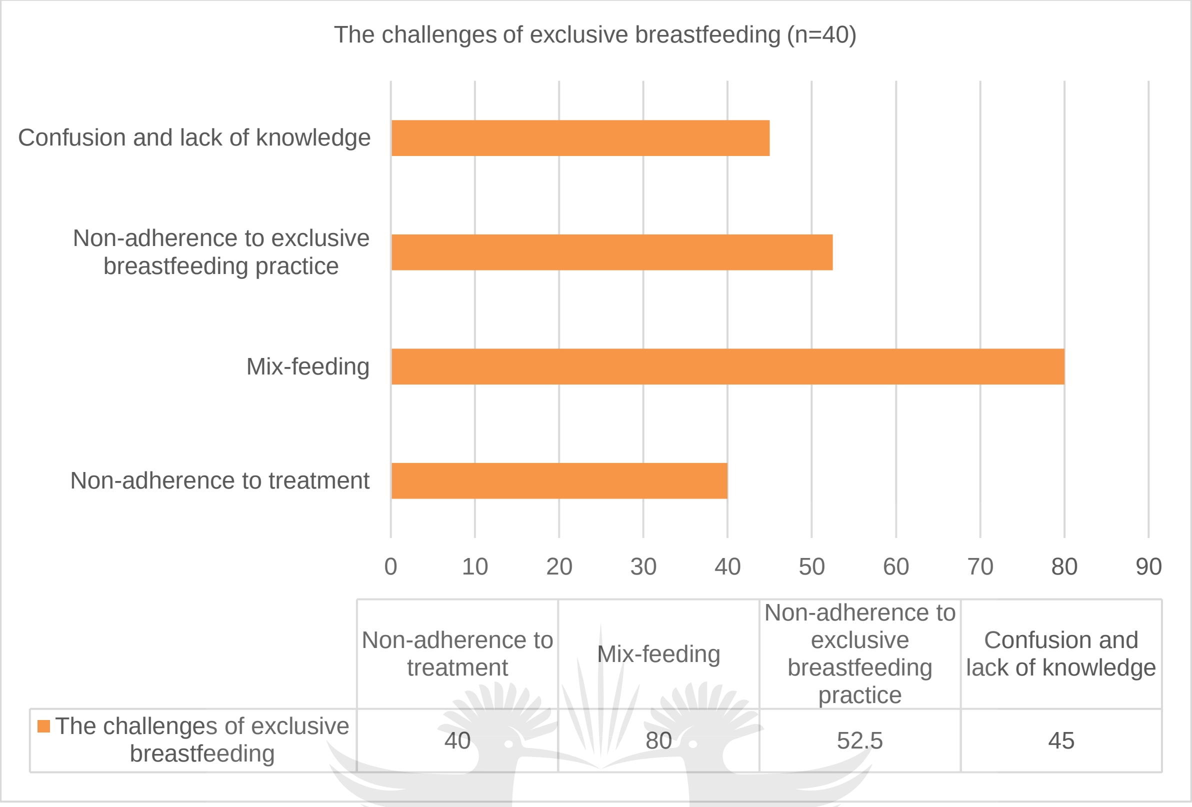
The nurses and lay counsellors were further asked to indicate which feeding method mothers mostly use. Figure 5.5 below shows that most of the respondents believe that HIV positive mothers use exclusive breastfeeding (65%), formula feeding (15%) and mix-feeding (2.5%). The findings show that the nurses and lay counsellors believe HIV positive mothers' practice exclusive breastfeeding.

Figure 5. 6: The feeding method most used by HIV positive mothers



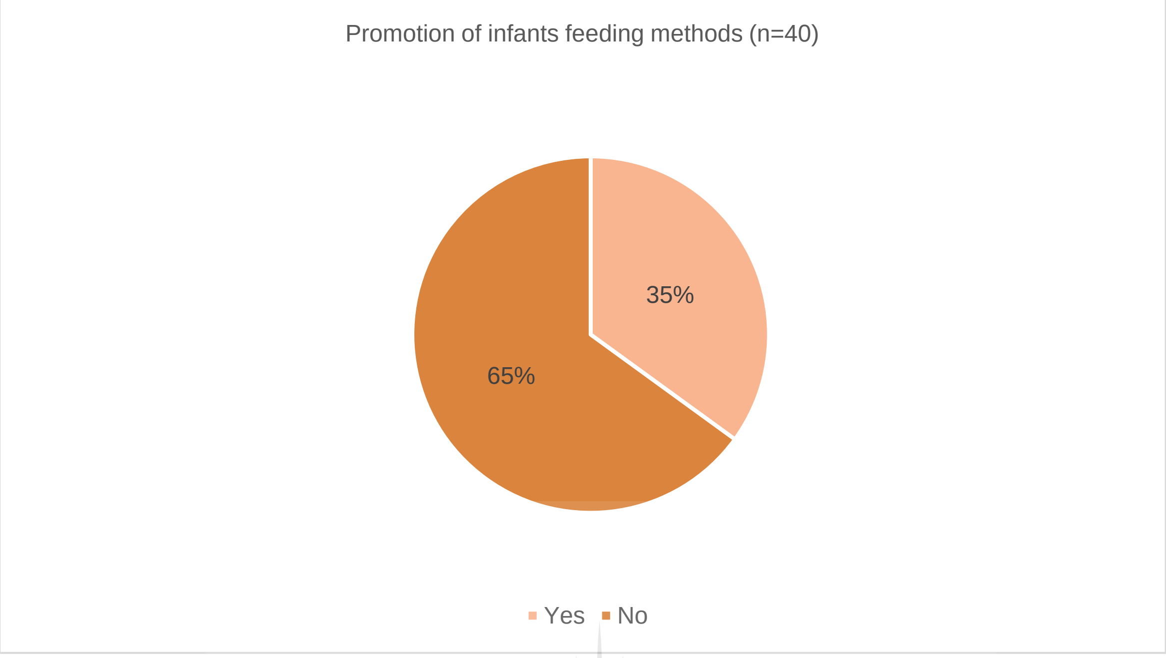
Furthermore, the nurses and lay counsellors were asked to indicate the challenges that mothers face when they practice exclusive breastfeeding. In figure 5.7 below, 80% of the respondents believe that mix-feeding is a challenge that HIV positive mothers face when they practice exclusive breastfeeding. This followed by non-adherence to the exclusive breastfeeding practice (52.5%), confusion and lack of knowledge (45%) and non-adherence to treatment (40%). The findings show that nurses and lay counsellors think the challenges HIV positive mothers face with exclusive breastfeeding practice is mix feeding.

Figure 5. 7: The challenges of exclusive breastfeeding



The respondents were asked if recommending the use of infant feeding methods at the health facilities is the reason HIV positive mothers are loss to follow-up. The majority of the respondents (65%) believed that endorsing the use of infant feeding methods such as exclusive breastfeeding and exclusive formula feeding is not the reason HIV positive mothers and their babies are LTFU. Nevertheless, 35% of the respondents felt that endorsing these methods influenced the loss to follow-up of HIV positive mothers (see figure 5.8). The findings show that nurses and lay counsellors think that endorsing the use of infant feeding methods such as exclusive breastfeeding and exclusive formula feeding is not the reason HIV positive mothers and their babies are LTFU.

Figure 5. 8: The influence of feeding instructions on LTFU of HIV positive mothers



5.3.4. Mothers' perceived meaning of breastfeeding

The mothers from the case and control groups express the importance of breastfeeding and that breastmilk is good for the baby's health and development. They view breastfeeding as a traditional mode of feeding. This is confirmed by a mother in the control group: *"So that the baby can be strong, breastmilk is good for baby's development"* (CIC P16, age 29). A mother in the case group supports this:

> It's not a problem if they are on treatment. Breastfeeding helps fight against diseases like infants' diseases. I only have a problem with this disease and not the other diseases (LTFU P15, age 27).

The mothers in the case and control group believed that it is important to breastfeed their babies and that breastmilk is important for the development of the babies. The excerpts from mothers in the case and control groups show that mothers believe breastfeeding is good for the health of their babies and emphasise the impact of breastmilk against other diseases. On the contrary, one of the mothers in the case group did not think it is right for HIV positive mothers to breastfeed their babies: *"I don't think is right, but I just see it happening"* (LTFU P7, age 29). Additionally, most CHWs believe that breastfeeding is important for HIV positive mothers and their HIV exposed infants. This is confirmed by a CHW who said: "*They must breastfeed because their breast milk is important"* (CHW P11). The finding shows that most CHWs believe that

HIV positive mothers should breastfeed their infants because breastfeeding is important for the development of the baby. However, one of the CHWs who is against the idea that HIV positive mothers should breastfeed their babies was worried that they risked MTCT.

> I do not want them to breastfeed their baby, in my understanding I don't support it because I'm worried that the baby will bite the breast and get infected through blood contamination, the baby will get infected (CHW P12).

The excerpt shows that not every person supports that HIV positive mothers should breastfeed their babies. As shown above, there is fear that the mothers' risk MTCT. Still, most CHWs believe that HIV positive mothers should breastfeed their babies.

5.3.5. Duration for exclusive breastfeeding and its meaning

The findings show that the participants in the case and control groups were able to indicate the duration for exclusive breastfeeding. They failed to provide the reasons for choosing the duration described though. This is confirmed by a mother who said:

> They say we breastfeed for six months and then should come back and get tested again to see if we can breastfeed or what, I do not know the reason for breastfeeding for six months (LTFU P14, age 23).

A mother with a similar response said this*: "I think they said three to six months, I don't know why I don't remember"* (LTFU P16, age 31). Likewise, the mothers in the control group were able to indicate the duration and commit to the instructions of exclusive breastfeeding their infants for six months but they were not clear on why they must exclusively breastfeed. This is confirmed by a mother who said: *"Is it six months? I think so I am not sure, I do not know"* (LTFU P5, age 31). Other mothers who were LTFU indicated the duration for breastfeeding but were not sure of their answer. This was supported by the mothers who said:

> It's for six months because after that the baby will have pimples in the mouth, when he starts having pimples if he bites me and I bleed he will be infected, is it six months? I think so, I am not sure, I do not know (LTFU P8, age 26).
>
> I am not sure, I decided to breastfeed my baby for seven months, I was using a breast pump to produce extra milk when he is not full enough, at the crèche they use to call me. I was not instructed by anyone; I have never received any instruction on how long to breastfeed my baby or any counselling regarding how long to breastfeed my child (LTFU P6, age 33).

The extracts above show that the mothers were not sure about the recommended duration to exclusively breastfeed their babies. A mother who decided to breastfeed for seven months explains that she breastfed her baby for seven months and she had never received counselling on how long to breastfeed her baby. The CHWs were asked what the duration for HIV positive mothers to breastfeed was. The findings show that the CHWs believe that HIV positive mothers should breastfeed exclusively for six months. This is supported by the CHWs who said:

> For six months, is when you are breastfeeding your baby without giving the baby any other food source. So, after six months the mother can breastfeed and give the baby other food (CHW P12).
>
> Exclusive breastfeeding for the baby for six months because food can damage the baby's stomach, the babies are not able to digest food, they are following instructions because most of them I see when they come to the clinic (CHW P11).

The CHWs were aware of the duration that the mothers are recommended to follow. They explain how mix feeding babies in the first six months affected their babies when they digested food.

5.4. Gender Dynamics, Stigma, and Discrimination

This theme presents the discussions on the experienced stigma or discrimination and gender inequalities that mothers faced when utilising the PMTCT programme. While the previous chapter only speaks about the mothers who were LTFU because of fear of HI disclosure, this theme incorporates experiences of all the mothers even those who were not LTFU but have not disclosed their status. The theme includes both the mothers from case and control groups to explore their disclosure patterns. This was to highlight importantly that other mothers have not involved their partners because of various factors like relationship break-ups or fear of intimate partner violence. The associated gender dynamics are that the mothers experience anger and relationship break-ups, lack of partner involvement, uncertainty if partners tested for HIV/AIDS, worries of intimate partner violence, and fears of negotiating for safer sex practices. These are further discussed below.

5.4.1. Anger and relationship break-ups

The findings show that some of the mothers who were unable to disclose their HIV status had already left the relationship and were raising their babies alone. The demographic information shows that most of the mothers in both the case group and control group were not married. These mothers were living with their family or extended family. The mothers who were married were living with their husbands in a single household, and mothers who were cohabitating were living with their sexual partner in a single household. Most mothers were never married and were not in a sexual relationship with their baby father because they have broken up and were single mothers. Single motherhood is common in South Africa, with 43% of mothers in South Africa been single mothers (Lippman et al. 2014). One of the mothers did not tell her partner because he left her while she was pregnant: *“My partner left when I fell pregnant, I have not told him my status since he left me”* (LTFU P17, age 23). The other mothers in the case group had this to say:

> No, the relationship was affected because he is not taking responsibility for his child (LTFU P6, age 33).
>
> We do not get along he is very difficult, the relationship is not good because of the things he says to me, we are no longer dating (LTFU P13, age 19).

The excerpts show that the mothers have been left with the responsibility to take care of their children and their partners are absent fathers. This broken relationship has resulted in mothers failing to disclose their HIV status to their partners. Furthermore, some of the mothers blame their partners for infecting them with HIV. The mothers had feelings of hurt and anger towards their partners, and this is the reason why they have not disclosed to their partners, they believe that their partners infected them with HIV: This is what the mothers said:

> No, I did not feel like telling him, he cheated on me, and I broke up with him a long time ago. I do not know if he knows or not, I don't have a partner right now but if I had a partner, I will think about telling him but I'm worried that if I tell him he will judge me and break up with me (CIC P8).
>
> I never invited him to come with me because we do not communicate anymore, I don't want anything to do with him. I have never given him a chance for him to confess, in my state right now I know I no longer communicate with him, I blame him (LTFU P18, age 32).
>
> He is the one who infected me, I blame him for infecting me because he knew his status and slept with me, it hurts me to think about it (LTFU P3, age 27).

The mothers project feeling anger and blame towards their partners for infecting them with HIV and for the infidelity. The first excerpt shows that the mother has not disclosed her HIV status to her partner because they have broken up because of the infidelity. The mother expresses fear of disclosing to her next partners, she fears that if she discloses to her next partner, he might be judgemental and break up with her.

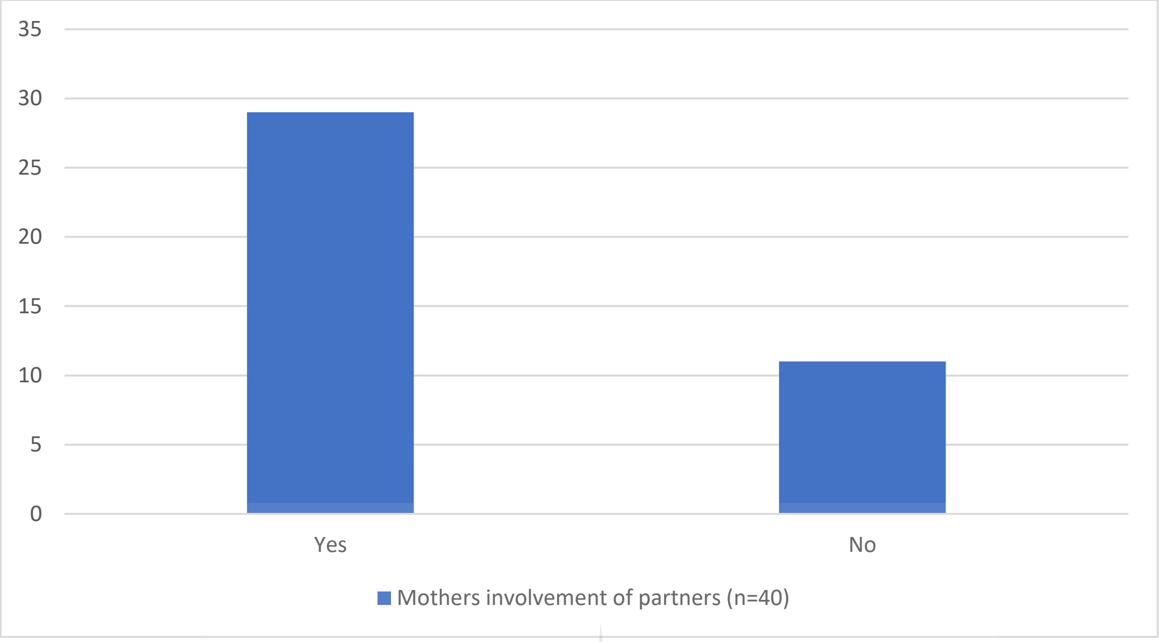
5.4.2. Involvement of partners: Unsure if partners tested for HIV/AIDS

Though most of the mothers are not in a relationship and have not disclosed HIV to their previous partners there those who disclosed. Though most of the mothers were never married and were living with either their family or extended family while other have broken up with their male or sexual partners or the father of their babies, there are mothers who were married or cohabitating or involved in non-marital intimate relationships and have disclosed their HIV status to their sexual partners. Most of these mothers from both the case, and control group have invited their partners for testing and counselling for HIV/AIDS, but they are not sure or do not know if their partners got tested. This is confirmed by mothers who said:

> Yes, but he did not come because of work, he says he doesn't have time. He is in denial, I cannot always remind him, I encourage him to come but I cannot always remind him about this. You know men want others to feel that they are men, I'm leaving it, as long as I am taking medication and using condoms (LTFU P15, age 27).
>
> I told the father of my child after birth, I asked him to come with me. He told me that he took his blood at work, so I asked him if he wouldn't like to know my status since we are dating and he said next time (LTFU P15, age 27).
>
> I told him, he refused saying he is not sick (LTFU P13, age 19).

The mothers disclosed their statuses to their partners, but the partners claim to have tested or delayed testing. The mothers who invited their partners for HIV testing and counselling claim that their partners delayed or refused to get tested for HIV. The nurses and lay counsellors were asked if mothers involve their partners in the PMTCT programmes. Most of the respondents 28 (70%) believe that HIV positive mothers involve their partners and 11 (27.5) believe that HIV positive mothers do not involve their partners (see figure 5.9). The findings show that nurses and lay counsellors believe that mothers involve their partners in participating in the PMTCT activities.

Figure 5. 9: Involvement partners for PMCT services from perceptions of nurses and lay counsellors



The nurses and lay counsellors were asked to indicate if they think mothers are supported by their partners and if gender inequalities influence LTFU and non-adherence to HIV treatment. Table 5.5 below shows that most of the respondents 30 (75%) believe HIV positive mothers are supported by their partners when utilising PMTCT services, 8 (20%) show that the mothers are not supported by their partners when utilising PMTCT services. The respondents were further asked if gender inequalities and lack of male involvement are the reasons HIV positive mothers are LTFU. Most of the respondents 22 (56.4%) show that nurses and lay counsellors believe gender inequalities and lack of male involvement are not the reasons HIV positive mothers are LTFU and only 17 (43.6%) believe they are the reason. The findings show that healthcare workers believe that gender inequalities and lack of male support are not the reason HIV positive mothers are LTFU, but other healthcare workers disagree. Most of the healthcare workers believe that HIV positive mothers are supported by their partners when utilising PMTCT services.

Table 5. 5: Healthcare workers views support by male partners in the PMTCT programme

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Gender inequalities and lack of male support are the reason HIV positive mothers are LTFU	Yes	17	43.6	40	100
	No	22	56.4	40	100
HIV positive mothers supported by their partners when utilising PMTCT services	Yes	32	75	40	100
	No	8	20	40	100

In Table 5.6 below, most of the mothers 39 (97.5) show that the health facilities provide male partners with HIV testing and counselling, only one (2.5%) disagrees. The respondents were asked if partners of HIV-positive mothers are counselled and tested for HIV. The results show that most of the respondents 35 (89.7) offered HIV counselling and testing for HIV-positive mothers and their male partners at the health facilities. The results further show that all the healthcare workers routinely ask clients to involve their partners 40 (100%). The findings show that there are HIV testing and counselling service that are available for male partners and that mothers are routinely asked to involve their partners. The partners of HIV- positive mothers get HIV counselling and testing.

Table 5. 6: Facilities support male partners

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Provision of male partners HIV testing and counselling	Yes	39	97.5	40	100
	No	1	2.5	40	100
Partners get counselled and tested for HIV	Yes	35	89.7	39	100
	No	4	10.3	39	100
Routinely requesting the involvement of partners	Yes	40	100	40	100
	No	0	0	40	100

5.4.3. Worries about intimate partner violence

Though most of the mothers were never married and were living with either their family or extended family, there are mothers who have broken up with their male or sexual partners or the father of their babies, and there are mothers who were married or cohabitating or involved in non-marital intimate relationships and have not disclosed their HIV status to their sexual partners. The findings show that there are mothers who were worried about violence from partners if they disclosed their status to their partners. This is confirmed by the mothers who said:

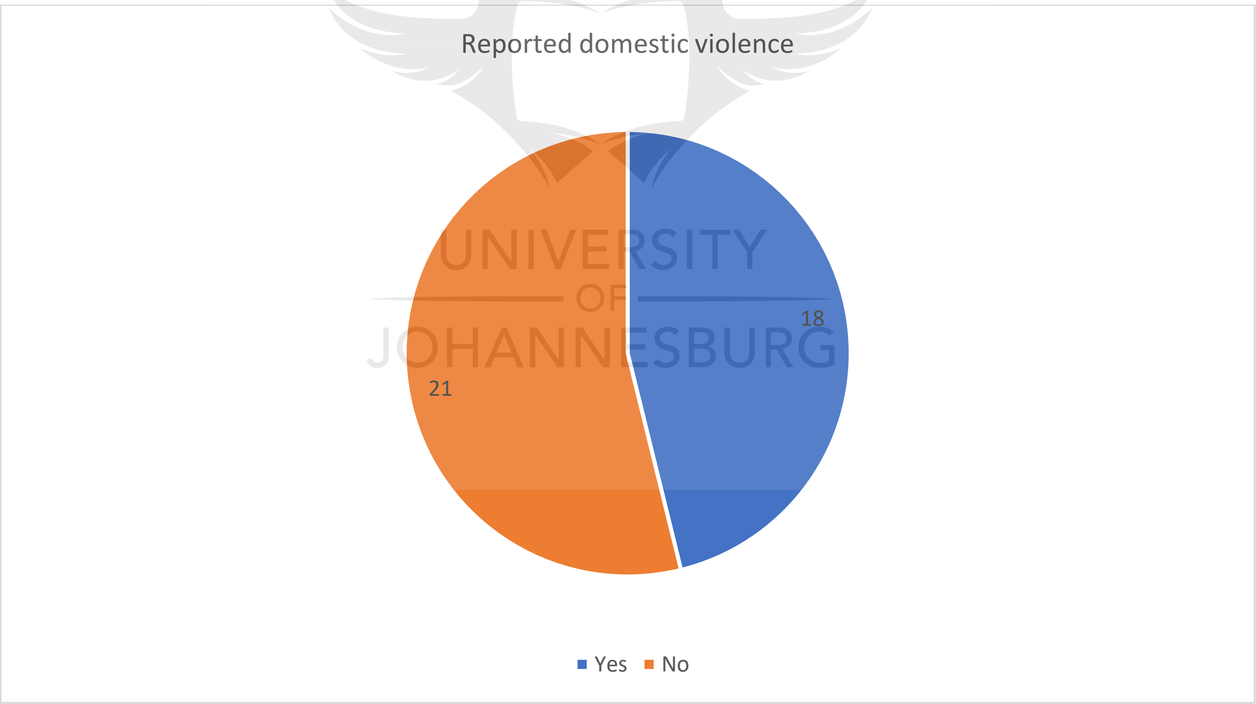
> I am not comfortable about telling him because I'm afraid of how he will react. I don't care if he says that he doesn't love me anymore I'm just afraid that he will kill me and my baby. I don't know what he's thinking, he will just kill me because I can hear him saying that if someone infected him, he would kill that person (CIC P9, age 28).

> He has the potential to be violent, he has never been violent but when he is angry, it shows that he can be violent (LTFU P12, age 19).

Most of the mothers as it is shown in the extracts above have never experienced violence from their partners, but they are worried that their partners might be violent if they disclose their HIV status. The mothers do not trust that their partners might react positively. One of the mothers experienced violence from their partner when he accused her of cheating: *"He accuses me of dating other people when I deny it he beats me up"* (LTFU P13, age 19). This evidence of intimate partner violence that the mother experienced in the relationship can influence non-disclosure. South Africa is a country with a high rate of gender-based violence. Intimate partner violence is the most dominant leading to an increasing rate of femicide (Abrahams et al. 2013). The excerpts above highlight the mothers' fears of intimate partner violence if they disclose their HIV status.

Though the mothers did not experience intimate partner violence they were not comfortable with HIV disclosure of their partners as they fear the possibility of intimate partner violence. The nurses and lay counsellors were asked if the client reported domestic violence from their partner. Most of the respondents - 21 (53.8%) indicate that the mothers did not report domestic violence from their partners, and only 18 (46.2%) indicated that the mother reported domestic violence (see figure 5.10 below). The findings show that most of the mothers have not reported violence from their partners. The findings from the nurses and lay counsellors show an alarming number of mothers who reported violence from their partners.

Figure 5. 10: Mothers report of violence from partners



5.4.4. Negotiating safe sex

The mothers were asked if they negotiate for safe sex practices with their partners. Although most of the mothers were not in intimate relationships and have not disclosed their HIV status to their previous partners, there are a few that were either married or cohabitating, and there were those who were in non-marital intimate relationships and have disclosed to their partners. The findings show that most mothers from both the case and control groups can negotiate for safer sex practices with their partners. This is confirmed by mothers who said:

> Since I have known my status, I have been using a condom. I told him if he does not know his status and does not use a condom, he must know that when he gets sick, he won't be able to get up again because I am already taking medication, and so he just said he will go (LTFU P15, age 27).
>
> No, he refuses, we do not use a condom, he says he wants to see if he has the virus too, I told him when he refuses to use a condom I will refuse (CIC P16, age 29).
>
> He always asks me why I want to use the condom, that I don't trust him, but when he refuses, we stop (LTFU P5, age 31).

Mothers say that they always use condoms and if their partner refuses to use protection they refuse to continue with sexual intercourse. These quotes also show that the male partners are in denial or lack knowledge or awareness about the danger of HIV and the importance of safe sex practices, like the use of a condom, especially with a partner who confesses to contracting HIV. The other mothers had challenges with their partners about the trust in the relationship when they negotiate for safer sexual practices. One of the mothers has this to say:

> No, I have never asked him to use a condom. I don't use a condom because he will ask why I want to start using a condom now (CIC P18, age 29).

The mother was worried that her partner might be suspicious if she asks her partner to use a condom. Some men just prefer to not use condoms and the mothers fail to provide reasons for wanting to use condoms, this is confirmed by a mother who said:

> We used the condom sometimes, not mostly. He refuses sometimes, he just says he does not want to use it at that time, I don't have a reason to say no (LTFU P8, age 26).

The other mothers do not make any effort to negotiate for safer sex practices because they do not think their partner will agree: *"I have never asked him to use a condom, if*

I ask him, I don't think he will agree." Also, the findings from CHWs show that HIV positive mothers struggle to negotiate for safer sex practices. This is confirmand by CHWs who said:

> They are afraid to ask their partners about using condoms because they're worried that the partner will ask why they want to use condoms. That means there is a problem, but we do talk about collecting condoms, but they are afraid to talk to their partner about it because they're afraid that their partners will be suspicious when they suddenly want to use condoms or protection, so they cannot negotiate with them well (CHW P1).
>
> They don't agree, they don't accept it, the reason is that they don't think their partners will agree on using condoms. They are afraid that their partners will suspect that they have been sleeping around, that's why all of a sudden, they want to use condoms (CHW P2).

The CHWs believe that HIV positive mothers fail to use safe sexual practices. The mothers are afraid that their partners will suspect that they are cheating. The excerpts above show that the mothers are afraid of negotiating the use of safe sex practices.

5.4.5. Experiences of stigma and discrimination

The findings show that most of the mothers from both the case and control groups have never experienced stigma or discrimination at home or by the public. Although the previous section reveals that there are mothers who feared stigma and discrimination, the findings presented here show that most of them have never experienced stigma or discrimination. One of the mothers said she had never been stigmatized or discriminated against but her aunt experienced stigma and discrimination:

> No I have never experienced it, people don't know my status, I don't look like I have HIV but I once saw my uncle`s wife HIV medication, she is taking the same treatment as mine but I did not make her aware that I know but I saw it, so the children in there I think they know now her status they started treating her different, they refuse to help her with a lot of things, even doing her hair, they say what if they find a pimple and its pop, this is happening currently, at home she tells them that is the treatment for something (LTFU P8, age 26).

The excerpt shows that the mother never experienced stigma and discrimination because she has not disclosed her HIV status and she does not look like she contracted the virus. However, she witnessed a family member who experienced HIV-related stigma and discrimination. Another mother said that her ex-partner is spreading rumours on social media, telling other people her HIV status: "*My ex-partner has told* *people about my status on Facebook"* (LTFU P13, age 19). The mothers in the control group also have never experienced stigma or discrimination. This is confirmed by a participant who said: *"No, I have never shown any signs of having the virus"* (CIC P14, age 32). In addition, the CHWs had not received reports of stigma and discrimination from the mothers. This was confirmed by a CHW who said: *"No they don't complain"* (CHW P11). Another mother said in the past there were complaints about stigma and discrimination but now there are no complaints:

> Yes, in the past but now there are no complaints, there's no stigma, in the past when we went to the household when you came out people were suspicious but now there are not like that (CHW P17).

The nurses and lay counsellors were asked to indicate if mothers experienced stigma and if the healthcare workers reported the incident. In Table 5.7 below, most of the respondents 32 (80%) believe that HIV positive mothers were not experiencing stigma and discrimination at the Clinics and only 8 (20%) believe that HIV positive mothers are not experiencing stigma and discrimination at the Clinics. The table further shows that 35 (87.5%) of the respondents have not witnessed stigmatisation and discrimination against HIV positive mothers at the clinic and only 5 (12.5%) witnessed stigmatisation and discrimination against HIV positive mothers.

The respondents were asked if they reported the stigma and discrimination against HIV positive mothers, only 16 (n=16) respondents answered this item. Of these sixteen who responded, 10 (62.5%) did not report the stigma and discrimination that they witnessed and 6 (37.5%) of the respondents reported the stigma and discrimination. The findings show that healthcare workers believe HIV positive mothers are not experiencing stigma and discrimination at the clinic. Most of the healthcare workers report that they have not witnessed HIV-related stigmatisation and discrimination on mothers at the clinic, and healthcare workers have not reported incidences related to stigma or discrimination against HIV positive mothers.

Table 5. 7: Healthcare workers witness and reporting of stigma and discrimination

Variables	Category	N	%	Total (N)	Total (%)
HIV positive mothers experience stigma and discrimination at the clinic	Yes	8	20	40	100
	No	32	80	40	100
Witnessing stigmatization or discrimination against HIV positive mothers	Yes	5	12.5	40	100
	No	35	87.5	40	100
Reported stigma and discrimination	Yes	3	60	5	100

Figure 5.11 below presents groups or individuals who stigmatise or discriminate against mothers according to nurses and lay counsellors. Most of the respondents believe that HIV positive mothers are discriminated against by the community members (42.5%) followed by the family of the client (37.5%), other patients (30%), colleagues (17.5%), partners of the client (12.5%), visitors at the clinic (10%) and 7% of the respondents indicated that HIV positive mothers do not experience stigma and discrimination at the facility. Overall, the findings show that most of the nurses and lay counsellors believe that community members stigmatise and discriminate HIV positive mothers. On the other hand, the findings from HIV positive mothers contradict these perceptions. The findings reveal that most of the mothers have never experienced stigma or discrimination.

Figure 5. 11: Healthcare workers perceptions on individual/groups that stigmatize/discriminate mothers:

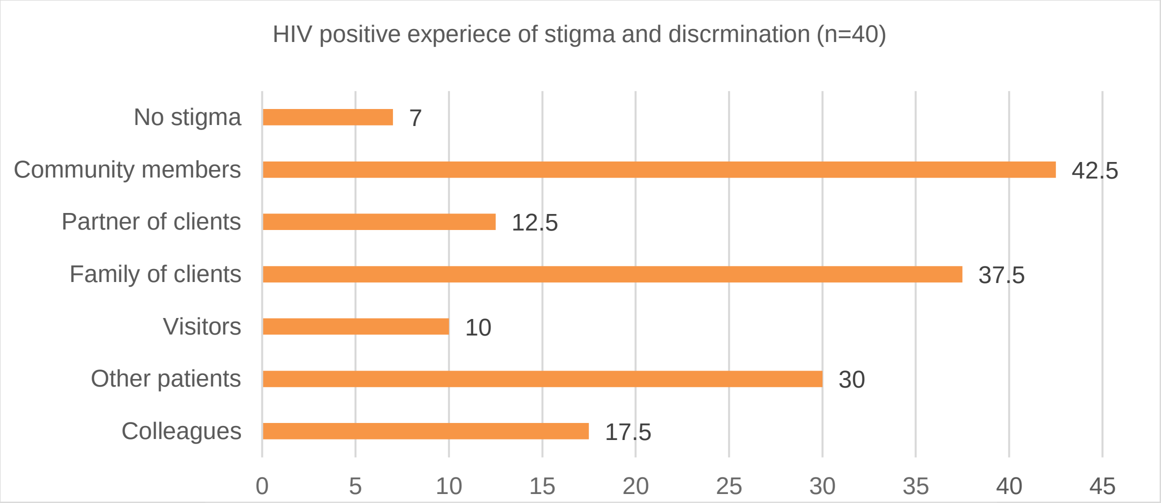


Table 5.8 below provides a summary of the availability of stigma and discrimination report systems. Most of the respondents 25 (62.5%) show that their facility does not have an active stigma and discrimination report system, only 15 (37.5%) have a reporting system. Also, the respondents were asked if the stigma and discrimination report system were working and twenty-two (n=22) responded to the question. Most of the respondents 13 (32.5%) show that the report system works and only 9 (22.5%) do not work. The findings show that the health facilities in this study do not have active stigma and discrimination report systems. Health facilities have operational active stigma and discrimination report systems.

Table 5. 8: Availability of stigma/discrimination report system at the health facilities

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Active stigma/discrimination report system	Yes	15	37.5	40	100
	No	25	62.5	40	100
If the report system works	Yes	13	32.5	22	100
	No	9	22.5	22	100

5.5. Health Care Systems and Community Barriers

This theme discusses the focus on the associated structural issues of access to care and utilisation of services in the PMTCT programmes and the effect of how the structural issues are rendered on HIV treatment and adherence. The following sub-themes emerged: Resources in the healthcare system, accessibility to health facilities, the challenges faced by healthcare workers (nurses and counsellors), and the barriers and challenges faced by CHWs in the PMTCT programmes.

5.5.1. Resources in the healthcare systems

Most of the mothers from both the case and control groups show that health facilities lack relevant resources such as test kits, medication, space and staff. This is confirmed by the mothers who said:

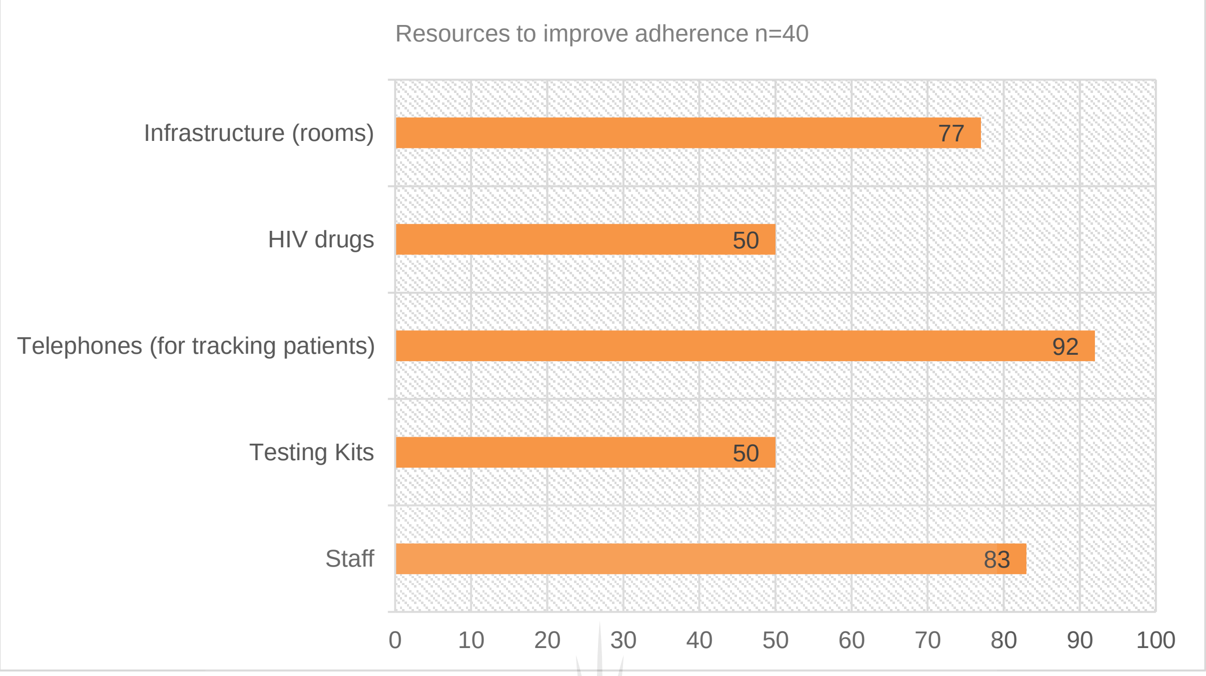
> The thing that I notice is that they are lacking testing kits, sometimes when I come here, they tell me they do not have testing kits. They give us another date (LTFU P8, age 26).
>
> There is a shortage of staff, there are few nurses, sometimes when I come to take medication, they say they don't have (CIC P15, age 37).
>
> No, they lack staff, most of the time when I come here you find only one nurse working and these delays (CIC P3, age 26).

The mothers demonstrate that health facilities lack relevant resources such as test kits, medication, space and staff and this delays service delivery. The findings show that the CHWs also believe that the facilities lack relevant resources such as space, testing kits, staff and medication. This is confirmed by the CHWs who said:

> There is not enough space, the space is small, you find that there can be only two people working and the people are so many (CHW P1).
>
> There are many people here in the community and there are no staff and consultation rooms, you find sometimes only two people are working and there are so many people (CHW P4).

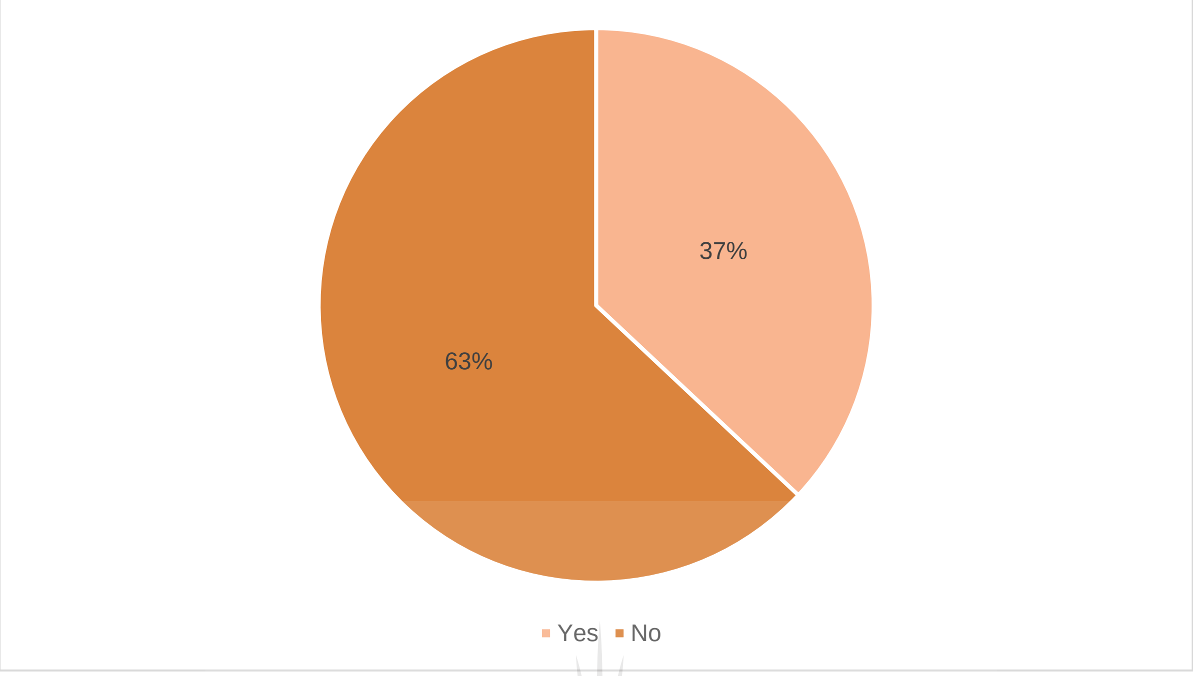
In Figure 5.12 below, most of the respondents who answered the item showed that the facilities need telephones for tracing (92%), followed by the addition of staff members (83%), and infrastructure or rooms (77%). Testing kits (50%) and HIV drugs (50%). The findings show that nurses and lay counsellors need telephones for tracing.

Figure 5. 12: The resources needed to improve adherence and LTFU



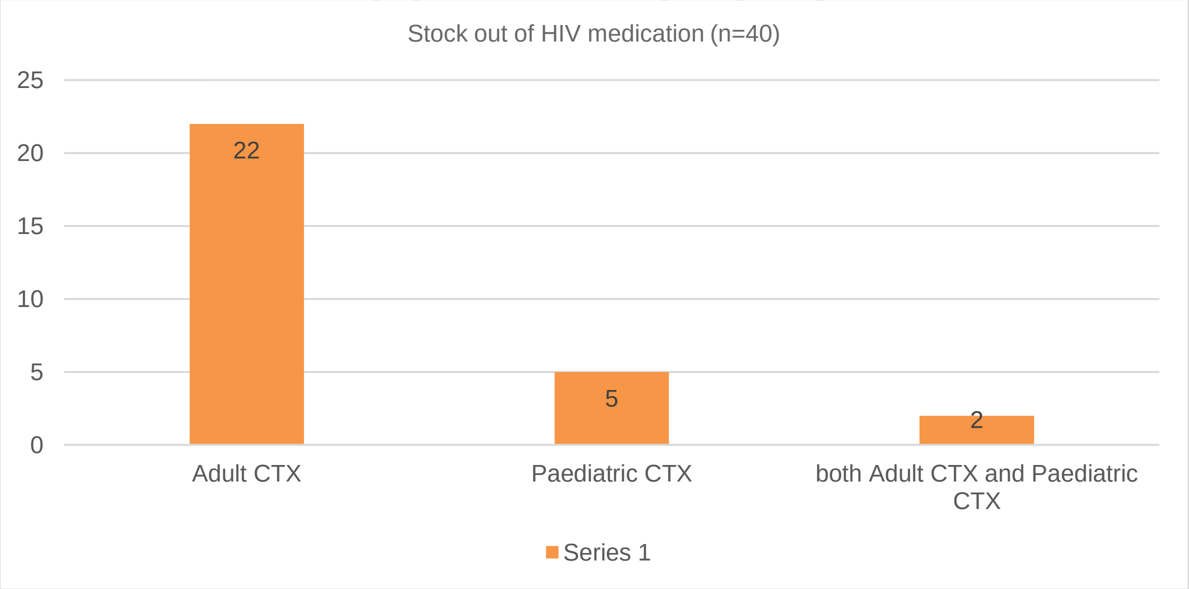
Furthermore, the nurses and lay counsellors were asked if they have any stock-outs of HIV drugs in the past three months from the time of the survey. Most of the respondents (63%) indicated that the health facilities have not experienced stockouts of HIV drugs and only 37% of the respondents have experienced stock-outs of HIV drugs in the past three months (see figure 5.13). The findings show that most of the nurses and lay counsellors have not experienced stockouts of HIV drugs in the past three months from the time data was collected.

Figure 5. 13: Stock-out of HIV drugs in the past three months



The respondents who experienced stockout of HIV medication were asked to indicate which category of medication they had stockout of. Most of the respondents (22%) who answered this item experienced stockout of adult Cotrimoxazole (CTX), followed by Paediatric CTX, only 2% of the respondents experienced a stock out of both adult CTX and paediatric CTX (see figure 5.14). The findings show that most of the nurses and lay counsellors experienced stock out adult CTX.

Figure 5. 14: Stock out of adult CTX and paediatric CTX



5.4.2. Accessibility of the health facilities

The nurses were asked if mothers struggle to access the health facilities and the PMTCT follow-up services. Table 5.9 below shows that most of the respondents 33 (82.5%) believe that their clients do not struggle to access PMTCT follow-up services, only six (15%) show that clients struggle to access services. The respondents were further asked if the facility is accessible for everyone in the community, most of the respondents 38 (95%) show that the facility is accessible for everyone in the community, only two (5%) show that the facility is not accessible. The findings show that nurses and lay counsellors think HIV positive mothers are not struggling to access PMTCT follow-up services and that the facilities are accessible to everyone in the community.

Table 5. 9: Mothers' access to PMTCT services

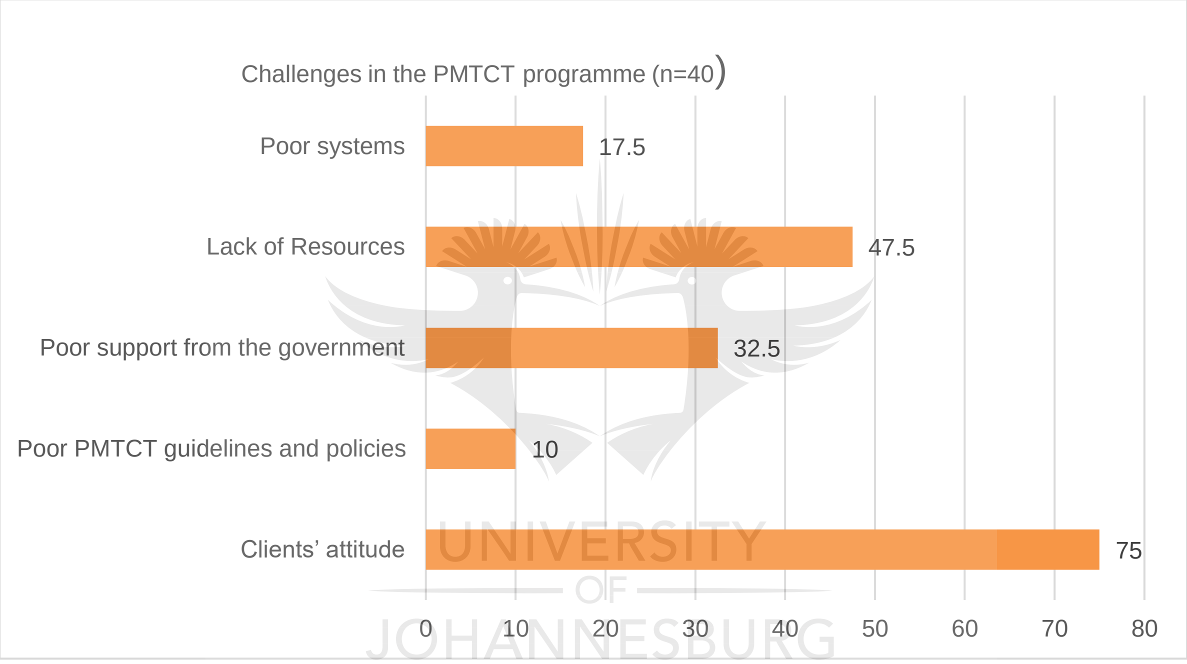
Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Clients struggling to access PMTCT follow-up services	Yes	6	15	40	100
	No	33	82.5	40	100
Facility accessible for everyone in the community	Yes	38	95	40	100
	No	2	5	40	100

Further, the nurses were asked to identify the obstacle that they believe mothers experience when accessing PMTCT services. In Figure 5.15 below, most of the respondents show transportation costs (58%) as an obstacle that prevents HIV positive mothers from accessing PMTCT services. This is followed by a lack of financial support (23%), distance from the clinic (10%), and others (9%). The findings show that healthcare workers believe transportation costs prevent HIV positive mothers from accessing PMTCT services.

5.4.3. Challenges faced by healthcare workers in the PMTCT programme

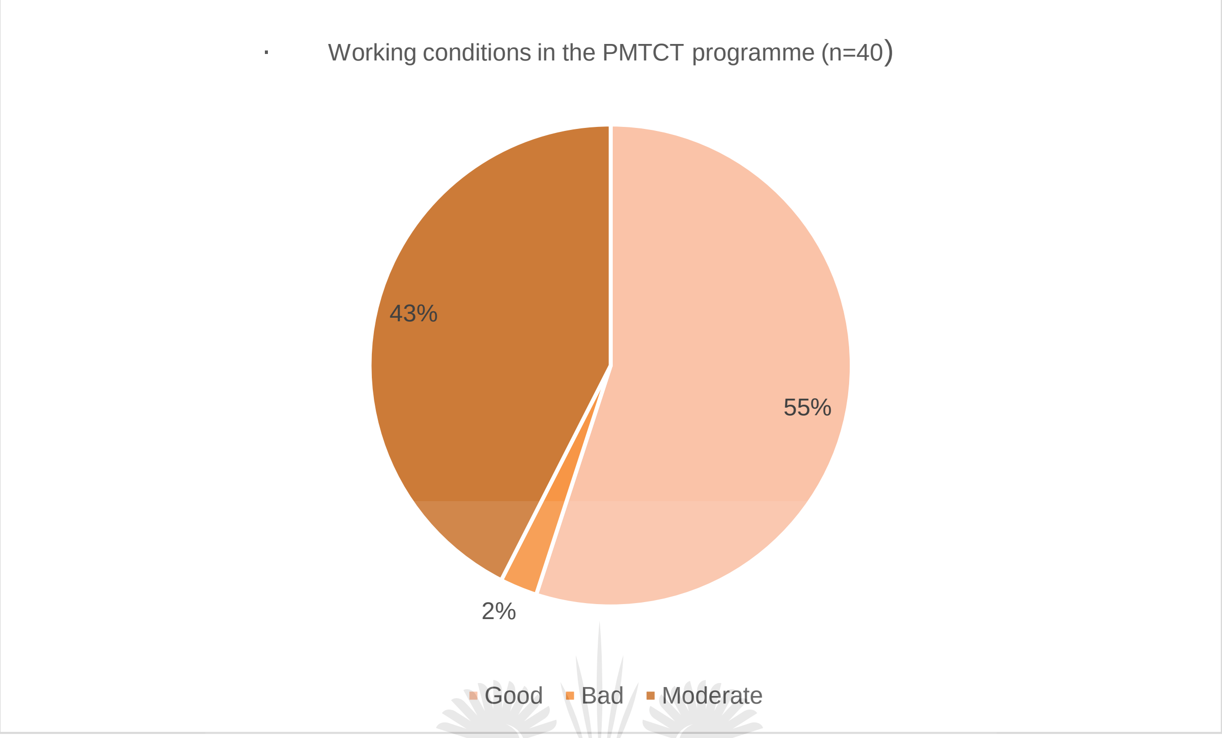
The respondents indicated the implementation challenges in the PMTCT programme. In Figure 5.15 below, most of the respondents (75%) show that clients' attitudes are the challenge experienced by respondents when implementing the PMTCT programme, this is followed by lack of resources (47.5%), poor support from the government (32.5%), poor systems (17.5%), and poor PMTCT guidelines and policies (10%). The findings show that clients' attitude is the challenge that nurses and lay counsellors experience when implementing the PMTCT programmes.

Figure 5. 15: Healthcare workers' challenges in the PMTCT programme



The nurses and counsellors were asked to indicate the working conditions in the PMTCT programmes. In Figure 5.16 below, most of the respondents (55%) show that the working conditions in the PMTCT programmes are good, followed by moderate conditions (43%), and bad conditions (2%). The findings show that the working conditions in the PMTCT programmes are good.

Figure 5. 16 Working conditions in the PMTCT programme



The respondents indicated the effectiveness of PMTCT guidelines and policies. In Table 5.10 below, most of the respondents 38 (97.4%) show that current PMTCT guidelines and policies are effective in dealing with non-adherence of ART, only one (2.6%) respondent disagreed. Most of the respondents (38 97.4%) believe that current PMTCT guidelines and policies are effective in dealing with the LTFU of mothers and their babies, only one (2.6%) respondent disagreed. The finding shows that nurses and lay counsellors have effective PMTCT guidelines and policies that deal with the non-adherence of ART and LTFU of mothers.

Table 5. 10: Effectiveness of PMTCT guidelines and policies

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Effectiveness of PMTCT guidelines and policies are in dealing with non-adherence of ART	Yes	38	97.4	39	100
	No	1	2.6	39	100
Effectiveness of the PMTCT guidelines and policies in dealing with loss to follow-up of mothers and their babies	Yes	1	2.6	39	100
	No	1	2.6	39	100

The respondents were asked to indicate the healthcare promotion challenges in the PMTCT programme. In Table 5.11 below, most of the respondents (80%) believe that the government are doing enough to promote the use of PMTCT follow-up services by mothers, only 20% of the respondents disagree. Most of the respondents (92.5%) show that their colleagues are doing enough to promote PMTCT activities. Also, most of the respondents (87.5%) show that their colleagues are doing enough to prevent the LTFU of HIV positive mothers and their babies to attend PMTCT services. The findings show that nurses and lay counsellors believe the government is doing enough to promote the use of PMTCT follow-up services by mothers. They are doing enough to prevent the loss to follow-up of HIV positive mothers and their babies to attend PMTCT services.

Table 5. 11: Health promotion challenges in the PMTCT cascade

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Government doing enough to promote the use of PMTCT follow-up services by mothers	Yes	32	80	40	100
	No	8	20	40	100
Colleagues are doing enough to promote PMTCT activities	Yes	37	92.5	40	100
	No	3	7.5	40	100
Colleagues are doing enough to prevent loss to follow-up of HIV positive mothers and their babies to attend PMTCT services	Yes	35	87.5	40	100
	No	5	12.5	40	100

5.4.4. The benefits, work, and opportunities for outreach workers

Responsibilities of CHW: The CHWs track patients, trace patients, register households, and most importantly promote health. The CHWs in this study expressed that the work they do involves educating clients about health issues. Their job descriptions include health talks about dangerous diseases, even the deadliest illnesses when combined with HIV and Tuberculosis (TB). This is confirmed by the CHWs who said:

> We [CHWs] go to the households and we teach them [patients] about health, we promote health So when we get to the households we register the

> households, we register everyone who stays in the households, and we ask them [member of the households] everything and also check their children's clinic cards for attendants. We check if there is anyone who is taking any medication and if we find individuals who have chronic diseases and are not on the treatment, we refer them to the clinic. We also go and check them regularly; we ask for the letter that shows the dates for their next appointments and we go on those days (CHW P16).

> Our job is to take care of patients at their homes, so we can give a health talk to help the patients or the community to be aware of certain health issues, sometimes people get sick, and they do not know where to get help. So, when we go to their households we give health talks about TB, HIV, and other STIs diseases, also cancer and high blood pressure, the person becomes aware of this health issue., We go to the households to teach people about these health issues and then the person sometimes tells us that he or she has health issues and then we refer them to the clinic. The first thing to do when we get to the households is to start by greeting them and telling them where we come from and why we are here. We tell them we've been sent by the government to assist them to come to the clinic. If we find a baby who missed an appointment, we refer the baby to the clinic to get the medication that the baby is missing (CHW P1).

The excerpts show that the CHWs are well aware of their job descriptions and how to achieve positive objectives in their work with the communities. They express that their work involves educating clients about health issues to improve their health outcomes.

HIV positive mothers' appreciation of CHWs: The CHWs job is to trace patients successfully and convince them to continue or restart HIV treatment with the facility. The CHWs had this to say:

> Yes, it can happen when I work in certain areas sometimes when I passed the households on my way to other households they [clients] call me to come to their households and they ask me about health issues which shows that they are interested in what we are doing, so they are interested in the health issues because some of them they don't know and then they want to know more about health, they will get tested and know more about health issues and other different health issues (CHW P16).

> They can see that we are important because some of them come to my house and tell me that what I told them was very helpful, they see the importance of us coming into their households, they have accepted us because when we talk to them and they are free, they can be free when we ask questions, and they answer (CHW P2).

The CHWs play a very important role in the PMTCT programmes and the lives of many patients who were LTFU or not adhering to HIV treatment. The findings suggest that CHWs are well perceived by their clients, the clients welcome and appreciate CHWs.

The CHWs could see that their clients appreciate their work, and the clients call them even when they are not assigned to work that day.

Education benefits for CHWs: The CHWs indicated that they have personally benefited from the educational experiences that come with the job, they can broaden their knowledge regarding health issues. The opportunity for the CHWs is to learn more about various illnesses and diseases, especially on how to prevent and treat them. This was supported by the CHWs who commented:

> For me, the benefit of being a CHW is to learn a lot of things that I did not know about health. I can prevent illnesses before they start, so I have learnt that people should not just sleep around. I did not see the importance of taking a child to the clinic for immunization in the past but now I've learned something, there are a lot of things that I've learned, at the clinic. They [nurses] also see that we are important, we don't have a problem with them (CHW 6).
>
> For me, it was helpful because I didn't know much about health issues, I am now aware of everything about health issues, at first, I didn't know how TB can be transmitted to a patient and how to treat it. I didn't know about HIV, how it is transmitted, or how it is treated (CHW P8).

The CHWs have personally learned the importance of their jobs in the community and at the health facilities. The excerpts show that the CHWs appreciate the education experiences of HIV prevention measures and other chronic diseases.

5.4.5. The barriers and challenges faced by CHWs in the PMTCT programme

Wrong addresses and information*:* One of the major challenges that CHWs encounter during tracking and tracing of patients is that patients provide false information and home addresses (Cataldo et al. 2018). The findings in this study show the majority of the CHWs face challenges of wrong addresses and information during the tracking and tracing of patients. The CHWs had this to say:

> The challenge is that the patients give us wrong addresses, like when a mother says that she is staying in a certain area, but she is not telling me the truth, they don't add their house numbers and we don't even know where to start when we trace them. This is the challenge that we are facing here.
>
> Our challenge is that we found that when we're there is a problem because when they give me someone to trace, I must find that person, but that person has given us the wrong address. They give us wrong information, so when I go there, I don't find them - when they give us the house/stands number you find that the person is not there. Sometimes they give us people who died three years ago to trace, so the problem is that at the facility some of the clients we find, we already know. Another problem at the clinic is the issue of referrals

> because we refer people here but they [nurses] don't fill our referrals. When you ask about it, they don't have good reasons, they just delay us, but they do help but it is a struggle, but not all of them (CHW P3).

The CHW expresses the frustration with tracing systems when the mothers provide incomplete or wrong addresses, making it difficult for CHWs to trace them. Another CHW also complained about wrong addresses that were provided is frustrated that wrong addresses result in them going to wrong areas or houses. The CHW further expresses her frustrations with the tracing data system, sometimes they trace people who are deceased for years. The CHWs also complain about a lack of support or collaboration with nurses. The nurses do not sign referrals from CHWs and delay their [CHWs] work.

Lack of acceptance or support from the community: In many communities, the CHWs find it difficult to perform their work freely due to a lack of support from community members. The findings in this study show that the CHWs experience lack of support from the communities in which they work. This is what one of the CHWs said:

> I work at the Paledi community, the community has accepted us but sometimes we have challenges, some have not accepted us, those that have not accepted us say that we're here to investigate them, they end up not opening their gates. Some they can see us coming and then tell us that they are busy, but at the clinic, they have accepted us, they see the importance of CHWs (CHW P10).
>
> You find that a person is tested and is HIV positive but when they see us coming wearing the uniform to their households, they reject us. CHWs work where they reside so if I stay at Ga-Thoka, I will trace patients from that area. I will work around that area, so sometimes we may think people don’t know us only to find that they do. So, when we go to the clinic and explain that we are from the clinic they end up thinking that we are here to expose their secrets related to their health, but some have accepted us, they don’t have a problem (CHW P5).

The community members are afraid that their secrets will be widely spread by CHWs, and it is hard for them to accept CHWs into their households, the excerpt above confirms this. The CHWs believe that the mothers fear that the CHWs might expose their HIV statuses. The CHWs can mitigate the effect of wrong addresses. They are assigned an area in which they reside because they are familiar with the area, and they can trace individuals in the same community or area.

Rejections by clients/mothers*:* The other challenge that CHWs experience during tracing of patients or household visits is getting rejected by the clients. In previous section, I have presented that CHWs lack support from the communities that they are assigned work. This sub-theme presents direct rejections from mothers/patients during home visits. Rejection by mothers who are LTFU in the PMTCT programme delays the progress of the programmes exposed the challenges of patient retention. This was confirmed by the CHWs who said:

> The challenges are that when we go to the field to assist patients, they reject us because people are not the same, sometimes they will lie even about taking medication and you know that we cannot force them, they have the right to reject our assistance.
>
> The challenge is when you help a patient and that patient changes their mind and says that they are okay - that they don't need the help anymore, that they will help themselves. Even when you can see that the person needs help, but they say they don't need help anymore. When you ask them for a reason, they just say they will do it on their own, the reason I think is that they don't want to see us coming into the house every day. They're worried about what other people are saying, so they are afraid of being discriminated against by the community that there is a sick person in the household and that they will be seen by their neighbours (CHW P9).

The CHW states the challenges of working in an outreach programme when the job is to convince mothers who are LTFU or fail to adhere to treatment. The mothers often reject the CHWs or lie that they are adhering to HIV treatment. Some patients change their minds about receiving help from CHWs and decline the assistance. The quote above shows that mothers are worried about CHWs tracing them at home. The mothers worry that the neighbours or the community will know their status and start to stigmatise or discriminate against them. The presence of CHWs in the community is making mothers uncomfortable with the fear of unintended HIV disclosure.

Lack of resources for every household visit: The findings show that CHWs lack stationary resources to perform household visits. In every household visit, the CHWs are required to draft a report about their visit. However, they need stationery material to be able to draft the reports, that many of the CHWs express they lack. This was supported by CHWs who said they do not have resources to work, especially the documents to record every household visit and hygienic products:

> No, we record household visits on our books, we do not have anything. We have shortages of everything, we do not have household documents, we do not have the equipment, we do not even have anything to wash our hands (CHW P1).

> No, they're not helping, we don't have the uniform and they do not provide us with resources such as TB masks, we do not have the masks and it's risky, with the masks we can protect ourselves. We also do not have transportation and umbrellas (MCHW 1).

The CHWs felt that they were not supported enough by the government or the department of health. The excerpt above shows that the CHWs lack documents such as household visit forms and referral forms. They complain about the lack of protective material such as Tuberculosis (TB) masks to protect themselves, without the protection it can be risky for CHWs during face-face interaction considering the contagious nature of the TB disease. The other materials that the CHWs struggle to acquire are the uniforms that they present themselves in during household visits. Another challenge is the lack of transportation considering the distance of clients' homes. The CHWs complained that they are forced to work in harsh conditions.

Performing work that is beyond their job description: The challenge sometimes is that CHWs are required or asked to perform jobs that are not part of their work scope. One of the CHWs has this to say:

> At the clinic, the problem that we face is that they [the nurses] give us jobs that are not in our scope. I would say that that is the problem we face here at the clinic. For example, they make us do vital signs and, in our scope, we are not qualified to do that, but they say that they have shortages of things.

This excerpt shows that the CHWs perform tasks that are not in their work scope. The CHWs complain about the nurses asking them to perform work they are not qualified to do as CHWs, this work includes checking patients' vital signs. The nurse asked the CHWs to do this work because they experience shortages of qualified health personnel to perform those tasks.

5.6. Chapter Conclusion

The mothers had some knowledge about MTCT, but they failed to explain how MTCT occurs during pregnancy, labour, and after birth. Unfortunately, single parents could not disclose their HIV status to their partners as the partners had already left them to raise their babies on their own. The mothers of infants who tested positive for HIV experience self-blame, guilt, and regret not adhering to HIV treatment earlier to prevent MTCT. Also, the mothers show protectiveness towards their infants' health. This was visible through an expression of their determination to ensure that their infants were adhering to treatment and continuously attending clinic appointments, and this happens while they fail to commit to clinic appointments. Infant feeding also highlights the motherhood feeding patterns that clash with the instructions from healthcare workers. Most of the mothers have never experienced HIV-related sigma or discrimination but feared negative reactions from disclosing their HIV status to their sexual partners, However, the nurses and lay counsellors believe that HIV positive mothers experience stigma and discrimination mostly from community members. The healthcare workers are also faced with challenges in the PMTCT programmes. The next chapter explores the strategies and support to improve care and utilisation in the PMCT programmes.

CHAPTER 6

MONITORING, APPROACHES, AND SUPPORT IN THE PMTCT PROGRAMMES

6.1. Introduction

This chapter presents the discussion on patterns of monitoring services, approaches/ strategies to improve care and service use and explore the opportunities, and support in the PMTCT programmes. This chapter addresses the following objective of the study:

- To explore the retention strategies, intervention, and communications to improve care, treatment, and utilisation of the PMTCT services.

Similar to the previous chapter, the qualitative findings from the HIV positive mothers are presented concurrently with the findings from the CHWs and the quantitative findings with the nurses and lay counsellors. The chapter incorporates the findings of HIV positive mothers with the findings from the CHWs, nurses and lay counsellors, presented concurrently with selected excerpts that reflect the participants' general views. The quantitative findings are presented with frequency tables, pie and bar graphs at the end of the theme. The discussions in this chapter are presented with two themes: 1. Monitoring and data use and 2. Improvement strategies, interventions, and supports. Below is a detailed presentation of the findings.

6.2. Monitoring and Data Use

This theme presents discussions on the communications, monitoring, and data used in the PMTCT programmes. The theme covers the tracking and tracing of HIV positive mothers and monitoring services for HIV positive mothers who are LTFU. Systems used to monitor ART adherence, monitoring clinics appointments, monitoring or measuring of loss to follow-up, as well as monitoring rates of adherence to ART. These are further discussed below.

6.2.1. Tracking and tracing of HIV positive mothers

Telephonic communication or household visits from health personnel are the most important process of tracing and ensuring that patients adhere to treatment (Department of Health 2016). Most of the mothers in the control group have never missed their appointments, therefore, there was no need for them to be traced or contacted. However, most of the mothers in the case group claim that they were not traced or contacted by the health personnel. For instance, HIV positive mothers explain that they did not receive communication from the clinics when they were LTFU:

> I don't remember they've called me because at work they don't allow us to take phone calls. I think I got a call from the doctor to come to the clinic regarding my baby (LTFU PE4).
>
> I don't know because they never called me, I don't know about others (LTFU P16, age 31).

Most of the mothers who were LTFU claim that they were not contacted during the time they were LTFU. The first quote shows the mother does not remember receiving communication regarding her LTFU status, but she has received communications regarding her baby. The second quote shows that the mother has never received communication regarding her LTFU status. One of the mothers did not receive any communication probably because she did not register her number on the patient's registry*: "I do not have a phone, so I registered with someone else's phone"* (LTFU P13, age 19). The mother did not have a mobile phone and registered at the health facility with someone's mobile number. This highlights some of the challenges that the healthcare workers encounter when tracking and tracing HIV positive mothers who are LTFU. Besides, other HIV positive mothers who were LTFU received communication from the health personnel regarding their missed appointments. For instance, a mother who claimed to be far was offered her transportation reimbursement when they contacted her:

> They called me, they told me to come to the clinic to talk about taking treatment. I explained to them that I cannot because I am staying very far, and I do not have money for transport. They told me to come, and they will give me money for transport, and I asked them if they can talk to me via mobile phone and they said no, they talk about this face-to-face (LTFU PN5).

The excerpt shows that the healthcare workers attempted to reintegrate mothers into the ART programmes. Yet, this mother failed to find time to go back to the clinic to collect her medication. This shows that other healthcare workers make efforts to initiate mothers who are LTFU back into the PMTCT programmes. Though this is the case, the findings show that most of the mothers in both the case and control groups believe that healthcare workers are not doing enough to trace mothers who are LTFU in the PMTCT programmes. One of the mothers was certain that the healthcare workers are not doing enough to trace HIV positive mothers who are LTFU:

> No, they should not have many defaulters, if that was the case, they should plan and visit people at their home rather than wait for the people to come to the clinic and do health promotions. While people are waiting in queues, sometimes I feel they should rather just go out there to the community (LTFU P10, age 27).

The quote above shows that the mother was not convinced about the healthcare workers' effort to trace mothers who are LTFU. The mother believes that the healthcare workers are not doing enough and that they should arrange home visits instead of waiting for patients to come to them, and also promote health at the health facilities. The other mothers in the control group believe that the healthcare workers are doing enough to trace HIV positive mothers. This is what they said:

> Yes, they are doing enough because they have home-based care who are coming to our home and tell us to come to the clinic (CIC P10 age 23).

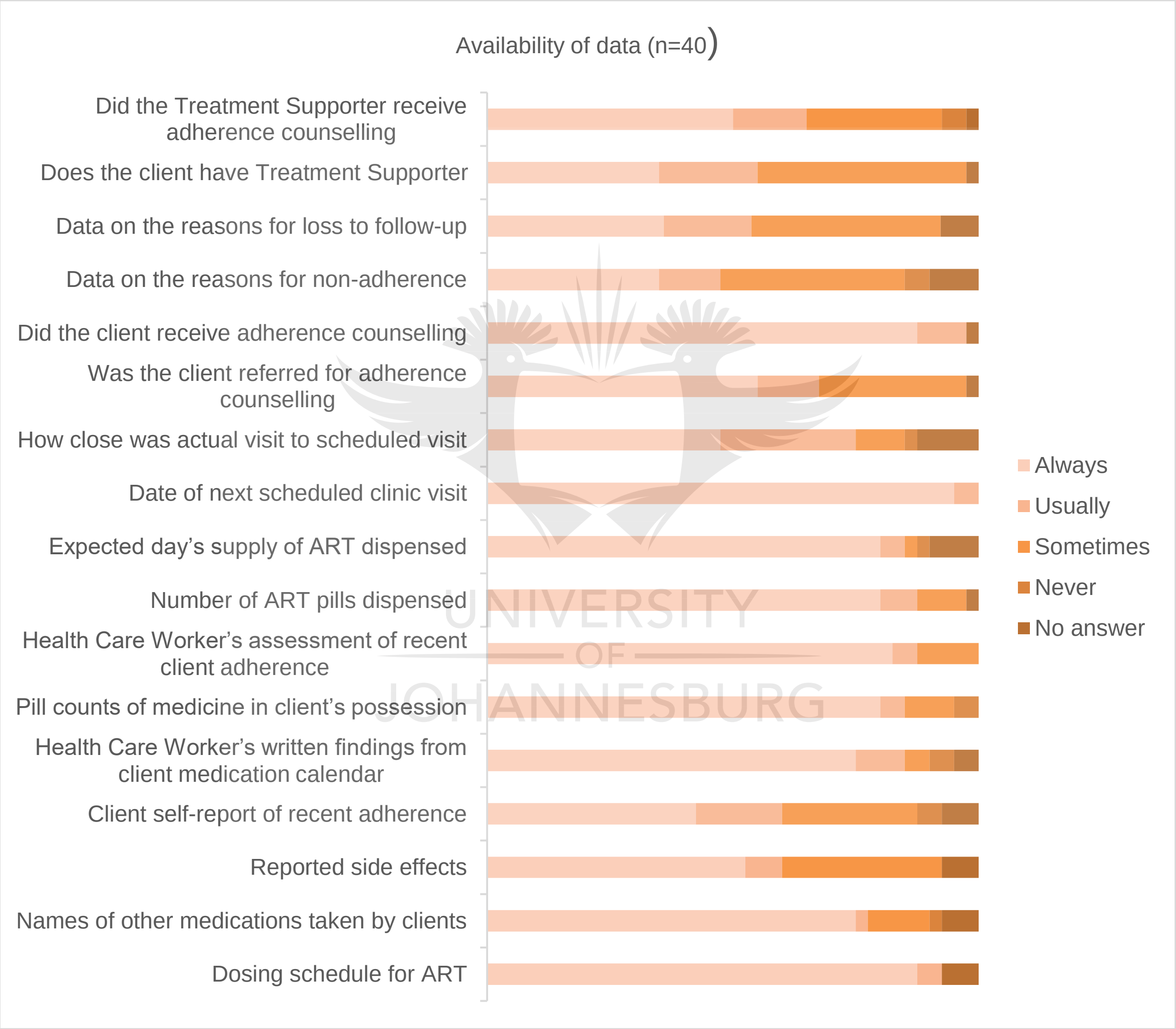
This shows that the other mothers in this study support the tracing system, that the healthcare workers make efforts to contact the mothers. The mother commands the efforts made by outreach healthcare workers. They are aware that home-based workers exist and do follow-up visits.

6.2.2. Data availability for tracking, tracing and monitoring

In Figure 6.1 below, the data that is mostly used or always available to monitor LTFU and non-adherence of HIV positive mothers at the health facilities is the data showing the date for the next scheduled clinic visit (95%), the dosing schedule for ART (87.5%), the client receives adherence counselling (87.5%), health care worker's assessment of recent client adherence (82%) followed by data on the number of ART pills dispensed (80%), and the expected day's supply of ART dispensed (80%); including data of the names of other medications taken by clients (75%) and health care worker's written findings from client medication calendar (75%). Additionally, the data that is always available also includes the reported side effects (52%) whether the client was referred for adherence counselling (52%), did the treatment supporter receive adherence counselling (50%), and did the client self-report of recent treatment adherence (42.5%).

The data that is sometimes available is the data to check if clients have treatment supporters (42.5%), the reported reasons for loss to follow-up (38.5%) and reported reasons for non-adherence (37.5%). The findings show that the most available data to monitor LTFU and non-adherence is the date for the next scheduled clinic visit of the patients. The findings also show that most of the health providers do not have data to monitor or track the reasons for LTFU or fail to adhere to HIV treatment.

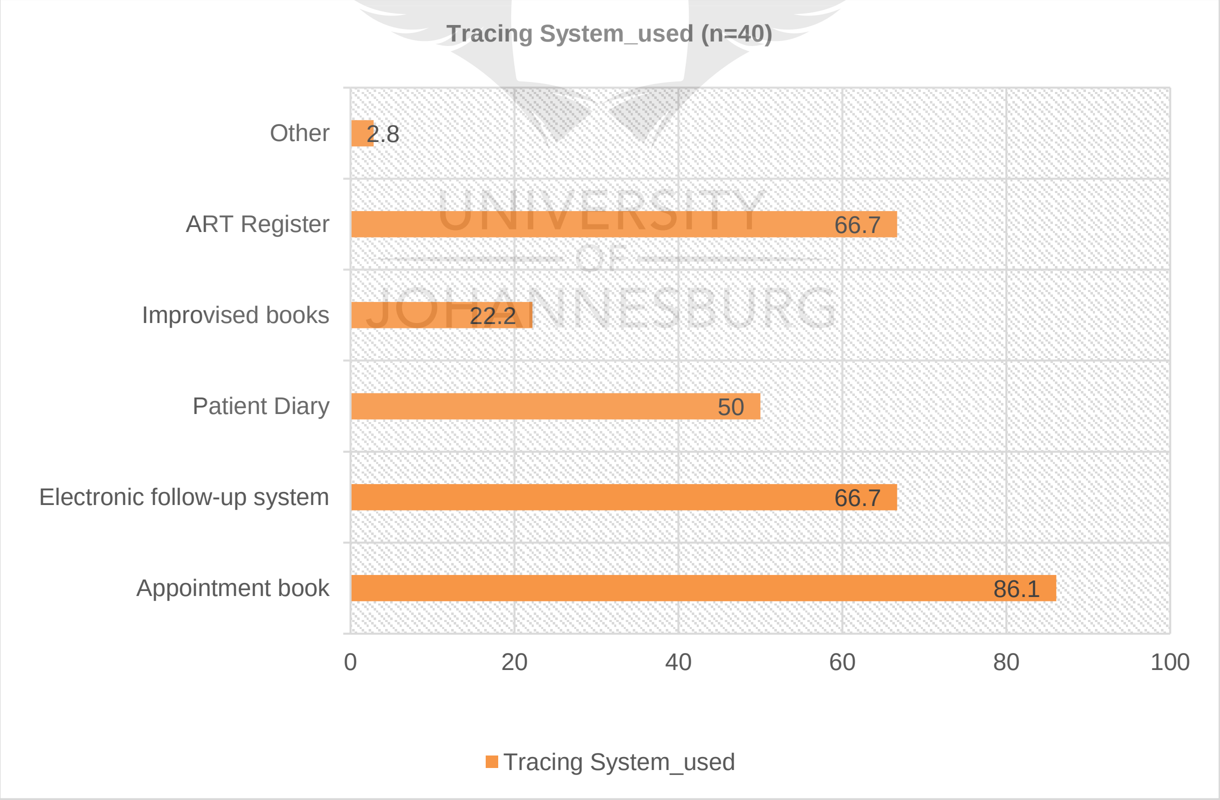
Figure 6. 1: Availability of data to monitor LTFU and non-adherence



6.2.3. Systems used to monitor ART adherence

Figure 6.2 below shows that 86.1% of the respondents use appointment books to monitor HIV positive mothers and their babies ART adherence. This was followed by an electronic follow-up system (66.7%), ART register (66.7%), patient diary (50%), improvised books (22.2%), and others (2.8%). The findings show that ART adherence for HIV positive mothers is monitored using appointment books. Every HIV positive mother's information is recorded in an electronic system and the appointment books (Department 2016). The appointment books are monitored and signed by the facility managers for accuracy and consistency. When patients are LTFU or defaulters in South Africa they are mostly identified from the clinic register or system. Thereafter, the health personnel responsible for tracking and tracing of patients will try to call them and if the patients are not reached through telephone, home visits will be conducted (Etoori et al. 2020). Health facilities in South Africa are required to have a register to record patients' appointments, either paper-based or electronic (Gourlay et al. 2015).

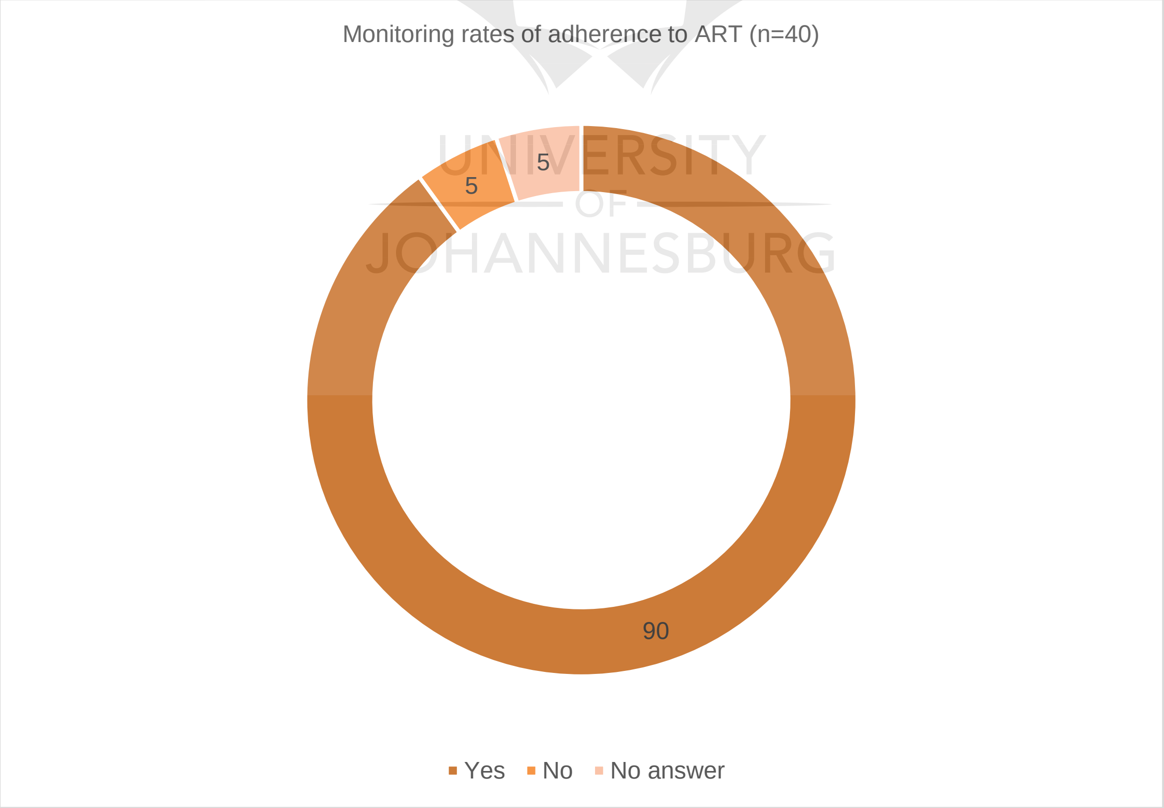
Figure 6. 2: Means to monitoring ART adherence of HIV positive mothers



6.2.4. Monitoring rates of adherence to ART

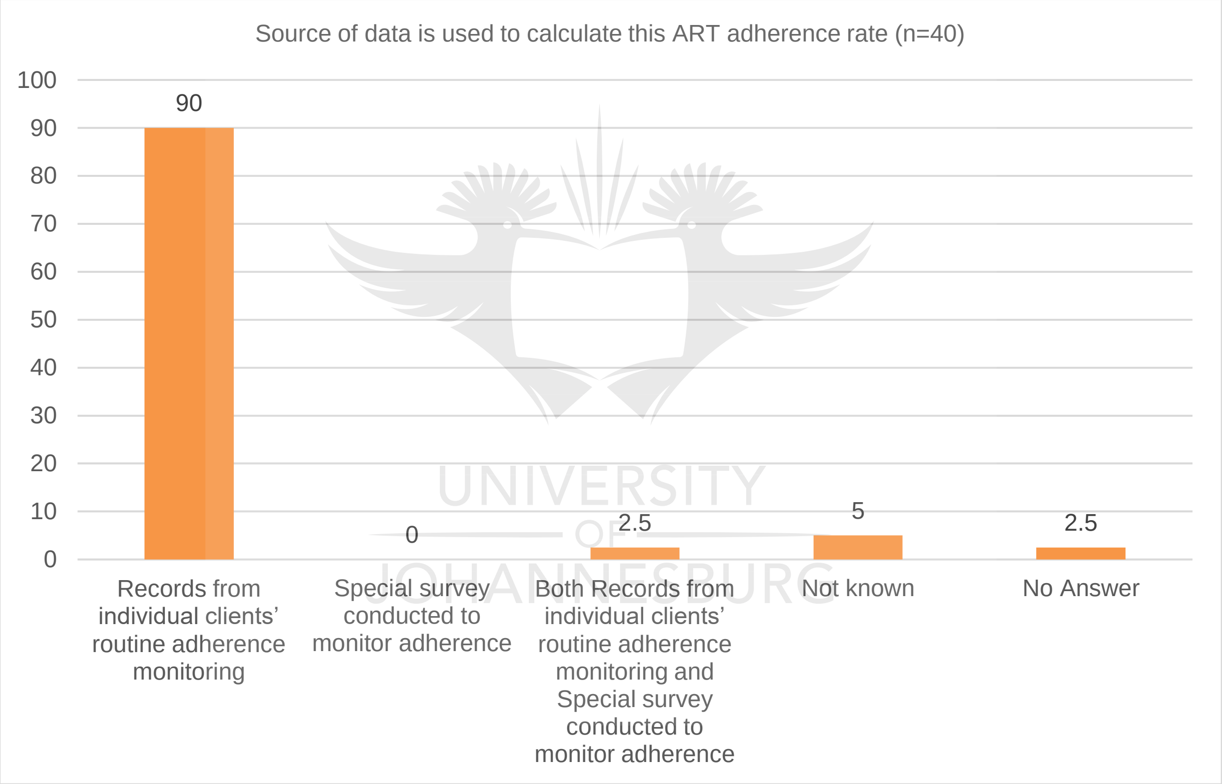
The nurses and lay counsellors were asked if they monitor the rates (statistics) of adherence to ART at the health facilities, the adherence rates averaged across multiple clients. The majority of the respondents (90%) show that adherence rates of ART are monitored at the facilities, only 5% of the respondents disagree, and 5% of the respondents did not respond to this item (see figure 6.3). The findings show that the rates of adherence to ART at the health facilities are being monitored. However, some are not monitoring the rate of adherence at their health facilities. Data collecting regarding the impact of the programmes derived from the rate of MTCT, new infections, child and maternal survival or health, and health services effect etc. These measurements must be performed at a national level to assess the PMTCT programmes coverage, sufficiency and impact. Data collection on PMTCT ARV and ART coverage is challenging considering concerns over the data quality and completeness in many countries, especially those in poor socio-economic settings (WHO 2012).

Figure 6. 3: Monitoring the rate of adherence to ART



Additionally, the respondents who indicated that they monitor the rate of adherence were asked to identify the methods or sources that are used to calculate the ART adherence rates at their respective health facilities. The majority of the respondents (90%) use records from the clients' routine adherence monitoring, following the use of both records from individual clients' routine adherence monitoring, and special survey conducted to monitor adherence (2.5%), only 2.5% of the respondents did not answer to this item (see figure 6.4). The findings show that the health facilities use records from individual clients’ routine adherence monitoring to calculate this ART adherence rate.

Figure 6. 4: Source of data used to calculate ART adherence rate



6.2.5. Monitoring clinics appointments

In Table 6.1 below, most of the respondents show that their health facility has a formal system to monitor HIV exposed infants scheduled appointments attendants 35 (87.5%), only 5 (10.3%) do not have a formal system to monitor HIV exposed infants scheduled appointments attendants in their health facility. The table further shows that in all the health facilities, the clients are given scheduled appointments for their next attendance, 35 (76.3%) of the respondents will only know if the clients are ill or have died or dropped out or if a client does not attend a scheduled visit, only 5 (13.2) do not know. Although most of the respondents 36 (92.3%) have systems to follow up with PMTCT clients who do not appear for an appointment at their facilities, only three (7.7%) do not have the system. The findings show that health facilities have a formal system to monitor HIV exposed infant scheduled appointments. In all the health facilities, the clients are given scheduled appointments for their next attendance and healthcare workers knows if clients are ill, have died or have dropped out, or if a client does not attend a scheduled visit. The health facilities have systems to follow up with PMTCT clients who do not appear for an appointment at their facilities. However, not every health facility has these systems.

Table 6. 1: Monitoring clinic appointments

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Formal systems to monitor HIV exposed infants scheduled appointments attendants	Yes	35	87.5	40	100
	No	5	10.3	40	100
Clients are given scheduled appointments for their next attendance	Yes	40	100	40	100
	No	-	-	40	100
HIV positive mothers not attending a scheduled visit; do you know if they are ill, have died or have dropped out	Yes	35	76.3	40	100
	No	5	13.2	40	100
Systems to follow up with PMTCT clients who do not appear for an appointment	Yes	36	92.3	40	100
	No	3	7.7	40	100

6.3. Improvement Strategies, Interventions, and Retention

6.3.1. Strategies to improve care, service and retention

The mothers in the case-control study were asked if they can provide strategies to improve the PMTCT follow-up services. These sub-themes present the strategies to improve PMTCT care and some of the strategies were briefly presented in previous chapters. Therefore, this sub-theme presents these strategies with more details. Most of the mothers from both the case and control groups show that the long waiting periods should be improved. The long waiting hour should be reduced to enhance the quality of services. Here is what one of the mothers said: *Waiting periods, I will not leave this clinic, but the waiting periods are a problem. I left another clinic because of the waiting periods (LTFU P8, age 26).* The quote shows that the long waiting hours need to be improved. The mother already left another clinic because of the long waiting hours. The mothers who are currently in care also suggest that the health facility should improve the waiting hours, including space and available consultation rooms. One of the mothers suggests that healthcare workers should provide appointments dates that are suitable for her:

> They must allow me to take medication on the dates that favour me, they must ask us the date that we can collect treatment, we cannot all collect at the same time (LTFU P6, age 33).

Additionally, the CHWs were also asked to provide strategies to improve the retention of HIV positive in the PMTCT programme. The findings show that CHWs ensures anonymity, privacy, and confidentiality of HIV positive mothers through proper counselling before every session. This is confirmed by a mother who expressed:

> When you know someone's secret you do not talk about it with other people, so I show them that when I talk to them, assure that the thing we talk about stays between us, I don't share it with others (CHW P4).
>
> We first explain to them about the privacy of the conversation, we sit down with them, and talk to them and tell them that for us right now we are going to hold this secret so they should not think that will share the information with their neighbours. We tell them that what we talk about here will stay here (CHW P1).

The findings show that CHWs provide counselling or health talks to convince HIV positive mothers to adhere to treatment and take their medication regularly. They show that CHWs rely on counselling or health talks to convince HIV positive mothers to continue with ART. The findings also show that CHWs believe that they need to expand their services and successes with relevant resources like stationary. This is confirmed by a CHW who said:

> The challenges are that when we go door-to-door we don't have resources in the harsh weather, and we don't have a choice but to go to work, they should provide us with umbrellas, we don't have them. Some have it but some don't have it (CHW P2).

The participants were asked if they want to continue services with their respective clinics. The findings show the participants wish to continue with the service at the clinic. A participant who is LTFU agreed to restart and continue with the service because the clinic is close to where she lives. One participant who is LTFU wants to restart and continue with the service only if the clinic accommodates her and allocates her clinic appointments that do not clash with her work schedules:

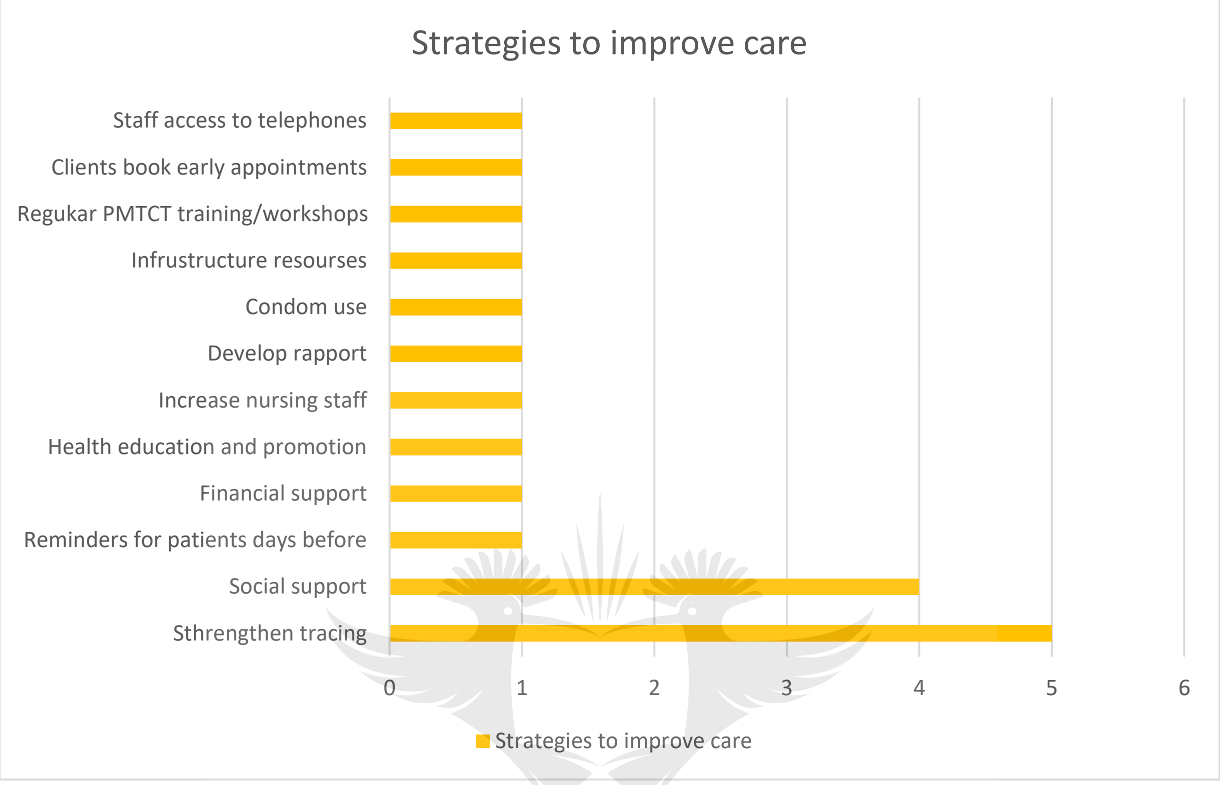
> I want to restart, only if they agree to give the appointment dates that do not clash with my work. I am comfortable with the current clinic I am using but it is a little far from my place compared to this one. But I have someone who collects treatments for me, and the zone 1 clinic can give me appointment dates that do not clash with my work, here they don't want to (LTFU P6, age 33).

Other LTFU participants decided that they will not restart the service at all due to the distance, they have self-transferred to other clinics. The CHWs were asked if the participants who are LTFU want to restart treatment and continue with the clinic. The CHWs believe that HIV positive mothers do not want to restart because they have already self-transferred to other health facilities: *"Some don't want to, some want to continue with another clinic and we do tell them are those who want to continue, but they have a problem with transportation"* (CHW P10). However, most of the CHWs believe that HIV positive mothers who are LTFU want to restart and continue the service at their respective health facilities. This is supported by CHWs who said:

> They want to continue with the clinic, those who we find mostly refer them back to the clinic, most of them are those that want to continue with the clinic because this is close to where they are staying. So, they don't want to go to another clinic because the clinic is closer to their homes (CHW 9).
>
> Yes, they do come back because we go to the households, they don't want to see our uniform in their households that's why they come back, they don't want us exposing them to their community when we come to the households (CHW 12).

Figure 6.5 below shows that most of the respondents indicated that strengthening of tracing (n=5) is a strategy to improve PMTCT follow-up services for the future. This is followed by social support (n=4). The strategies include financial support (n=1), health education (n=1), increase nursing staff (n=1), develop rapport (n=1), booking early for appointments (n=1), the use of condoms (n=1), Infrastructure resources (n=1), access to telephones for staff (n=1), accelerate training on PMTCT (n=1), and remind clients a day before (n=1). The finding shows healthcare workers think the strategies to improve PMTCT follow-up services for the future is to strengthen tracing.

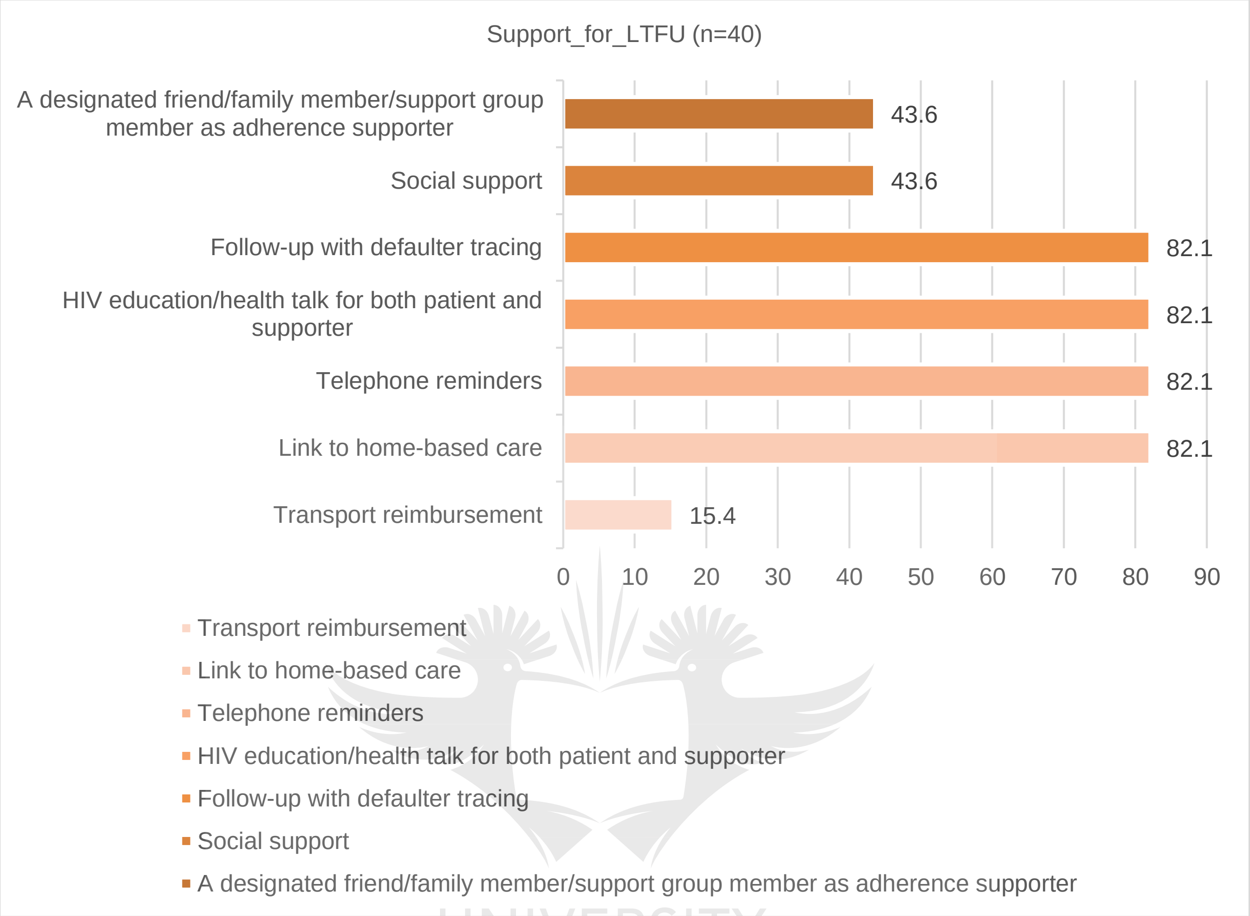
Figure 6. 5: Strategies to improve PMTCT services in the future



6.3.2. Interventions for retention of HIV positive mothers who are LTFU

In Figure 6.6 below, 82% of the nurses and lay counsellors provide a link to home-based care and 82% provides follow-ups with defaulter tracing to support LTFU mothers. This is followed by 82% who provide HIV education/health talk for patients and adherence supporters, and 82% who provide supporter telephone reminders. The other services are designated friend/family member/support group member as adherence supporter (43%), Social support (43%), and transport reimbursement (15%). The findings show that HIV positive mothers are provided linked to home-based care and follow-up with defaulter tracing, including HIV education/health talk for patients and supporters, and supporter telephone reminders. The community-based health programme serves as a bridge between the community and the health care, to track and trace HIV positive mothers. Without these programmes, HIV positive mothers who are LTFU will not be traced and reintegrated into the PMTCT programmes. HIV positive mothers who are not traced will continue to be LTFU and not adhere to HIV treatment.

Figure 6. 6: Outreach supportive services LTFU mothers



6.3.3. Monitoring interventions

In Table 6.2 below, the majority of the respondents 38 (95%) use interventions to improve the health provider's motivation to promote better client adherence, only two (5%) do not use interventions to improve the health provider's motivation to promote better client adherence. Most of the respondents (85%) have evaluated intervention approaches to improve adherence to ART at their health facilities 6 (15%) and do not evaluate. The findings show that healthcare workers used interventions to improve the health provider's motivation to promote better client adherence. In addition, healthcare workers have evaluated intervention approaches to improve adherence to ART at their health facilities.

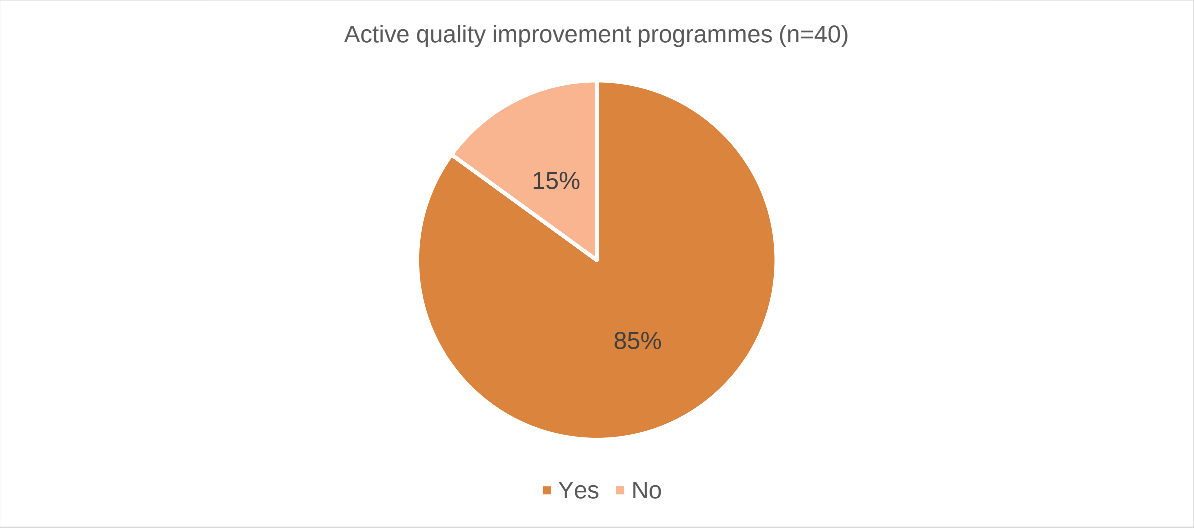
Table 6. 2: Monitoring the interventions approaches

Variables	Category	N	%	Total (N)	Total (%)
The use of Interventions to improve the health provider's motivation to promote better client adherence	Yes	38	95	40	100
	No	2	5	40	100
Evaluation of your intervention approaches to improve adherence to ART at this facility	Yes	34	85	40	100
	No	6	15	40	100

6.3.4. Active quality improvement programme at the facilities

The respondents were asked if they have active quality improvement programmes. The majority of the respondents (85%) show that the facilities have active quality improvement programmes, only 15% of the respondents lack active quality improvement programmes at their health facilities (see figure 6.7). The findings show that health facilities in this study do have active quality improvements programmes.

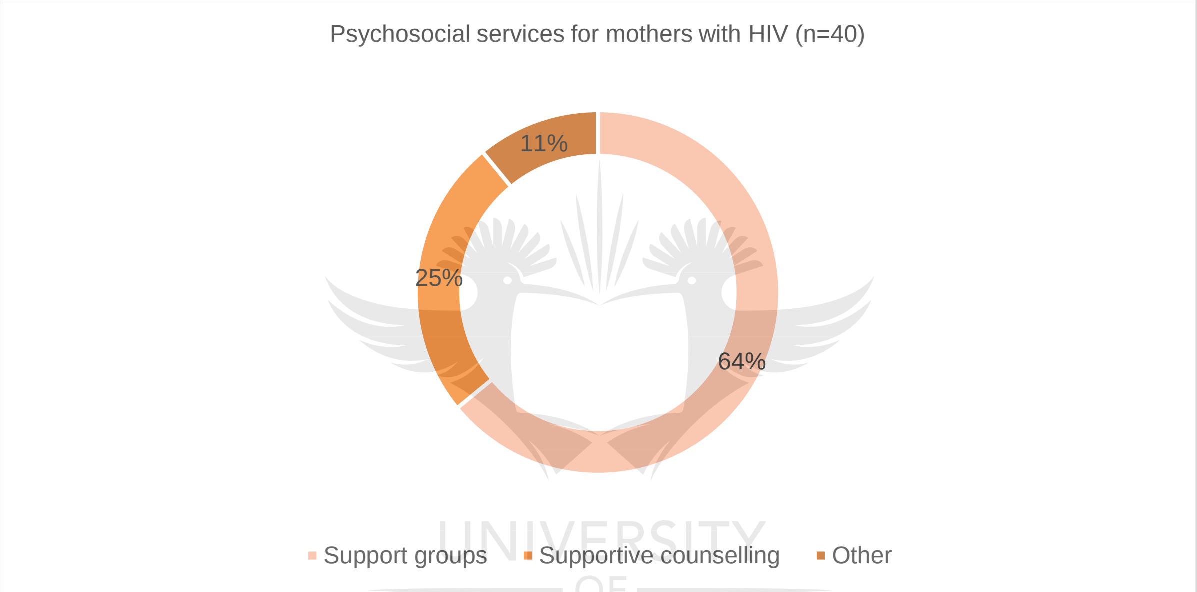
Figure 6.7: Active quality improvement programmes



6.3.5. The psychosocial services provided for mothers with HIV

In Figure 6.10 below, most of the respondents show that their facilities routinely provide support groups (64%) for HIV positive mothers followed by supportive counselling (25%) and others (11%). The findings show that facilities routinely provide support groups for mothers with HIV. The support groups help mothers in terms of education of medication adherence and other challenges faced in the PMTCT programme. This shows that mothers are supported by the health facilities to tackle the challenges of LTFU and non-adherence to treatment.

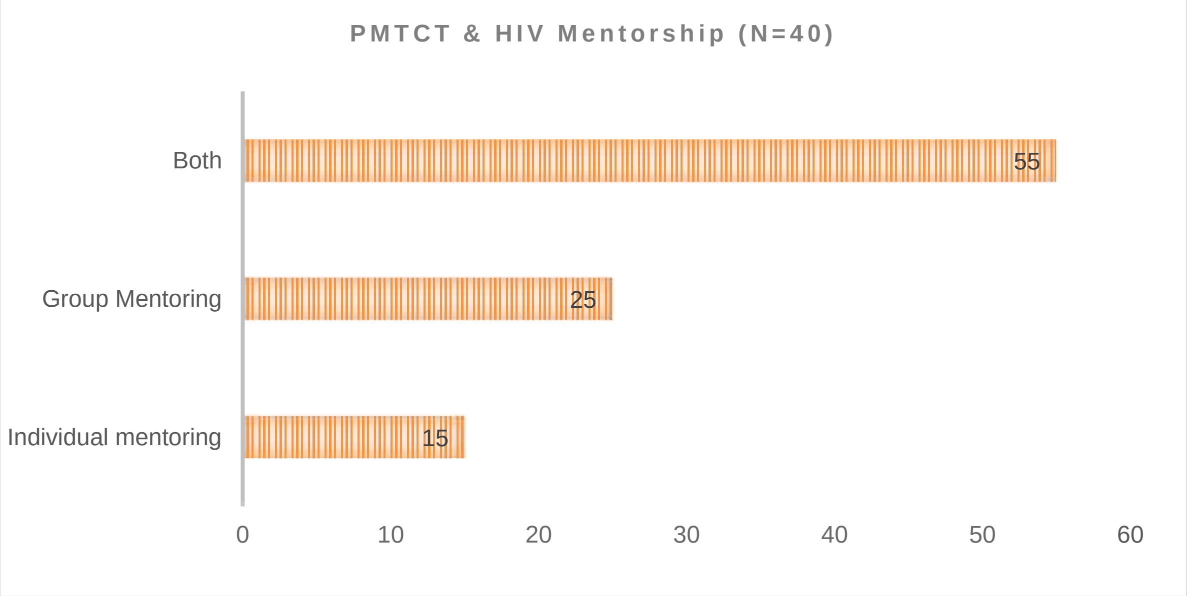
Figure 6. 8: Psychosocial services for mothers with HIV



6.3.6. PMTCT & HIV mentoring

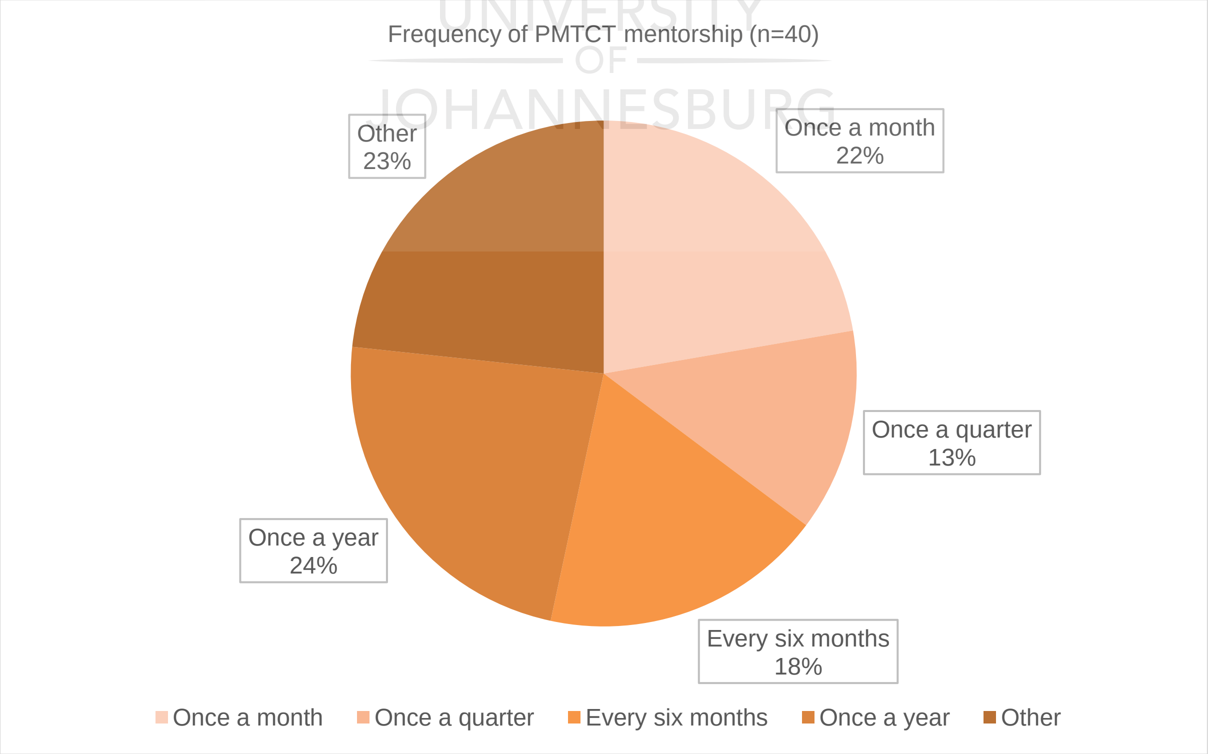
The respondents were asked to indicate the kind of PMTCT & HIV mentoring they received at their respective health facilities. In Figure 6.8, most of the respondents received both individual and group mentorship (55%). This is followed by the respondents who received only group mentorship (25%) and the respondents who received only individual mentorship (15%). The findings show that the nurses received both individual and group PMTCT & HIV mentorship.

Figure 6. 9: PMTCT & HIV mentorship



The respondents were asked to indicate how often they receive PMTCT and HIV mentorship at the facilities. In Figure 6.9, most of the respondents received PMTCT and HIV mentorships once a year (24%). Others receive mentorship once a month (22%), every six months (18%), and once a quarter (13%). The findings show that healthcare workers receive PMTCT and HIV mentorship once a year.

Figure 6. 10: Frequency of the PMTCT & HIV mentorship



6.3.7. Suggestion box

In Table 6.3 below, most of the respondents (97.5%) have a suggestion box for patients to provide feedback on the quality of care at the facilities, only 2.5% of the respondents do not have a suggestion box at the health facility. In addition, most of the respondents (87.5%) with a suggestion box shows that the suggestions from the patients have been reviewed in the last three months, only 12.5% of the respondents have not reviewed suggestions from patients. The findings show that health facilities have a suggestion box for patients to provide feedback on the quality of care at the facilities and the nurses and lay counsellors claim that the suggestions from the patients have been reviewed in the last three months

Table 6. 3: Using the Suggestion box

Variables	**Category**	**N**	**%**	**Total (N)**	**Total (%)**
Suggestion box for patients to provide feedback on the quality of care	Yes	39	97.5	40	100
	No	1	2.5	40	100
Suggestions from patients have been reviewed in the last three months	Yes	35	87.5	40	100
	No	5	12.5	40	100

6.4. Chapter Conclusion

Most of the mothers in this study who were LTFU claim that they were not traced or contacted by health personnel. On the other hand, the nurses and lay counsellors believe that HIV positive mothers are provided with the link to home-based care and follow-up with defaulter tracing. The most available data for the nurses and lay councillors to monitor LTFU and non-adherence is the date for the next scheduled clinic visit of the patients. They do not have data to monitor or track the reasons for LTFU or failure to adhere to HIV treatment. The mothers believe that long waiting hours should be improved with the quality of services while the nurses and lay councillors recommend improved adherence monitoring as a useful intervention approach to promote adherence rates at the facilities. The next chapter discusses these findings in detail.

CHAPTER 7

DISCUSSIONS OF THE FINDINGS

7.1. Introduction

This chapter summarises the extent to which the objectives of the study were achieved in alignment with the research findings. This study was conducted with multiple groups of HIV positive mothers and healthcare workers. It found substantial evidence regarding social patterns of LTFU and non-adherence to HIV treatment and other PMTCT activities. The interest to conduct this study was drawn from the existing gap of social patterns of LTFU and non-adherence in the Limpopo province PMTCT programmes. There is a gap of knowledge on the social meanings of LTFU and non-adherences to HIV treatment in rural settings. The study provided a sociological understanding of the barriers that are linked to social institutions such as family, education, gender relations and health systems.

The study explored social patterns of LTFU and non-adherence of HIV positive mothers in the Limpopo province PMTCT programmes and aimed to inform policy on PMTCT care, utilisation and retention. The nurses and lay counsellors and the CHWs experiences in the implementation of the PMTCT programmes contributed to the patterns related to the provision of services, which can be explained based on health systems barriers like care, health resources, community engagement, and other related issues. The professional healthcare workers and CHWs opinions or assumptions were expressed through their lived experiences in the PMTCT ward-based and public outreach programmes. The findings relied heavily on the opinions the healthcare workers attained from the responses or reasoning of HIV positive mothers during the tracking, tracing, retention processes and routine clinic consultations.

7.2. The research findings

7.2.1. Underlying reasons why mothers are LTFU and fail to adhere to HIV treatment

The study found the following social patterns that influenced LTFU and non-adherence to HIV treatment: The gender and family dynamics of HIV disclosure where characterised by fear, guilt, and struggles with methods of HIV disclosure to sexual partner, family and community members. Some mothers self-transferred to alternative health facilities (to be closer to home or because of rigid health systems). The patterns of delays and interruptions of ART (unreadiness and unwillingness to initiate ART, denial of HIV and beliefs that HIV is cured, work responsibilities) were noticeable and influenced by the intake of HIV medication. This study documents medication-related barriers (fear of getting sick from the medication side effects, lack of support to cope with the side effects, taking alternative medicines and lack of food to take with the medication) and health-system barriers (long waiting periods at the health facilities and poor treatment from the healthcare workers and lack of support when medications runs-out). These social patterns are discussed further below and are incorporated with literature.

- Fear of disclosing HIV to a sexual partner

The gender-related patterns of non-adherence to treatment and LTFU reflects on the mothers' fear of inadvertent HIV disclosure to sexual partners, feeling guilty, for not disclosing HIV to sexual partner and struggles with methods or ways to disclose their HIV status. The mothers feared negative reactions (being blamed or judged) that come with disclosing HIV status to their sexual partners. Similarly, a study by Mitiku et al. (2016) found that most of the mothers who participated in the study did not disclose their HIV status to their partners and feared being physically or verbally abused. The CHWs support this and believe that HIV positive mothers fear being rejected, interrogated, or blamed by their partners if they disclose their HIV status. They believe mothers endure negative reactions that lead to fights, breakups, or divorces in the relationships and these negative reactions are influenced by HIV disclosure to partners. Other studies have documented similar findings, Anindita and Shaluhiyah (2016) found that the reason HIV positive women fail to disclose their HIV status to their partners is that they fear that their partners might leave the relationship. The findings above resonate with a qualitative study by Kanguya et al. (2022) in Zambia which found that women in the PMTCT expressed fear of divorce as a prominent barrier to disclosure to their partners.

In this study, some mothers failed to adhere to their clinic appointments and HIV treatment because they were worried about inadvertent disclosure of their status at home (these mothers were either cohabitating or married). There is existing literature suggesting that mothers who are cohabitating or married may struggle with treatment adherence, especially when they fear disclosing their HIV status to their partners (Frizelle, Solomom & Rau 2009; Muchedzi et al. 2010; Mitiku et al. 2016). The mother avoided suspicions from their partners by halting ART or intentionally missing their clinic appointments because they struggled with finding an explanation for attending clinic. Some mothers were worried about taking HIV medication in secret, in case the partners might accidentally find the HIV medication and they would fail to find a good explanation for being on medication. The findings above echo a qualitative study by Madiba and Josiah (2019) in Botswana that investigated the perceived stigma and fear of unintended disclosure among HIV positive adolescents found that the participants feared unintended disclosure of their HIV status and opted to hide and take their medication in privacy, and this led to them missing doses. Studies suggest that mothers struggle with treatment adherence, especially when they fear unintended disclosure of their HIV status (Muchedzi, Chandisarewa & Keatinge 2010; Mitiku et al. 2016). The mothers who fear untended HIV disclosure struggle with disclosure and are more likely to be LTFU or fail to adhere to HIV treatment (Adedimeji et al. 2012).

On the hand, the CHWs avoided inadvertent disclosure of the mothers' HIV status during household visits by adhering to confidentiality and privacy practices. They pretend to be unaware of mothers HIV status when the partners/husbands ask many questions during household visits, they referred the mothers to the health facilities instead. However, a study by Thorsen, Sundby and Martinson (2008) contradicts the findings above because it found that PMTCT home visits increase the risk of exposing the HIV status of women and the risk of gossiping behaviours. A similar study conducted in five African countries (Cote D'Ivoire, Democratic Republic of Congo [DRC], Malawi and Uganda) by Besada et al. (2018) reveals concerns about the confidentiality practices among volunteer cadres for patients who are LTFU and living with HIV.

Although the mothers in this study did not disclose their HIV status to their partners, they understood the effectiveness of HIV treatment and the importance of HIV disclosure. They were planning to disclose to their partners in the future. However, they struggled with ways or methods of disclosing their HIV status to their partners. The findings above concur with a study conducted by Madiba (2013) in South African

ART clinics which shows that the ways or skills to disclosure HIV are a challenge. The study investigated the impact of fear, stigma, and parents` HIV disclosure to their children and found that parents delayed disclosing their HIV status because they lacked skills to disclose their status and needed health care providers to support them with HIV disclosure (Madiba 2013). One of the mothers in this study described an ideal scenario where she would come to the clinic with her partner and test for HIV so that they could take the treatment together. The CHWs noted pretence as a strategy for the mothers to disclose their HIV status to mitigate the negative consequences of disclosure by inviting mothers with their partners for HIV testing and counselling, and the mothers to pretend as it is their first time to test for HIV. Support from CHWs is important, this is confirmed by a study conducted by Lukyamuzi, et al. (2022) in Uganda on CHWs contribution in improving HIV disclosure among HIV-affected sexual partners which found that CHWs are able to provide support during disclosure process among adults living with HIV and expand community-based HIV care and management for patients experiencing challenges relate to disclosure to sexual partner.

The difference between the case and control group in this study is that the mothers in the case group were influenced by fear of inadvertent disclosure at home because they were either married or cohabitating and were at risk of unintended HIV disclosure. Most of the mothers in this study, both cases and controls were single. The mothers who are not married or cohabitating could experience lower risk of inadvertent disclosure of HIV to sexual partners compared to the mothers who are married or cohabitating. The findings shows that women are asked to bear the responsibility for the health of the couple and are expected to manage their HIV status and that of their partners.

- Fear of disclosing HIV to family

Family-related patterns of HIV disclosure were found to be the reason why mothers were LTFU and failed to adhere to HIV treatment. The mothers in the case group were LTFU when they feared inadvertent HIV disclosure to family and struggled with ways to disclose their HIV status. The findings above support a study by Yee et al. (2020) which found that HIV positive mothers not attending the PMTCT programmes was influenced by fear of accidental disclosure of HIV status to extended family. Similarly, a qualitative study by Liamputtong and Haritavorn (2016) in Thailand explored the experiences of disclosing HIV status to family members and found fear of stigma and discrimination that led to women decided to not disclose their status to their parents and children, some were rejected and discriminated against by their family members.

The mothers in the control group support this and believe that HIV positive mothers do not disclose their HIV status to their parents, and this is the reason they are LTFU. The mothers in the case group who feared HIV disclosure to their families or parents were all young adults (between the age of 23 and 25). These young mothers were unable to disclose their HIV status to their families and worried about being judged. Hence, the mothers planned to disclose their status to the parent and felt guilty for living in secrecy. The findings above echo a study by Wong et al. (2017) which found complex interactions regarding HIV disclosure to family members that involve complex interactions of guilt, shame, perceived stigma and need for secrecy. The CHWs in this study support that HIV positive mothers miss clinic appointments as they have not disclosed to their family, specifically their children. They believe that the family members could help the mothers as treatment supporters and emphasise that most mothers who have not disclosed their HIV status lack social support from their families. Several studies conducted in Africa (Zimbabwe and South Africa) have demonstrated the importance of social support for women to adhere to PMTCT services (Falnes et al. 2011; Shroufi et al. 2013).

- Fear of inadvertent HIV disclosure to neighbours/community members Regardless

The mothers who were LTFU feared inadvertent HIV disclosure to the community members at the health facilities. The findings concur with a study by Dirisu et al. (2020) which found that the participants believe that their fear of stigma is associated with fear of being seen at health facilities when utilising HIV-related services. The mothers in the case group were afraid that the people from their community might discover their HIV status. Adedimeji et al. (2012) supported the findings and revealed that HIV positive mothers who are LTFU fear that their status will somehow be exposed if they attend the appointments. The CHWs and HIV positive mothers in the control group support the statement above and believe that HIV positive mothers are LTFU when they fear inadvertent disclosure of their HIV status at the health facilities. According to

Yee et al. (2020), fear of unintentional HIV disclosure to neighbours impacts service use in the PMTCT programmes. Regardless, in this study, the mothers in the control group continued to adhere to their clinic appointments. These mothers showed commitment to adhering to clinic appointments and HIV services even when they might discover their neighbours at the health facilities.

- Mobility or self-transfers to health facilities closer to home

Self-transfer outcomes are an important contribution to this study to explore and understand the social meaning, patterns, or reasons why HIV positive mothers self-transfer to other health facilities, and to explore whether they transferred to reputable and sustainable health facilities. Mobility or self-transfers patterns interrupt the healthcare system and hinder the success of the PMTCT programmes. The mothers in the case group self-transferred to other health facilities and failed to apply for transfer letters. Similarly, Hickey et al. (2016) found that 78 patients who were LTFU had no official transfer, 38 (49%) eventually returned to care, 22 (28%) transferred to another facility and 18 (23%) never returned to care.

The letters are required at the health facilities for patients who are transferring from other health facilities. Some mothers were completely unaware that they have to obtain transfer letters before they move to other health facilities. They blamed a lack of awareness or prior knowledge of this clinic processes. Some of the mothers who were aware of the transfer letter process did not bother or think about obtaining the transfers letters even when they clearly understood the importance of transfer letters as a means to access a new health facility. The statement above resonates with a qualitative study by Bengtson et al. (2019) in Malawi which found that women enrolled for Option B+ self-transferred to other health facilities and were aware of the need to obtain a formal transfer but failed to do so, which led self-transfers to new clinics. In the case group, one of the mothers wanted to be reintegrated to a clinic at home but she was not sure whether the health facilities will allow it because she did not have a transfer letter. This addresses the complexities of moving from one health facility to another without transfer letters. Therefore, delays the reintegration to the PMTCT programmes or influences LTFU in the PMTCT programmes. Likewise, a study by Sikombe et al. (2020) in Zambia found that re-entry of HIV patients into new facilities with unofficial transfer often interrupts and delays treatment.

The mothers in the case group who self-transferred to health facilities that were closer to their home and showed patterns of regret or initial error in selecting health facilities that were far from their community or home. The mothers show patterns of constant mobility where they move from one health facility to another and in different areas multiple times. The findings resonate with a systematic study by Davey, Cowan and Hargreaves (2018) which found that mobility among the participants was associated with reduced initial healthcare access and interruption of ART. Escamilla et al. (2015) found that uptake of PMTCT was influenced by the distance to the health facilities, 103 of 145 (71%) participants who lived within 1.9 km of the PMTCT facilities used the services compared to 65 of 109 (60%) who lived farther away from the PMTCT facilities. The recording and tracking systems at the health facilities failed to record these mobility patterns making it look like the programmes are less effective. Akin to the findings above, a study by Sikombe et al. (2020) in Zambia found that 46 out of 178 (25.8%) of the participants who obtained official transfer letters from their original health facilities were not captured on the facilities database.

The mothers who self-transferred to health facilities that were closer to their home experienced problems with the distance and travel costs and were rectifying their initial selection error. The CHWs support this and believe that the mothers who are LTFU are influenced by the distance and travel costs. A study by Tweya et al. (2014) in Malawi supports the statement above based on the findings that the participants indicted travelling away (38%) and travel costs (16%) as the reasons they are LTFU. Another study in Malawi by Tenthani et al. (2014) with 2930 women found 16% of the participants experienced issues related to transport money and that is the reason they stopped ART. Adedimeji et al. (2012) report the findings from the focus group discussions with women in the PMTCT programmes and reveal that women travel long distances and struggle to reach health facilities. Nevertheless, there are mothers in the case and control group who did not experience issues with the distance and could walk to the health facilities which eliminates the need for transportation.

- Mobility or self-transfers due to rigid health systems

There are mothers in the case group that self-transferred to other health facilities because of overlapping clinic appointments. There is a challenge of rigid health providers, the healthcare workers were not willing to assist or be flexible with their services. Similarly, Hickey et al. (2016) found that HIV patients interrupt treatment when they migrate or self-transfer to other health facilities and that they experience obstacles in their current health facilities. In this study, mothers blame poor communication and attitude from the healthcare workers during negotiation for clinic appointments that do not clash with their school or work schedule. A qualitative study by Chamberlin et al (2022) in Malawi also found inflexible appointment schedules that constrained the ability of the participant to adhere to HIV care considering unexpected life events that led to them missing their clinic appointments. In this study, the mothers expressed the need for healthcare workers to accommodate their daily life activities or work schedules. The mothers failed to adhere to treatment because they were committed to their work or school responsibilities. The findings above resonate with the WHO (2009) report that women who are working may struggle with the adoption of the HIV medication regime especially when they have work responsibilities or household work, like cooking and taking care of their children. The mothers who self-transfer to health facilities do not always select health facilities that are sustainable considering that they are on lifelong Option B+ treatment regimen. Hence, the mothers in this study showed a great deal of resourcefulness in finding places that can accommodate their needs. Rigidness and non-flexibility can lead to LTFU and hinder the success of the PMTCT programme. Though the mothers in this study were resourceful and found health facilities that accommodate their needs, this is exemplified by one of the mothers finding a mobile clinic as a substitute health facility. Contrary to the findings above, a study conducted in Georgia by Henkhaus (2021) on the issues of using mobile clinics found that mobile HIV care breaches confidentiality and influences stigma, mobile care has safety concerns and community members have not accepted these services.

- Unreadiness or unwillingness to initiate ART

The other mothers who were LTFU displayed social patterns of deliberately delaying or interrupting ART initiation. The mothers in the case group struggled with acceptance of their HIV status and were not ready or willing to initiate or continue with ART. Consequently, they delayed ART even though they were well aware of the importance of HIV treatment. They intentionally delayed treatment at least until they were ready. Unreadiness to initiate ART or take HIV treatment explains why some mothers are LTFU and do not adhere to or continue with HIV treatment. There is evidence of social patterns that influence unreadiness or interruptions of ART initiation, losing interest in the HIV treatment regimen, the desire to focus on motherhood duties, gathering enough information about the HIV treatment regimen and unwillingness to acquire information about the next clinic appointments. Similarly, a study by Tlebere et al. (2007) reveals that women's unwillingness and unreadiness to initiate or continue ART was influenced by their desire to prioritize the health of their family members or the health of their children. Kouassi et al. (2014) conducted a study in Cote d'Ivoire also found that patients who believed they had not been well prepared by facility staff before ART initiation. In this study, the mothers in the case group were not ready to initiate ART from the beginning while the mothers in the control group showed commitment to continue with their HIV treatment. However, contrary to the findings above, a study conducted in Nigeria by Danladi et al. (2020) reveals positive attitudes from pregnant women attending antenatal clinic regarding the readiness to take HIV treatment. The findings in the study reveal that the women attending the programmes were ready to initiate ART and end the HIV pandemic by taking their medications (ARV drugs).

- Denying HIV status and beliefs that HIV is cured

The mothers in the case group were in denial of their HIV status or believe that their HIV is cured. They could not understand the importance of taking HIV treatment because physically they do not feel sick or ill. A qualitative study conducted by Wringe et al. (2009) in Tanzania also found denial of HIV status, and the participants` perceptions of illness severity influenced HIV clinic attendance, relating to changes in physical symptoms. In this study, beliefs that HIV is cured is common among mothers who were LTFU, yet there is currently no cure for the virus. Chomat et al. (2009) conducted a study in India and found dangerous misconceptions about HIV diagnosis, most of the participants believed that practitioners offer a cure for HIV. The mothers in this study decided to stop HIV treatment because they are under the impression that the virus is not affecting them. In line with the findings above, a cross-sectional study by Abdisa and Tenaw (2021) with 254 participants found that 88.2% of the respondents were adhering to Option B+ PMTCT and 10 (33.3%) had missed their ARV medication, and of those who missed their medication, 52% indicated that the reasons for non-adherence or stopping treatment is that they were feeling better.

The present study found patterns, where mothers in the case group believed that their low viral load was an indication that their HIV status show negative test outcomes. This was one of the reasons why HIV positive mothers believed that they are healed or free from HIV. The CHWs support this and believe that HIV positive mothers are in denial or do not believe that they have HIV after their retests of their HIV show false-negative. Thus, the mothers decided that they are cured after false-negative retests results or when they performed self-health assessments and started to believe that they do not need HIV treatment. False-negative tests is a term used to describe an error made by the testing devise, the test fails to detect the virus even though the patient is HIV positive (Centers for Disease Control and Prevention (CDC) and Association of Public Health Laboratories 2016). This kind of errors are prevalent in many health facilities. For instance, a study by Shanks, Klarkowski and O'Brien (2013) conducted in DRC, Burundi found a total of 44 patients with false-positive test results and some of these results had been abandoned. The mothers lack awareness and knowledge regarding HIV and the importance of Option B+ treatment regimens. There are mothers in the control group who do not believe that they are HIV positive and question the effectiveness or importance of HIV treatment. Nonetheless, they continued with their HIV treatment for reasons that include taking treatment for their children or taking treatment because they were instructed by the healthcare workers during HIV testing and counselling sessions. Ramoshaba and Sithole (2017) also reveal that most of the mothers in the PMTCT acknowledged the importance of HIV treatment.

- Committed to work responsivities

Another important social pattern is the interruption of ART because of work obligations/responsibilities. Employment is a major factor that influences treatment adherence. Most of the mothers in the control group were unemployed compared to the mothers in the case group. In the case group, all the mothers who were employed were affected by their work obligations, thus, halted ART. In line with the findings above, WHO (2009) report that women who are working struggle with the adoption of the HIV medication regime especially when they have work responsibilities or household work, like cooking and taking care of their children. Work responsibility influences mothers' adherence to clinic appointments and HIV treatment because there is little or no time for mothers to attend these appointments to collect HIV medications. The above findings echo a study by Chamberlin et al. (2022) which found that most of the participant in their study missed ART appointments due to funerals, work, and other unexpected events.

The mothers barely find time to attend clinic appointments because of the harsh work schedules and employers rejecting an application for leave of work. Work provides money or a source of income to provide for families. Consequently, the mothers could not afford to miss work or apply for unpaid leave, they need the money to buy items like formula milk. Social roles compel mothers to commit to their daily responsibilities or daily life activities to provide for their families. The mothers' commitment to work obligations led to LTFU and non-adherence to HIV treatment, the mothers prioritize their financial security. Moving to other areas to start work or attend work duties or tasks that influences LTFU when mothers fail to transfer to a reputable health facility in that area. Similarly, a qualitative study that was conducted by Oguejia & Omotoso (2021) in Nigeria found that pregnant women could not attend the PMTCT programmes because of the social roles they have to play in their families and are pressured to fulfil these roles or obligations, and some of these roles are perceived with cultural significance.

- Fear of being sick from HIV medication side effects

Experiences of HIV medication barriers influence adherence to clinic appointments and HIV treatment. During tracking and tracing sessions, the CHWs reveal that HIV positive mothers complains about the HIV medication side effects and had stopped or halted HIV treatment after experiencing severe side effects. The case-control study found social patterns of halting or stopping HIV treatment due to a fear of getting sicker from the HIV medication side effects. The findings above echo a study by Mpinganjira et al. (2020) which reveals that HIV positive mothers are LTFU by stopping ART due to the side effect. Similarly, a study by Kweyamba et al. (2018) reveals that HIV positive mothers are LTFU due to fear of swallowing antiretroviral drugs. The mothers in the case group reiterate the discomfort they felt when taking HIV medications and react immediately to medication side effects by stopping or halting HIV medication intake. They believe that the medication ramps up or elevates their sickness. The findings above concur with a qualitative study by Katirayi et al. (2016) which found that women feared the side effects that are caused by ART. Abdisa and Tenaw (2021) also found that the adherence level was associated with HIV medication side effects and 89% of the respondents who experienced the side effects were less likely to adhere to treatment compared to those who didn’t experience side effects. A similar study by Kouassi et al. (2014) found that the patients who experience side effects were three times more likely to discontinue their HIV treatment compared to those who do not experience side effects.

The severity of the side effects impacts daily life activities like work responsibilities, making it difficult to perform work tasks. I have already discussed the impact of work responsibilities as a very important social pattern that the mothers commit daily. According to WHO (2009), women who are working may struggle with adoption of the HIV medication regime especially when they have work responsibilities or doing household work like cooking and taking care of their children. Social patterns of timing the intake of HIV medication is important for adherence to HIV treatment. Choosing a certain time to take HIV medication can impact daily life activities and responsibilities considering the severity of the HIV medication side effects. The mother may have obligations at the time that they have to take medication, which brings the question about the best time to take the medication considering the severity and longevity of the side effects. Ammassari et al. (2002) confirmed this and found that the reasons the participants in the study failed to adhere to the ART were because of the routines of taking HIV medications, the participants struggled with integrating the treatment schedule with daily life activities (36-57%) and forgetting to take medication (30-66%). In this study, the mothers in the control group continued adhering to HIV treatment when they experienced the side effects, while the mothers in the case group believed or feared that the medication or the side effects were causing their physical health to deteriorate.

- Lack of support to cope with HIV side effects

Lack of support to cope with the medication side effects was visible from the professional healthcare workers. The mothers struggled to cope or manage the side effects, especially how to handle the side effect severity. Managing or coping with the side effects is often difficult for other patients especially when the side effects are severe and non-stop. Hence, the healthcare workers are not supportive of mothers who experience these side effects or assist them with ways to cope with the side effects of the medication. A study by Johnson and Neilands (2008) reveals that non-adherence is seen as a strategy to cope with HIV medication side effects, and was associated with poorer provider relations, poor knowledge, and higher beliefs of treatment effectiveness. The healthcare workers failed to give the mothers valuable advice or strategies on how to cope with the side effects and when the mothers ask the healthcare workers, they are accused of not taking the ART serious. In line with the findings above, Chopra et al. (2005) found that through observation of the counsellors, only one HIV positive mother was informed about the HIV medication side effects, but all the HIV positive mothers were not informed about how to cope with the side effects when they happen.

Women are more invested in body positivity and attractiveness and were concerned about the weight loss that appears after taking the medication. There is a lack of clarity on the impact or severity of the side effects, and this can easily influence non-adherence. The poor treatment from the healthcare workers influenced LTFU or treatment non-adherence because the mothers were not assisted on ways to cope with the side effects, by the cadre that gave them the medication. King et al. (2021) conducted a study in Uganda where the participants emphasised the importance of counselling related to HIV medication side effects as a critical factor in helping patients with their adherence. In this study, the mothers projected patterns of seeking information about their health and most of these mothers wanted to continue with their HIV treatment but they [healthcare workers] ignored them. Likewise, a study conducted Dovel et al. (2021) found that mothers desired counselling sessions to help cope with HIV (the study reveals that several of the mothers reported being sad and overwhelmed), the belief and addition of stress management, and marital advice will be helpful services. This study found that mothers in the case group stopped ART when they were ignored or not supported by the healthcare workers regarding how to cope with the side effects, while the mothers in the control group continued with their treatment after the healthcare workers advised them to ignore the side effects. Despite mothers complaining about lack of support from healthcare workers, the CHWs had make efforts to convince mothers to continue with the treatment and provide support and insights on how to cope with the side effects of the HIV medication.

- Using alternative medicines

The social patterns of using alternative medicine to treat HIV are common among HIV patients. They intentionally delayed initiating ART to try alternative methods as substitute medicines or treatment and believe that they can treat or cure HIV. The mothers believe that these alternative medications work, as they are physically healthy and are yet to be severely ill. These alternative medicines include vitamin supplements, church, and traditional medicines. The CHWs support this finding and believe that HIV positive mothers use the church or African traditional medicines to treat HIV. A survey conducted in South Africa by Peltzer et al. (2008) also found that 36% of rural adults consult traditional healers for HIV treatment. The CHWs in this study noticed that during tracking and tracing of mothers that the mothers were already using alternative religious medicines and asked to finish their religious course before they can return to the clinics for HIV treatment. This shows patterns of delaying or interrupting treatment to finish religious medicine courses. They use multiple health systems (medical pluralism) to treat HIV, mixing Western medicine with religious medicines. A qualitative study by Moshabela et al. (2011) in South Africa reveals that medical pluralism was practiced among HIV patients and HIV treatments were delayed despite early contact with healthcare systems, the use of medical pluralism before ART initiation led to the delay of ART initiation. The CHWs report that most of the mothers were not sure of which system to follow or whether they can use multiple health systems. The CHW explain how it is difficult and take time to convince mothers to adhere only to Western HIV treatment.

In this study, the CHWs report that HIV positive mothers believe HIV is witchcraft and that church or traditional medicines are helpful. Peltzer et al. (2008) also found that the participants had consulted traditional healers for HIV treatment, they believe that traditional medicines are better compared to Western medicines. These beliefs can be disastrous when the traditional medicines fail to work, and their health conditions deteriorate. It is a dangerous when the patients start to use alternative methods as their only option to treat HIV (Frizelle, Solomon & Rau 2009). According to Varga and Brooks (2008), HIV positive women believe HIV is witchcraft or spiritual forces and they use alternative treatments from the churches and these treatments may go against instructions from the healthcare workers. Despite views from CHWs that HIV positive mothers use alternative medications to treat HIV, the findings in the case and control group with HIV positive mothers shows that most of the mothers were not using alternative medications and trusted medical doctors/nurses and only used western medicines (ART) to treat HIV. This is supported by the quantitative findings with nurses and lay counsellors. The nurses and lay counsellors believed that patients trust medical doctors/nurses (66%) to manage HIV, followed by traditional healers (17%), priests (15%) and others (2%).

- Lack of food to take with the HIV medication

The other mothers who were underprivileged failed to adhere to the medication due to the lack of food to take with the medication. Poverty is the biggest enemy affecting many South African, there are many people with little or no money to afford basic needs like food to eat. Falnes et al. (2011) argue that the male partners control the household finances in this poverty driven country (South Africa), where most women are unemployed and dependent on their partners or family for transport money or food. The CHWs in this study believe that the mothers were not adhering to HIV treatment when they run out of food to take with the medication. Though, HIV medication can be taken without food (preferably during bedtime) food is important to take with the medication (after eating or before eating). Similarly, a study by Nagata et al. (2011) found that vegetables and fruits are commonly used and were the most frequently food items used by persons living with HIV/AIDS.

In the case-control study, a mother in the control group who adhered to clinic appointments and collects her medication every month failed to adhere to HIV treatment when she runs out of food to take with the medication. Every month the mother runs out of food especially toward the end of the month and she is under the impression that the HIV medication can only be taken with food. The finding shows that not all the mothers in the control group (mothers who were not LTFU and adhere to their clinic appointment and collect their medication) adhere to HIV treatment according to the instructions from the healthcare workers. The CHWs believe that mothers fail to adhere to treatment because they lack food, and they cannot take their medication if they have not eaten, and the mother lacked the money to buy food or the assistance from the government in the form of social grants. As stated by the Department of Health (2013), South Africans experience socio-economic difficulties when it comes to utilising health care services. In resource-poor settings, women struggle to access government grants as a means for financial security (Frizelle, Solomon & Rau 2009).

- Medication runs out

It is important for mothers to collect their medication every month and for the medication to be available at the health facilities. The shortage of medical supplies delays the progress of the PMTCT programmes (Department of Health 2008; Mute, Akondé & Doumbia 2011; Kweyamba et al. 2018). The mothers in this study were LTFU when the medication ran out and it happened when the health facilities experienced shortages of medication supply. As claimed by a study conducted in India, the CHWs revealed shortages of HIV testing kits, shortages of antiretroviral drugs, and infant NVP prophylaxis hindered the PMTCT programmes (Suryavanshi et al. 2018). Mute, Akondé & Doumbia (2011) argue that the general services delivery protocols are affected by delays posed by shortages of resources like staff and medications. The mothers attend clinic appointments but experience poor treatment from healthcare workers and shortages of medication at the health facilities. They expressed frustrations and disappointments related to the lack of medications every time they attend clinic appointments. One of the mothers received poor treatment when she attended her clinic appointments, the healthcare workers shouted at her when she shared her grievances. Another mother tried to collect her medication at another clinic when HIV medication ran out and was rejected by the healthcare workers, and as a result, she stopped ART. The mothers who failed to adhere to their HIV treatment because they ran out of medication were from the case group, the mothers in the control group made sure they collected their medications before they ran out.

- Poor treatment and attitude from healthcare workers

The mothers' experience poor treatment from healthcare workers and that impacts negatively on their trust and progress in the PMTCT programme. In every health care facility, the concept of empathy is emphasized for every employee to better communicate, care for the patients, and increase the utilisation of services. The HIV positive mothers in this study feared being yelled at when they collect HIV medications from healthcare workers. In line with the findings above, a study by Mpinganjira et al. (2020) with 30 HIV positive mothers and 30 healthcare workers reveals that the mothers were LTFU because of poor treatment from healthcare workers, the health care workers shouted at them after missing appointments. The negative treatment from healthcare workers impacts negatively on HIV treatment adherence and the success of the PMTCT programmes. Most of the mothers in the control group did not experience poor treatment from the healthcare workers. The mothers in the case group missed clinical appointments fearing that the nurses will extend their negative behaviour towards them during the time they collected their medication. The mothers show that they have experienced poor treatment from the nurses before, therefore, they are trying to avoid a repeat of the harsh experience. A qualitative study by Painter et al. (2004) in Cote d'Ivoire also reveals that the women failed to attend follow-up visits because they were afraid of the staff.

- Long waiting hours

The health care system barriers that influenced LTFU and non-adherence of HIV positive mothers are the long waiting periods at the health facilities and poor treatment from healthcare workers. The CHWs also believe long waiting periods at the clinic is the reasons mothers miss their appointments. A study by Kweyamba et al. (2018) reveals that HIV positive mothers are LTFU because of long waiting times at the health facilities. Kouassi et al. (2014) conducted a similar study in Cote d'Ivoire found 40% of patients complained about the long waiting hours and 46% are likely to discontinue treatment. Mute, Akondé & Doumbia (2011) argue that the general services delivery protocols are affected by long waiting periods from delays posed by shortages of resources like staff and medications. Deressa et al. (2014) found that the mothers who participated in the study complained about the long waiting time to receive services. The mothers in the case and control group also experienced long waiting hours before receiving assistance at their respective health facilities. However, that did not influence LTFU or adherence to treatment. The CHWs on the other hand believe that HIV positive mothers are LTFU and fail to adhere to treatment because they struggle to cope with long waiting hours at the health facilities.

- Lack of social support, stigma and discrimination

Farther, the quantitative findings collected with the nurses and lay counsellors have provided valuable quantitative data regarding the reasons why HIV positive mothers are LTFU and fail to adhere to treatment. The nurses and lay counsellors believe that the reason HIV positive mothers are LTFU is that the mothers lack social support (74.4%), fear stigma and discrimination (71.8%), religious beliefs (66.7%), cost of transportation (56.4%), change of health facility (59%), waiting hours (46. 2%), lack of knowledge and awareness (41%), the distance of the health facility (38.5%), lack of resources (33.3%), poor services (23.1%), issues of privacy, confidentiality and anonymity (23.1%). The nurses and lay counsellors indicated religious beliefs, cost of transportation, change of health facility, waiting hours, the distance of health facility, lack of resources, poor services, issues of privacy, confidentiality and anonymity, and lack of knowledge and awareness which are similar findings from HIV positive mothers and CHWs.

Hence, the results from the nurses and lay counsellors highlight the lack of social support as a major influence of LTFU. Social support is important for any person who is living with HIV. Shroufi et al. (2013) argue that adequate support helps mothers to cope with the stress of contracting HIV. Also, the nurses and lay counsellors in this study believe HIV positive mothers who are LTFU experience stigma and discrimination. The findings with HIV positive mothers have presented patterns of fear of negative reactions from partners or family and this exposes the issue of social support. The finding from mothers also presented a lack of support from the healthcare workers on how to cope with the medication and support regarding flexible appointments. According to UNAIDS (2012) women are likely to adhere to clinic appointments and treatment when they are supported.

Concerning non-adherence to HIV treatment, the nurses and lay counsellors indicated that the reasons HIV positive mothers fail to use or adhere to HIV treatments are they fear stigma and discrimination (81.6%), lack of social support from family (78.9 %), religious beliefs (76.3%), medication side effects (73.7) and change of facility (50%), the distance of the health facility (47.4%), confidentiality and anonymity (34.2 %), lack of resources (28.9%), poor service (28.9%) and long waiting hours (4.5%). The findings show that healthcare workers think HIV positive mothers who fail to adhere to HIV medication fear stigma, discrimination, and lack of support from family. The mothers in this study did not experience stigma and discrimination. However, the mothers show fear and misconceptions about HIV, they associate HIV with death.

The CHWs believe that HIV positives do not experience stigma and discrimination and that they have not received reports on stigma and discrimination from HIV positive mothers. The nurses and lay counsellors believe that HIV positive mothers are discriminated against by the community members (42.5%), the family of the client (37.5%), other patients (30%), colleagues (17.5%), partners of the client (12.5%), and visitors at the clinic (10%). Multiple reports/studies have shown that mothers have not disclosed their HIV statuses fearing stigma and discrimination from the family (SANAC 2015; Dirisu et al. 2020; Mpinganjira et al. 2020). The other reasons presented by nurses and lay counsellors are similar patterns that were discussed earlier from the findings from HIV positive mothers and CHWs. The nurses and lay counsellors indicated religious beliefs, cost of transportation, change of health facility, waiting hours, the distance of health facility, lack of resources, poor services, issues of privacy, confidentiality and anonymity, and lack of knowledge and awareness. These social patterns have proven to influence treatment non-adherence among HIV positive mothers in the PMTCT programmes.

7.2.2. Knowledge, awareness, and attitude about MTCT

Most of the mothers in the case and control groups were not aware that a mother can transmit HIV to her child. Similar findings from Ethiopia reveal that 60.7% of the participants were well-informed about the risk of MTCT (Asefa and Beyene 2013). Asefa and Dirirsa (2018) support this and reveal that 145 (80.6%) of the HIV pregnant women who participated in their study believed that HIV-infected pregnant women can transmit HIV through MTCT. Despite been aware of MTCT, most of the mothers in this case-control study did not know that a mother can transmit HIV to her child during pregnancy and labour/delivery. The mothers who were aware of MTCT during breastfeeding including those who were aware that they can transmit HIV to their babies during pregnancy and labour/delivery failed to clearly describe the process of MTCT. In line with the findings above, a study by Deressa et al. (2014) found that 91 (12%) of the respondents who claimed to know MTCT of HIV were unable to mention how the virus can be transmitted from mother to her infant, majority of the respondent in their study believes that MTCT occurs through breast milk (72.4%), followed by during pregnancy (49.7%), and delivery (49.5%), and 198 (26%) respondents correctly identified all the three phases (during pregnancy, delivery and through breastfeeding) that a mother can transmit HIV to their infants.

Though most of the mothers in this case-control study were aware of MTCT during breastfeeding they believed that breastmilk does not have HIV. Breastfeeding was not considered as a mode of MTCT. Ekanem and Gbadegesin (2004) conducted a study in Nigeria of women in the PMTCT programmes, the study reveals that most of the women (41.7% the women) in the study did not associate HIV transmission with breast milk. However, contrary to the findings above, Deressa et al. (2014) found that the majority of the respondents who participated in the study believe that the MTCT of HIV occurs through breast milk (72.4%).

In the current study, the mothers were aware of prevention measures and emphasise the importance of HIV treatment as a measure to prevent MTCT. They were also aware that PMTCT post-natal services are important in reducing the spread of HIV. Even with the knowledge about HIV treatment and how to prevent MTCT, the mothers failed to adhere to treatment and clinic appointments. Perhaps knowledge about MTCT and prevention measures does not influence health-seeking behaviours. As claimed by Peltzer et al. (2009), there is a link between the mothers' knowledge about HIV and PMTCT activities and the use of HIV drugs by the mothers with the administration of the HIV drugs for their baby. The CHWs in this study believe that the HIV positive mothers lack knowledge of MTCT and that they are not following the instructions to prevent MTCT. Hence, the CHWs were not aware and did not know that a mother can transmit HIV to her child during pregnancy. However, they were aware of MTCT during breastfeeding and labour/delivery. The CHWs need to understand how MTCT occurs because they must share the information or knowledge with mothers who are LTFU or those [mothers] who are not adhering to HIV treatment.

The nurses and lay counsellors on the other hand were aware of the different stages of which a woman can transmit HIV to her baby. The findings show that (n=37) of the nurses and lay counsellors were knowledgeable that MTCT can occur during labour, and only (n=3) lack knowledge that MTCT can occur during labour. Most of the nurses and lay counsellors (n=36) show knowledge that a mother can transmit HIV to her baby during breastfeeding while (n=4) of the respondents disagree. Though most of the nurses and lay counsellors were aware of the different stages at which a woman can transmit HIV to her baby, there is a concerning number of healthcare workers who were not knowledgeable of MTCT during pregnancy, labour, and breastfeeding. Haffejee et al. (2016) conducted a study in South Africa with 12 healthcare workers found that most of the respondents were unable to specify how a mother transmit HIV to a baby, but they were aware of MTCT. Similar findings emerged in a study by Hentgen et al. (2002) in Madagascar which shows 73% of the healthcare workers were unaware of interventions to reduce MTCT of HIV and reveals that doctors were more knowledgeable than nurses concerning PMTCT activities. Furthermore, the nurses and lay counsellors believe that their colleagues in the PMTCT are knowledgeable about PMTCT activities, but several healthcare workers disagree.

- PMTCT training

The CHWs express the need for PMTCT training, especially on MTCT to effectively perform their jobs during household visits and counselling. They were worried that they will fail to properly communicate about PMTCT activities, and this might lead to confusion or lack of awareness or understanding of the importance of PMTCT services. A study by Suryavanshi et al. (2018) in India reported that the CHWs complained about the lack of training/knowledge related to PMTCT infant feeding guidelines. In this study, most of the nurses and lay counsellors (85%) needed technical/training support, only 15% of the nurses and lay counsellors do not need technical/training support. The nurses and lay counsellors who indicated that they need technical support needed paediatric training/workshops (65%), mentorship on adult ART (60%) and mentorship on paediatric ART (60%), PMTCT training (57.5%), and telephonic consult (27.5%). As mentioned by Frizelle, Solomon & Rau (2009), training provides education and psychological support for the healthcare workers and thereafter the mothers who are receiving PMTCT services. Many healthcare workers report that they are not getting enough training or guidelines to share relevant information, especially on exclusive breastfeeding, side effects and other practices in the programmes (Chopra & Rollins 2008; Laar et al. 2018).

7.2.3. Information access, sharing and networks

Church and African traditional organisations play a role as a referral for mothers living with HIV and advise mothers to adhere to the treatment and comply. The HIV positive mothers were not affected or negatively influenced by religious leaders. The religious leaders were able to assist HIV positive mothers against the spread of HIV and prevent MTCT. The churches and African traditional organisations were believed to be aware and educated about the importance of HIV treatment. Most of the mothers in the case and control group practised Christianity and were constantly advised to adhere to clinic appointments. As maintained by Zou et al. (2009), some of the church leaders influence behaviour, making people living with HIV believe that HIV is a curse or punishment from God and that the virus can only be cured through prayers. In support, Campbell, Skovdal and Gibbs (2011) reveal that there are church organisations that preserve HIV/AIDS-related stigma through moralistic attitudes and conservative gender ideologies. However, there are churches organisations that contribution positively to HIV/AIDS management by promoting social control for HIV prevention and contribute to care and support.

- Safety of traditional or church medicines

Most of the mothers in the case and control group did not believe in the use of traditional medicines as HIV treatment and question their use. Traditional and church medicines are not safe, they are believed to be very strong and could affect the patient’s HIV treatment process negatively. The CHWs do not support the use of alternative medication, especially in the church and African traditional medicines as they believe that these medicines are strong and that they reduce the effectiveness of Western HIV medication. Peltzer et al. (2008) confirmed that 36% of the participants in their study had consulted traditional healers for HIV treatment, as they believe that traditional medicines are better compared to Western medicines. These beliefs can prove to be disastrous when the traditional medicines fail to work, and their health conditions deteriorate. In this study, the nurses and lay counsellors believe that it is not safe for HIV positive mothers to use traditional medicines and disregard ARVs, that traditional medicines impact negatively on the patient immune system. They believe that religious beliefs promote beliefs that prayers/anointed water can cure or reduce the spread of HIV and beliefs that traditional medicines are effective more than Western medicines. A cross-sectional study with 233 traditional healers by Peltzer, Mngqundaniso and Petros (2006) in South Africa found that most of their participants had knowledge about HIV transmission and prevention methods. However, the study confirmed that traditional methods of treating HIV are not safe, and the study reported unsafe practices in the form of reuse of razor blades and reuse of unsterilised enema equipment.

7.2.4. Motherhood and infant feeding patterns

Despite failing to adhere to clinic appointments, the mothers in the case group understood the importance of bringing their infants to the health facilities to attend scheduled clinic appointments. The mothers in both the case and control groups prioritize the health of their infants more than their own by ensuring that their infants adhere to clinic appointments and receive proper health care. King et al. (2021) conducted a study in Uganda and found that the health of the baby is more valued than the mothers' health, there are beliefs that the baby's health is more important and prioritised. Another recent study by Nkhonjera et al. (2021) in Malawi also found that retention of the mothers was inspired or motivated by the aspiration to have a healthy baby. The infants/babies in this study have not missed their scheduled clinic appointments to date and the mothers relied on the assistance of the family as a support system. On the contrary, a study conducted by Van der Merwe et al. (2020) in South Africa (Western Cape province) assessed the intrapartum HIV rate after roll-out of universal ART found 25% of infants were lost to follow-up after birth. Similarly, a study conducted by Rawizza et al. (2015) with 31,504 pregnant women in Nigeria reveals that only 20,679 (66%) completed the entire PMTCT cascade and in post-natal care, only one infant's follow-up visit was recorded.

In this case-control study, the mothers whose infants were HIV positive regret and blame themselves for failing to protect their children from HIV infections. They felt guilty for intentionally delaying or hesitating ART and blame themselves for not reacting in time. It is important for pregnant women to test for HIV early and for HIV positive mothers to bring their infants early in the PMTCT for HIV treatment. The delays of bringing infants to the health facility risk MTCT. As stated by Toska et al (2020), early motherhood and HIV increases the vulnerability of young mothers and their children. Initiating ART is difficult for these young mothers because they often discover their HIV status when they are pregnant while attending clinic appointments and it may delay ART initiation (Nuwagaba-Biribonwoha et al. 2018; Ronen et al. 2017). The mothers lacked knowledge and awareness about the risk of MTCT at an earlier stage of pregnancy and the importance of early initiation of ART.

In this study, the negative situations where the babies were infected with HIV filled the mothers with regret and guilt. The mothers maintain that they will not repeat the same mistake in the future. A qualitative study conducted by Lazarus, Struthers and Violari (2009) found that while mothers of HIV-negative babies had a sense of relief, mothers of HIV-positive babies expressed a sense of responsibility and guilt and were generally distressed. Moshoeshoe and Madiba (2021) conducted a similar study in South Africa and found that mothers experienced self-blame and guilt for unintentionally infecting their babies, the mothers report the experience of been a mother to baby living with HIV as stressful, that include intense feelings of anxiety, stress and sadness.

- Infant feeding patterns

Concerning the infants feeding patterns, most of the HIV positive mothers in the case group were mix feeding while most of the mothers in the control group were exclusively breastfeeding. Their mix feeding patterns were influenced by motherhood instincts to feed their babies when they start to cry, and to ensure that the babies stop crying. The mother project fears when their baby cries and they mix feed to ensure that the baby is well. The mothers were influenced by the desire to help with the baby’s growth and were under the impression that the baby is not getting enough food for growth. Another feeding pattern is that the baby does not get enough breastmilk, thus, getting hungry or thirsty and crying. Some mix feed when their breasts start to produce less milk to feed the baby. The mothers produce breastmilk sometimes, but it is not enough and sometimes only water comes out instead of breastmilk. Maru et al. (2009) found that women described insufficient breast milk as the reason for mixed feeding. A similar study by Madiba (2015) found that reasons mothers were mixed feeding was because of their insufficient breast milk to satisfy their babies (n=53, 50.9%). Other mothers in this study experience pain on their breast from developed pimples and they mix feed because of the unbearable pain on their breast during breastfeeding.

There are mothers who follow traditional ways of infant feeding and weaning patterns. The family traditional practices influence mothers to mix feed their infants, this risks transmission of HIV through MTCT (Laar & Govender 2011). In this study, family members often pressure mothers to introduce solid food to ensure that the baby is well-fed. The mothers mix feed their babies by following what they were told about how their grandparents raised them when they were young/infants. The pressure from the family to follow the traditional way of feeding prompts mothers to abandon advice from healthcare workers. Chaponda, Goon and Hoque (2017) conducted a study South Africa the study found that grandmothers have influences on the mothers' feeding options, including other relatives like the sisters and aunts. Maru et al. (2009) conducted a similar study in Nigeria and found that women described family pressure as the reason for mixed feeding.

Some mothers experienced complexities involving daily activities or obligations that they encounter which often force them to ignore feeding instructions from the healthcare workers. They were mix feeding because they are not available most of the time due to school, work and other daily responsibilities. They have to leave the babies with their babysitters who mix feed their babies to stop them from crying. The mothers' commitment to their daily life obligation has been one of the major issues that influence the adherence to treatment and clinic appointments. The social patterns where mothers chose to commit to their daily life obligations were discussed earlier in the thesis and have been the highlight of the discussions. Mothers' knowledge and awareness about infant feeding instructions did not influence their infant feeding behaviour. The mothers were aware that they are mix feeding and that they are not supposed to mix feed.

The CHWs also believe that HIV positive mothers mix feed their infants. However, the CHWs provide health talks for mothers to exclusively breastfeed for six months after birth. Suryavanshi et al. (2018) reveals structural-level challenges that CHWs experienced in the PMTCT programmes included cultural norms around infant feeding. In this study, the CHWs believes that when the mothers' mix feed breastmilk or solid food with formula milk, they sometimes fail to follow the proper methods to prepare the formula milk and are not sure whether the mothers are following the recommended feeding methods at their homes. Sethuraman et al. (2011) conducted a qualitative study in Vietnam and found that the mothers did not meet the WHO conditions for safe replacement feeding and introduced complementary feeding early, the barriers to safe replacement feeding in their study were lack of safe water and poor hygiene and the mothers complained about receiving little or no guidance on infant feeding from health care providers.

The nurses and lay counsellors in this study believe that HIV positive mothers are exclusive breastfeeding (65%), formula feeding (15%) and mix-feeding (2.5%). They believe that the challenges that HIV positive mothers face when they practice exclusive breastfeeding are mix-feeding (80%), non-adherence to the exclusive breastfeeding practice (52.5%), confusion and lack of knowledge (45%), and non-adherence to treatment (40%). According to a joint report from WHO and UNICEF (2016), mixed feeding in the first six months of life is discouraged since it is associated with a high rate of MTCT. Again, HIV positive mothers are bound to infect their infants if they lack the understanding that breastfeeding infants without treatment is risky for their baby (WHO & UNICEF 2016; WHO 2018). The mothers who lack prior knowledge about recommended feeding methods often fail to follow instructions given to them by the healthcare workers (Department of Health 2016).

The mothers in case-control study and the CHWs express the importance for mothers to breastfeed their babies. They believe breastmilk is good for the baby's health and development. The mothers were aware of exclusive breastfeeding method, and most were able to indicate the duration for exclusive breastfeeding, but they failed to provide the reasons for selecting the duration. The CHWs on the other hand were able to explain that HIV positive mothers should breastfeed exclusively for six months and the reasons why they should breastfeed for six months, but they are those who disagree with the practice. In support of the contractions among healthcare workers, a review study conducted by Coovadia and Bland (2007) found confusion about infant practices among healthcare workers had led to a complete avoidance of the topic regarding infant feeding during. The majority of the nurses and lay counsellors (65%) shows that endorsing the use of infant feeding methods such as exclusive breastfeeding and exclusive formula feeding is not the reason HIV positive mothers and their babies are

LTFU. However, 35% of the nurses and lay counsellors show that endorsing these methods influence the loss to follow-up of HIV positive mothers. Perhaps this is why mothers continue to mix feed because the feeding instructions are against their feeding patterns, and most of these feeding patterns have cultural significance. However, Hazemba, Ncama and Sithole (2016) found that promoting exclusive breastfeeding was understood by mothers as important instructions or recommendation from the healthcare workers rather than the mothers' own informed decision.

7.2.5. Associated gender dynamics of HIV disclosure

The demographic information show that most of the mothers in both the case group and control group were not married. These mothers were then living with their family or extended family. Most of the mothers who were never married were not in a sexual relationship by the time of data collection. This is because they have broken up with their partners and were single mothers at that time. The single parents in the case and control group failed to disclose their HIV status to the father of their babies because of broken relationships. Hence, this did not influence LTFU or non-adherence to treatment. In the study, most of the mothers were never married or in a sexual relationship because they have broken up with their partners. Single motherhood is common in South Africa with 43% of mothers in South Africa been single mothers (Lippman et al. 2014). A study conducted in various Sub-Saharan African countries Odimegwu by Mutanda and Mbanefo (2017) also confirms that single motherhood is prevalent and correlates with age at first birth, number of living children, religion, level of education, wealth index and place of residence. In this study, sexual partners left the mothers in both the case and control groups to raise their babies on their own. The mothers demonstrated feelings of anger and blame towards their partners for infecting them with HIV. Similarly, Garson (2005) conducted a study in Soweto (South Africa) and found high levels of anger among women, and it was directed toward their male partners for being in denial of their roles and responsibility in the PMTCT programmes.

Though most of the mothers who disclosed their HIV status invited their partners for HIV testing and counselling they were not sure or did not know if their partners were tested for HIV, the partners refused to engage in issues related to HIV. The partners refused to go for HIV testing and counselling while denying that they had contracted the virus. Deressa et al. (2014) also found that 60% of the respondents were aware and acknowledged that their partners tested for HIV and 35% of the respondents indicated that their partners did not test for HIV including the following reasons: that their partner's lack time (29%), their partners live in other areas (8.8%), their partners were tested before the current pregnancy (8.4%), the faithfulness of the partners (5.4%), the lack of awareness about the importance of HIV testing (4%), and the fear of being positive for HIV (3.4%).

The CHWs in this study believe that HIV positive mothers do not invite their partners to the clinic for HIV testing and counselling and believe that their partners do not get tested or counselled for HIV. Most of the nurses and lay counsellors: 28 (70%) believe that HIV positive mothers involve their partners and 11 (27.5%) believe that HIV positive mothers do not involve their partners. Most of the nurses and lay counsellors indicated that 35 (89.7) of HIV-positive mothers' partners were counselled and tested for HIV, only 1 (2.5%) disagreed to be tested and counselled. All the nurses and lay counsellors: 40 (100%) indicated that they routinely ask mothers to involve their partners. However, contrary to the findings above, a study in the United Republic of Tanzania found a lower male testing rate (3%) at the antenatal clinic (Falnes et al. 2011). Similarly, Mullick, Kunene and Wanjiru (2005) conducted a study in South Africa involving men in maternity care and found that the majority of the men are not involved in reproductive healthcare.

Concerning intimate partner violence related to HIV, the mothers (in the case and control groups) who did not disclose to their partners were worried about the possibilities of violent intentions from their partners. South Africa is a country with a high rate of gender-based violence and intimate partner violence is the most dominant factor leading to an increasing rate of femicide (Abrahams et al. 2013). The mothers in this study did not trust that their partners might react positively. Though most of the mothers did not experience intimate partner violence they were not comfortable with disclosure of their HIV status as they feared the possibility of intimate partner violence. A study by Colombini et al. (2016) in Kenya also found that women's narratives demonstrate the importance of discussions on the risks of partner violence and their fear of HIV disclosure during HIV counselling and testing. Comparably, in this study, at least 18 (46.2%) of the nurses and lay counsellors indicated that HIV positive mothers reported violence from their partners but 21 (53.8%) of the nurses and lay counsellors show that clients did not report domestic violence from their partners. Colombini et al. (2016) reveal that health services accept the role of assisting women to prevent and reduce fear of partner stigma and violence in order to eradicate barriers to HIV disclosure and responded suggested couple counselling and separate counselling sessions for men.

The mothers from both the case and control groups were not able to negotiate for safer sex practices with their partners. Most of the mothers were not in involved in intimate relationships and have not disclosed their HIV status to their previous sexual partners. However, there are mothers who were either married or cohabitating or mothers who were in non-marital intimate relationships. Still, the mothers failed to negotiate for safe sexual practices and struggled to engage with their partners about the topic. Popoola (2009) conducted a study in South-western Nigeria and found that only 32% of women were comfortable with discussing sexual matters with their husbands, the strategy for negotiating safer sex was constant negotiating, withdrawal, and begging. The mothers in this study were afraid of negative reactions, fear of being suspected, accused of infidelity or cheating. Some male partners just prefer not to use condoms and the mothers fail to provide the reasons for wanting to use condoms. The other women do not see the importance of negotiating for safer sex practices because they do not think their partners will agree. The CHWs support that HIV positive mothers struggle to negotiate for safer sex practices. They believe that the mothers are afraid that their partners will suspect them of cheating. Langen (2005) conducted a study in Botswana and South Africa that found gender imbalance that impacts women’s ability to negotiate for safer sex practices like the use of condoms with their partners.

7.2.6. Associated structural and system barriers

The mothers in the case and control group believe that the health facilities lack relevant resources such as test kits, medication, space and staff. Also, the CHWs believe that the facilities lack relevant resources such as space, testing kits, staff and medications. The nurses and lay counsellors indicated that the health facilities need telephones for tracing (92%), the addition of staff members (83%), and consultation rooms (77%), testing kits (50%) and HIV drugs (50%). Skinner et al. (2005) found a lack of telephones to communicate or make a referral or tracing in a rural area of South Africa.

The nurse and lay counsellors experienced stock out of Adult CTX at the health facilities. Though most of the facilities in this study did not have a stock of expired ARVs, a few facilities had a stock of expired ARVs. The CHW's lack of resources to perform household visits, including stationary material and importantly, protection gears to protect against contractable diseases like TB. Suryavanshi et al. 2018) reveal that the CHWs in India experiences shortages of HIV testing kits, shortages of antiretroviral drugs, and infant NVP prophylaxis in the PMTCT programmes. Etoori et al. (2020) contend that relevant resources such as additional health care staff, infrastructure for space and testing kits are important in ensuring that the PMTCT programmes are a success. According to Kweyamba et al. (2018), shortages of healthcare workers who provide VCT for mothers and their infants hinder the quality of the PMTCT services and may influence LTFU and non-adherence to treatment.

The nurses and lay counsellors experienced challenges when implementing the PMTCT programmes, these challenges are the clients' attitude (75%), lack of resources (47.5%), poor support from the government (32.5%), poor systems (17.5%), and poor PMTCT guidelines and policies (10%). About the attitude of HIV positive mothers, a study by Danladi et al. (2020) in Nigeria found a positive perception of PMTCT services and the women were ready to end the HIV pandemic by taking their medication. The mothers who are not ready to initiate ART experience challenges of initiating ART, challenges such as work responsibility, non-disclosure, unreadiness, and poor treatment from healthcare workers have been vastly discussed earlier in the chapter. The findings above echo a study by Kouassi et al. (2014) that addressed the challenge of the unreadiness of mothers to start ART and found that the mothers believed they had not been well prepared by facility staff before the ART initiation. Poor collaboration between nurses and clients is the challenge that nurses face in the PMTCT programmes (Cumber et al. 2016).

The nurses and lay counsellors in this study indicated that the working conditions in the PMTCT programmes are good (55%), others indicated moderate conditions (43%), and only 2% indicated bad conditions (2%). According to Frizelle, Solomon & Rau (2009), health personnel experience poor working conditions, poor quality, and adequate training or guidelines. Despise indicating lack of resources as challenges that impact on the programmes the nurses and lay counsellors in this study experienced good working conditions. However, contrary to the above findings, a study by Manzi et al*. (*2005) and revealed how low retention of staff in resource-poor settings are also influenced by poor working conditions for health care workers. In South Africa, the retention of staff may be influenced by poor incentives and remunerations (USAID 2005). The nurses and lay counsellors in this study deem the PMTCT guidelines and policies as effective in dealing with the non-adherence of ART. A study by Mnyani & McIntyre (2013) with healthcare workers in South Africa also revealed that most of the respondents (80.0%) were satisfied with the PMTCT guidelines and the knowledge they obtained, 96.3% were confident about managing the PMTCT programmes and HIV positive women.

7.2.7. Monitoring and data use

- Tracking and tracing

Most of the mothers in the case group were not traced or contacted by health personnel during the time they were LTFU. Some of the mothers who were traced or contacted only received communication regarding their baby's HIV test results. One of them did not have a mobile phone and registered with someone else's mobile number at the health facility. This finding shows similar patterns related to challenges that the CHWs experience, for example, missing information of the patients during tracking and tracing. I encountered similar challenges when conducting this study as well. Some mothers were not successfully traced because of missing residential and contacts information or non-existent numbers or voicemail calls. Ineffective recording systems compromise PMTCT services and care in the health facilities, and sometimes mothers just failed to report their health status to health personnel (Woldesenbet et al. 2010). Similar to the findings above, a recent study by Nkhonjera et al. (2021) in Malawi found that patients provided fake names on the registers to avoid being tracked and traced by the health facility staff. A study in rural South Africa by Etoori et al. (2020) found that the challenges for effective tracking and tracing of patients were missing data and documentation. Brinkhof et al. (2009) also outline the challenges for tracing patients who are LTFU, which include challenges of missing telephones numbers and home addresses.

This study found at least one HIV positive mother in the case group that had been offered transportation reimbursement to return to a health facility for a face-to-face session. This mother however failed to find time to meet the healthcare worker for a face-to-face session at the clinic and collect medications. This shows that some healthcare workers attempted to re-initiate mothers into the ART programmes, but the mothers do not make any effort to return to the health facilities. However, most of the mothers in the case group believe that the healthcare workers are not doing enough and that they should arrange home visits instead of waiting for patients to come to them. Still, the mothers in the control group believe that the healthcare workers are doing enough to trace HIV positive mothers. This shows that the other mother in this study supports the tracing system, that the healthcare workers make effort to contact the mothers. The mothers in the control group commended the efforts made by outreach health workers. Woldesenbet et al. (2010) affirm that weak tracing systems encourage inconsistency or enforce poor childcare management to identify HIV exposed infants throughout the PMTCT cascade. This is supported by a study that was conducted with 433 patients in the PMTCT programmes by Yotebieng et al. (2016) to investigate whether or not the provision of conditional cash transfers improves service use and retention in the post-natal. The study found that the women who were provided conditional cash transfers interventions were likely to be retained in care (Yotebieng et al. 2016).

The health facilities have a formal system to monitor HIV exposed infants scheduled appointments and attendants in their health facility, only five do not have. The health facilities provide scheduled appointments for their next attendance and know if the clients are ill, have died or dropped out and if a client does not attend a scheduled visit. Most of the nurses and lay counsellors have systems to make follow-ups with PMTCT clients who do not appear for an appointment at their facilities, only three do not have the system. In a study by Gourlay et al. (2015), health facilities in South Africa are required to have a registry to record patient appointments, either paper-based or electronic.

The CHWs in this study have personally benefited from the educational experiences that come with their job, they broaden their knowledge regarding health issues. They work as health promoters and some of the HIV positive mothers appreciate their work.

The challenges that the CHWs face in the PMTCT programmes is that the mothers provide wrong addresses or miss contact information on the register during tracking and tracing of patients. A multi-country study in Uganda, Malawi and Zimbabwe by Cataldo et al. (2018) also found that the CHWs when asking the women who are LTFU the reasons for not coming back to health facilities is that they choose not to be traced and provide a false address at enrolment. Another challenge that the CHWs in this study experience is a lack of support from other community members who are yet to accept the nature of their work and are rejected by the mothers. Research by GrantI et al. (2017) in five primary health care clinics located in KwaZulu-Natal in South Africa found that the CHIWs experience barriers related to trust on confidentiality and are not accepted to provide maternal and child health services. The CHWs in this study performed tasks that are not on their work scope and complain about the nurses asking them to perform work they are not qualified to do as CHWs, this work includes checking patients' vital signs. The nurse asks the CHWs to do this work because they experience shortages of qualified health personnel to perform those tasks. The findings concur with a study by Marindi (2019) in Soweto (South Africa) which exposed that CHWs were subjected to poor working conditions that result in long working hours. These conditions are influenced by inadequate resources and have led to an increasing level of precarity in the workplace.

- Data use

The data that is not always available is the data to check if clients have a treatment supporter (42.5%), the reported reasons for loss to follow-up (38.5%) and reported reasons for non-adherence (37.5%). In agreement with WHO (2012) facility-based surveys and follow-ups assist programme planners in compiling data that monitors the impact of the PMCT programmes. It is important to evaluate and document the outcomes of LTFU in the PMTCT programme to successfully measure or quantify the magnitude of LTFU (Kouassi et al. 2014). Continuous monitoring or tracing of mothers and their infants provide the opportunity for programme planners to explore the estimated outcomes of LFTU and inevitably measure the impact of the PMTCT programmes (WHO 2012). The majority of the nurses and lay counsellors monitor adherence rates of ART at their health facilities, only 5% of the nurses and lay counsellors do not monitor adherence rates of ART at their health facilities. Though the rates of adherence to ART at the health facilities are being monitored, some facilities do not monitor the rate of adherence at their health facilities. According to WHO (2012), data collection regarding the impact of the programmes that includes the rate of MTCT, new infections, child and maternal survival, health and health services effect etc. These measurements must be performed at a national level to assess the PMTCT programmes coverage, sufficiency, and impact.

7.2.8. Retention strategies and interventions

Long waiting hours should be improved along with the quality of services and providing appointment dates that are suitable for patients. The mothers suggest that the healthcare workers should not take long during their lunch breaks and that they should not all go to lunch at the same time. They suggest that the healthcare workers should be flexible and allow mothers to collect their HIV medication at a time that the clinic appointments do not clash with their daily life responsibilities. The CHWs recommend pretence as a strategy for the mothers to disclose their HIV status to mitigate the negative consequences of disclosure by inviting their partners for HIV testing and counselling and pretending as if it is the first time they are testing for HIV. Most of the mothers do not have a problem returning to the health facilities. However, they have conditions involving quality health care and services from healthcare workers and flexible health systems. The CHWs support that LTFU patients want to restart care except for the mothers who self-transferred to other health facilities. The CHWs improve care, treatment adherence, and retention of clients by constantly providing counselling or health talks to convince HIV positive mothers to adhere to treatment and take their medication regularly.

The nurse and lay counsellors indicated that strengthening tracing is a strategy to improve PMTCT follow-up services for the future. This is followed by social support, financial support, health education, increase nursing staff, developing rapport, booking early appointments, the use of condoms, infrastructure resources, access to telephones for staff, accelerate training on PMTCT, and reminding clients a day before for their clinic appointments. The interventions that are offered for mothers who are LTFU are links to home-based care and follow-ups with defaulter tracing to support LTFU mothers. This was followed by HIV education/health talk for patients and supporters, and the supporter telephone reminders. The other services are designated friend/family member/support group members as adherence supporters, social support and transport reimbursement. Similarly, a study in South Africa by Tomlinson et al. (2014) supports found that interventions were effective at 12 months and the mothers who are benefiting from the interventions were more likely to bring their infants to the clinic in the first week of life.

The nurse and lay counsellors in this study received both individual and group mentorship (55%). This is followed by the nurse and lay counsellors who received only group mentorship (25%) and the respondents who received only individual mentorship (15%). Mentorship provides education and psychological support for the healthcare workers and thereafter the mothers who are receiving PMTCT services (Frizelle, Solomon & Rau 2009). There is insufficient mentoring in the PMTCT programmes including insufficient supervisory support systems that are influenced by policy changes (Doherty, Chopra, Nsibande & Mngoma 2009). Most of the respondents (85%) shows that the facilities have active quality improvement programmes, only 15% of the respondents lack active quality improvement programmer at their health facilities. The respondents (97.5%) have a suggestion box for patients to provide feedback on the quality of care at the facilities, only 2.5% of the respondents do not have a suggestion box at the health facility. Furthermore, most of the respondents (87.5%) with a suggestion box shows that the suggestions from the patients have been reviewed in the last three months, only 12.5% of the respondents have not reviewed suggestions from patients. The healthcare workers also provide adequate information and ongoing monitoring (Frizelle, Solomon, & Rau 2009; WHO 2009). Ongoing monitoring of the PMTCT provides feedback on the implementations to identify potential successes and failures to improve and facilitate timely decisions about future project implementations (WHO 2012).

7.3. Chapter Conclusion

The chapter discussed the research findings conducted with HIV positive mothers in the qualitative case-control study, qualitative study with CHWs, and quantitative questionnaire surveys with nurses and lay counsellors. The Social Ecological Model (SEM) guide the study to explore the individual, interpersonal, organisational, community, and societal factors. The study explored the social meaning of LTFU and the reason why mothers were not adhering to HIV medications. The chapter captured discussions related to the participants and respondents' knowledge of family and gender dynamics, motherhood, and infant feeding patterns. Also, the health care systems, community, and public outreach barriers, communications, support, and strategies to improve care, treatment, and utilisation of the PMTCT services. The next chapter addresses the study recommendations and conclusions.

CHAPTER 8

CONCLUSIONS AND RECOMMENDATIONS

8.1. Introduction

Poor uptake of PMTCT services by HIV positive mothers hinders the success of the PMTCT programmes. This study investigated the social patterns of LTFU and non-adherence among HIV positive mothers. The chapter presents the conclusions of the findings and implications of the study to improve PMTCT services, this includes recommendations for future studies. The research inquiry adopted a mixed method of both qualitative and quantitative approaches. The study used a novel qualitative unmatched case-control approach to collect data of HIV positive mothers. The case group consisted of HIV positive mothers who were LTFU, and the control group consisted of HIV positive mothers who were not LTFU in the PMTCT programmes. The mixed methods included a qualitative approach with the CHWs and quantitative surveys with nurses and lay counsellors.

The qualitative inquiry provided data on the lived experiences of the participants in this study. This allowed mothers and CHWs to express their feelings by narrating their experiences in the PMTCT programmes. Clinical patterns of LTFU that includes implementation challenges in the PMTCT programmes have been highly researched. This study offered the opportunity to understand the social patterns by exploring the narrative from the participants. The study covers the gap in the experiences in the rural PMTCT outreach programmes. This introduces the lived experiences of the CHWs to understand patterns of service provision, care and retention. The addition of the quantitative inquiry provided mathematical expressions of LTFU and non-adherence to treatment patterns from the lived experiences of professional healthcare workers (nurses and lay counsellors). These explore relationships between the healthcare workers and the mothers in the PMTCT programmes. This study was based on the Social Ecological Model (SEM), which guided the interviews and questionnaire schedule.

8.2. Key Findings

Using the Social-Ecological Model (SEM), the study found social patterns that influence LTFU and non-adherence to HIV treatment. The SEM describes the relations between individuals and their social environments with regards to health (McLeroy et al. 1988). The model is explained through five multiple levels that influence individuals` health and behaviour: intrapersonal, interpersonal, community, organisational and societal level (Stokols 1996). Below are the key findings corresponding with these multiple levels that influenced health behaviours.

- Intrapersonal/individual factors

Individual factors are characteristics such as knowledge, attitudes, skills and beliefs that influence behaviour (Stokols 1996). The intrapersonal level emphasises on the notion that knowledge about a disease provides more information about the health risks involving the disease and how vulnerable an individual is to the health threat (McLeroy et al. 1988). In terms of knowledge, the mothers in the case and control groups lacked knowledge and awareness about MTCT during pregnancy and labour/delivery. Though the nurses and lay counsellors were aware of MTCT during pregnancy, labour and breastfeeding the CHWs lacked knowledge and awareness of MTCT during labour. Changing individuals` behaviour linked to health risks is an important component of the SEM, which includes individuals` attitude towards health and services (McLeroy et al. 1988; Stokols 1996). Relating to the attitude of mothers towards PMTCT services, the mothers in both the cases and control groups were aware that PMTCT post-natal services are important in reducing the spread of HIV. Some mothers in the case group struggled with acceptance of their HIV status and were not ready or willing to initiate ART or continue with ART.

The level of interventions can be identified by individual and environmental changes. For example, the intrapersonal level aims to change an individual` skill to modify behaviour (McLeroy et al. 1988). Concerning skills, most the mothers in the case-control study were unemployed and completed high-school or secondary education. Nevertheless, the mothers barely find the time to attend clinic appointments or adhere to recommended feeding instructions because of daily life obligations like harsh school/work schedules. Health promotion fields ignore background forces that influence health behaviour and are criticized for focusing mostly on lifestyle changes

(McLeroy et al. 1988; Sallis, Owen, & Fisher 2008; Stokols 1992). The SEM recognises beliefs as individual characteristics that motivate health behaviour, and are embedded within one or more social systems (Sallis, Owen, & Fisher 2008; Stokols 1992). Regarding beliefs, mothers who experienced medication side effects believed and feared that they are getting sicker from the HIV medication. There are mothers who were denial of HIV status and believe that their HIV is cured. The CHWs support this finding and believe that HIV positive mothers use the church or African traditional medicines to treat HIV.

- Interpersonal/relationships factors

The interpersonal level of the SEM emphasises on the process of social identity and role definition such as partner, friends, and family as influencers of health behaviours (McLeroy et al. 1988; Stokols 1996). Regarding HIV disclosure, the mothers in the case group were LTFU because they feared inadvertent HIV disclosure and being judged by family, sexual partners, and community members. The SEM emphasises that HIV outcomes or risks are associated with social influences such as social networks, access to information, social engagement, and intimacy contact (Poundstone, Strathdee & Celentano 2004). In line with the social factors identified by the SEM, the associated gender-related patterns that influence HIV disclosure to sexual partners were broken relationships where the mothers in both the case and control groups failed to disclose HIV to their partners, who had left them to raise the babies on their own. The SEM also includes social groups such as the individual`s physician, nurses, and other key leaders (Stokols 1996). Similar to the SEM, the healthcare workers serve different roles in the lives of HIV positive mothers and their relationship is familiar in the context of health care, social and emotional support. The finding demonstrates that mothers` health-seeking behaviour can be influenced by inadequate knowledge that is communicated through healthcare workers regarding important PMTCT activities.

- Organisational/Institutional factors

The organisational/institutional factors dwell on the rules, policies, and formal and informal structures (Stokols 1996). In terms of rules, there are mothers who self-transferred to health facilities because of overlapping clinic appointments and mothers blame poor communication or rigid healthcare workers. Concerning policies, there are nurses and lay counsellors who show that endorsing these infant feeding methods influence the loss to follow-up of HIV positive mothers. The organisational level is not limited to incentives policies, referral systems, rather, it encompasses confidentiality/privacy, parental consent, and stigma (Stokols 1996). Though the mothers in the case and control group have not experienced HIV-related stigma and discrimination, there are fears and misconceptions about HIV, they associate HIV with death.

- Community factors

The community factors focus on established norms and values, standards, and social networks (Stokols 1996). This includes availability and location of resources such as transportation, social/cultural norms, recreation facilities, health care services, social networks, and social norms (Stokols 1996). Some mothers self-transferred to health facilities that are closer to their homes and regretted their initial decision to select health facilities that are far from their community or home. Most of the mothers could walk to the health facilities, eliminating the need for transportation to attend health care services. Though many of the mothers did not experience challenges with accessing PMTCT services, the CHWs believe that the distance and travelling costs are the reasons mothers are LTFU. The CHWs experience a lack of support from the other community members and are rejected by mothers during household visits. However, most of the mothers in the case group insisted that they were not traced or contacted by health personnel during the time they were LTFU.

- Societal policy factors

The societal policy factors address the cultural context, including local and national policies on health (McLeroy et al. 1988). In relation to the local policies on health, the study revealed that there is ongoing monitoring of the PMTCT services to provide feedback on the implementation setbacks, and identify potential successes, improvement areas and facilitate timely decisions about future project implementations. Most of the mothers do not have a problem returning to the health facilities. However, they have conditions involving improvement of policies on health, which include quality health care and services from healthcare workers and flexibility of the healthcare systems. The societal level and other levels can influence strategies or interventions to influence behaviour (McLeroy et al. 1988; Stokols 1996). The nurse and lay counsellors indicated that strengthening tracing is a strategy to improve PMTCT follow-up services for the future. This is followed by social support, financial support, health education, increase nursing staff, developing rapport, booking early appointments, the use of condoms, infrastructure resources, access to telephones for staff, accelerate training on PMTCT, and reminder services for clients at least a day before their clinic appointments. Ongoing monitoring of the PMTCT to provide feedback on the implementations to identify potential successes and failures was found to improve and facilitate timely decisions about future project implementations. However, information regarding PMTCT guidelines and policies was not well distributed among CHWs, especially on integrations of services that adopt new trends. The CHWs are not informed about the PMTCT guidelines or policies.

8.3. Recommendations

Based on the findings of the study, the following recommendations are made to promote the use of PMTCT services. The health care system plays a very integral part in the retention of HIV positive patients in the PMTCT programmes. Based on this study, the findings highlight the need for these improvements in health care.

Support for disclosing HIV to sexual partners: This study advises on counselling to address the mothers' fear of disclosing HIV to their sexual partners. The counselling should dwell on how HIV positive mothers can disclose their HIV status without compromising their safety or relationship status. The methods to disclose HIV can reduce the pressure and fear of being blamed in the relationship. Since the mothers could not find the reasons to explain to their partners, the healthcare workers could provide counselling that offers strategies to help the mothers to collect or take their medication without the partners' interference. One of the strategies to support HIV disclosure to sexual partners is for HIV positive mothers to invite their partner to clinic or any HIV awareness programmes or testing stations and motivate their partners to voluntarily test for HIV as a couple. The mothers who are unable to disclose their status under various circumstances should be advised on strategies to take medication at home without exposing their status. Counselling for these mothers should include safe sex education like the use of condoms and adherence of HIV medication. The aim is to encourage or motivate patients to reach HIV remission where the virus is suppressed.

Ongoing promotion of male involvements: The mothers must involve their sexual partners so that their partners can also take their medication, this will help combat the spread of HIV. Consequently, it is prudent that healthcare workers advise mothers to involve their partners through proper counselling regarding HIV disclosure to their sexual partners. HIV positive mothers should be motivated by healthcare workers continuously to invite their partners to the clinic or any HIV awareness programmes for voluntarily couple HIV counselling and testing, this could be extended through home-base visits and mobile clinics. The mothers should be motivated to involve their partners throughout their pregnancy and even after birth. Emphasis should be on the importance of male involvement as part of the PMTCT support system.

Ongoing counselling for single mothers to disclose HIV to partners: Some mothers have been abandoned by their partners to raise their babies alone, and the mother expressed anger and blaming. Therefore, the healthcare workers could motivate mothers during counselling to invite partners in the PMTCT programmes even when they are not on good terms in their relationships. Counselling on relationship and family should be extensive to address issues related to broken relationships among couples who are exposed to HIV. The mothers who are not comfortable with contacting their former sexual partners can give consent to the healthcare workers to track and trace their male partners who are exposed to HIV

Ongoing counselling on how to negotiate the use of condoms: The mothers should be well counselled on ways to negotiate the use of condoms with their partners. Consequently, ongoing counselling on the use of condoms is strongly advised. Condoms used between HIV positive partners can prevent the accumulation of the viral load which increases the strength of the virus. The mothers can consider the use female condoms if they struggle to convince their partners to use condoms. The government and healthcare providers should consider the provision of free female condoms to patients who come from previously disadvantaged backgrounds.

Counselling for the young mother to disclose the HIV to parents/family: Family dynamics of HIV disclosure should be addressed in detail during counselling. The mothers should be comfortable to disclose their feelings, experiences and behaviours without fear or judgment. Counselling is advised to develop strategies or methods that will assist HIV positive mothers to share their HIV status with difficult family members.

Counselling should further be extended to the family of mothers to promote family support and education about HIV, MTCT and other PMTCT activities. The mothers who are unable to disclose their status under various circumstances should be advised on strategies of taking medication at home without exposing their status. This can be achieved by using non-labelling packaging containers to put on their medication or hide their medications or take their medication during a time when they are engaging in other social activities outside their households or when they are not at home.

Addressing the confidentiality and privacy practices at the health facilities: Concerning the fear of HIV disclosure at the health facilities or by the neighbours, the healthcare workers should ensure that the health facilities strictly adhere to confidentiality, anonymity, and privacy ethical regulations. Healthcare workers should address the mothers` fear of being spotted by the people who are familiar to them or address issues of disclosing HIV at the clinic by integrating health services and ensure confidentiality, anonymity, and privacy in the health facilities. Counselling should be clear for mothers regarding the assurance and strict practices of ethical consideration meant to protect them and their HIV statuses. The healthcare workers should be trained to be aware of the environment in which they speak about their patients HIV status. The healthcare workers are reported as having poor communication skills and were not secretive regarding the mothers' HIV status. It is recommended that the health department should offer continuous workshops for healthcare workers about awareness of the environment in which they speak about the mothers' HIV status. Disciplinary system should be enhanced for health facilities that do not follow or adhere to confidentiality and privacy practices. Health facilities should be boosted with quality infrastructure that support confidentiality and privacy practices.

Improved treatment and attitude from the nurses and lay counsellors: The healthcare workers are recommended to not yell or shout at patients when they fail to collect medication, at least understand the reasons that forced mothers to miss appointments in the first place. Therefore, the provincial and national health departments should implement active programmes that continuously addresses the mistreatment of patients by healthcare workers at the health facilities. In addition, patient satisfaction should be part of the key performance indicators of clinic managers. The disciplinary system should be improved to address healthcare workers who mistreat their patients. Health facilities need to provide ongoing trainings and workshops for quality services that include the provision of palliative care to all patients.

Education about the importance of the health facilities transfer letters: During counselling, the healthcare workers should emphasise the importance of applying for a transfer letter while encouraging mothers to apply for transfer at the health facilities. The healthcare workers should educate mothers about the importance of formal transfers and the negative impact of self-transfers. This can be done through on-going counselling sessions or through awareness and healthcare programmes and promotions. The health facilities should have an integrated electronic health care system for all the health facilities to allow access of patients' previous health facility records and avoid self-transfer errors.

Encourage mothers to start ART at the health facilities closer to their home: The mothers show regrets for the initial selections of the health facilities that are far from the places where they reside. The healthcare workers should assist and counsel mothers to initiate ART at the health facilities that are closer to their homes to avoid the issue of distance and travelling costs. The healthcare workers should also promote the application of official transfers of mothers who want to move to other health facilities closer to their home to avoid being self-transferred.

Flexible healthcare worker and health services: Encourage the selection of appointment dates that do not overlap with work/school schedules. The healthcare workers are advised to be considerate and allow mothers to choose appointment dates that are suitable and do not overlap with their work or school schedules, or any other important daily life activities. The healthcare workers should develop the capability in communication skills that offer attention and support for the mothers. The mothers who are affected by daily life responsibilities (school, work, or family roles) should be motivated to collect their medication on the days, dates or times that are suitable to accommodate their work schedules. It will also be helpful if they receive their medication in advance to limit the time they have to come and collect the medication at the health facilities. They should be advised about suitable times to collect their medication and accommodate their daily life obligations. This can be achieved through continuous communications with HIV patients about the suitable time for mothers to take medication.

Promote early use of ART and address the unreadiness patterns: The healthcare workers should provide detailed counselling regarding the importance of starting ART early to prevent MTCT. Counselling is required for mothers who delay ART. The counselling should be in detail regarding the risk of HIV, MTCT and the importance of early HIV prevention or initiation of ART. The healthcare workers should address health system beliefs about HIV treatment or cure, the education should be about the danger of health beliefs regarding HIV treatment. Also, healthcare workers should address the mothers` fears about HIV treatment and other social aspects like gender and family dynamics. The challenges of universal test and treat should be addressed, especially with patients who are still coming to terms with their HIV status. Same-day initiation of ART may be effective in other context, but they also increase the risk of LTFU. Earlier counselling sessions should be continuous in addressing the psychosocial impacts and emphasis more on the health benefits of early initiation to ART for people living with HIV. All patients that were on UTT or same-day initiation of ART should be monitored through the tracking and tracing programmes, throughout the entire PMTCT cascade.

On-going counselling or clarity on false-negative HIV results: This study recommends that the healthcare workers advise mothers who receive false-negatives during the HIV testing to continue with ART and come back for more HIV testing. The mothers should be counselled about the meaning of false-negative HIV results. This should be included in every counselling session. To avoid errors healthcare workers are encouraged to double-check the results to ensure accuracy. Continuous HIV testing should be encouraged to confirm the HIV results.

Offer continuous reminders and clarity about mothers' next clinic appointments: Healthcare workers should clearly emphasise the importance of ART and adhering to follow-up visits. Appointments dates should be clearly stated for mothers to recall, and perhaps reminders should be sent out before appointments. The reminders can also be sent to treatment supporters of HIV positive mothers who enlisted and approved involvement of treatment supporters or reminders. This can be done though support groups or through technological communications such as WhatsApp communications, phone calls and messages.

On-going counselling on the danger of opting to use unapproved alternative medicine to treat HIV: During counselling, the information regarding the beliefs about the HIV treatment should be addressed in much detail. The use of alternative medicines to treat HIV should be avoided as there is no known cure for HIV. The healthcare workers could advise mothers of the danger of using the church and African traditional medicines while abandoning Western medicines. In cases where the mothers refuse to abandon religious medicines as a treatment for HIV, the healthcare workers should advise mothers to include Western HIV treatment (use of multiple health systems or medicine pluralism). The healthcare personnel can engage with the community leaders to assist in the promotion of HIV medication adherence. Workshops can be extended to various community-based organisations especially on the importance of HIV treatment and encourage a safe integration of religious or cultural systems with healthcare systems in combating the spread of HIV through MTCT.

Financial support and food supply or referral assistance for poverty affected mothers: It is recommended that the healthcare workers help mothers with linkage to social workers so that mothers can apply for social grants, afford food, and transport costs. The other alternative is for healthcare workers to counsel mothers to take the medication with available fruits and other food sources or ask for financial assistance from family, neighbours or friends.

Management support for medication side effects: Education and counselling regarding the side effects of the medication and their severity should be extensive. The counselling should address the beliefs and misunderstandings about the side effects. It is important to provide detailed counselling and be sympathetic when the mother confides about the side effects. The healthcare workers should offer sufficient support and counselling regarding the side effects and assure mothers that the HIV treatment is safe for use, that the side effects do not deteriorate or risk their health. They should offer methods or strategies that can assist mothers in coping with the side effects. They must show the respect and sympathy of mothers and offer valuable information that can help mothers cope with their health issues. They should develop capabilities to support mothers with strategies and empathy for side effect management. Also, the healthcare workers should advise on the timing to take HIV medication for HIV positive mothers who are committed to their social roles and responsibilities such as school and work most of the time; and promote HIV treatment among mothers who are affected by work responsibility.

Improve waiting hours: At the health facilities, long waiting hours should be avoided. Healthcare workers are recommended to consistently provide quality services that are effective and fast. The mothers in this study provided recommendations that long waiting hours should be reduced to allow effective care and service utilisation. They also mentioned that long waiting hours can influence them to leave the health facilities in the future. It is important to address the issues of long waiting hours, which mothers believe is because of lazy healthcare workers or healthcare workers who decide to start service late. The healthcare workers should start PMTCT services early and not waste time on unnecessary activities. Continuous monitoring of clinic staff members should be extensive and adhered by health facilities supervisors and managers.

Ongoing counselling about MTCT during pregnancy, labour, and breastfeeding: Strengthened health education on MTCT risks during pregnancy, labour and breastfeeding: Mothers need to be counselled in the process of MTCT. If the mothers clearly understand the process of MTCT or how MTCT happens during pregnancy, labour, and during breastfeeding, they will understand the need to adhere to ART early. Education or counselling should be deeper into the process of MTCT and how to prevent MTCT. The healthcare workers should provide detailed counselling on how MTCT occurs during breastfeeding. This includes education on the practice of exclusive breastfeeding and the duration in which mothers are supposed to exclusively breastfeed their infants. The healthcare workers should provide detailed counselling about the risks of MTCT during breastfeeding. During health education, the risk of MTCT during early mix feeding of infants should be strongly emphasised.

Address motherhood feeding patterns and feeding methods: The healthcare workers should address these complexities related to infant feeding, some feeding patterns are unavoidable. Consequently, the healthcare workers should provide safe replacement feeding that meets AFASS criteria especially for mothers who are not producing breastmilk or have painful breasts. The healthcare workers should provide adequate and detailed information about recommended feeding options using the AFASS criteria. Ongoing counselling on the risk that MTCT poses by mix feeding of infants should be highly emphasised. The healthcare workers should consider the mothers' daily life activities like work and school that affect adherence to the feeding instructions. The counselling should educate the mothers on ways to avoid family, community, and pressure regarding infant feeding, including daily life pressure.

Supply of resources (medication, infrastructure, test kits, and hiring of staff): Perhaps the department of health could reach out and hire more staff to allow effectiveness in service provision. The inclusion of male CHWs, nurses and lay counsellors can pave the way or motivate men in various social and cultural settings to support their partners, to develop positive health-seeking behaviours. The government should improve infrastructure to allow space during consultation hours, a continuous provision of HIV medication, and testing kits. The health facilities should consider fundraising and seek donations from other public and private sectors to assist with the supply of necessary resources.

Continuous tracking and tracing support for patients: Early community-based support and tracing patients are advised to prevent continuous interruption of ART. In this compilation, most of the mothers who were LTFU claimed that they have never received communications or home visits from the healthcare workers. The community healthcare workers should be provided with daily updates or lists of patients who are LTFU. The CHWs who are well trained on ethical conducts should be allowed access to the electronic system that help track LTFU of patients.

Staff training: Staff training and retraining on PMTCT activities should be updated. The CHWs need to be provided with basic PMTCT training to enhance reasoning or knowledge during the tracing and retention of patients. Workshops should include updated information about counselling strategies or methods. The government should provide intergraded workshops for CHWs, nurses and lay counsellors on PMTCT activities, especially workshops on MTCT and recommended infant feeding methods.

Improve data systems: The healthcare workers should check if mothers filled or completed relevant information on home addresses and contact details. This will allow the smooth tracking and tracing of LTFU patients. Records of the mothers should be completed and checked continuously. Complete data will allow for the smooth early tracking and tracing of mothers. A central computerised registry is recommended to allow coordination at the local municipal and district levels, and even at the provincial levels.

Supportive resources for the CHWs: The CHWs should be offered support related to materials that will aid with tracking and tracing of mothers in the PMTCT programmes. The resources include stationery, uniform, transportation, and protective gear. The department of health and non-government organisations should offer integrated efforts to assist CHWs. The CHWs should also seek donations for the resources from various government departments and other non-government organisations.

8.4. Recommendations for Future Research

The findings of this study suggest that future researchers could investigate the knowledge and awareness levels of MTCT during the pregnancy and throughout the post-natal phase. This study recommends that future research should explore the knowledge and awareness about MTCT, especially on how a mother transmits HIV through MTCT including prevention measures and promotion of early initiation of ART. When HIV positive mothers lack knowledge or awareness that they transmit HIV to their children in the early stages of pregnancy or early motherhood they risk MTCT. The study should explore the knowledge and awareness and patterns of information access, use and networking.

The future research should explore the relationship between knowledge about MTCT prevention measures, or other PMTCT activities and health-seeking behaviours. It has been proven that HIV positive mothers who are LTFU stop or halt HIV treatment and are aware of MTCT preventions. Consequently, is important to understand the extent to which knowledge or awareness about MTCT prevention measures impact service utilisation. Research has focused entirely on clinic patterns of MTCT like the use of HIV medications as a prevention measure. Emphasis should be placed on the social patterns that promote the use of HIV treatment and prevention MTCT.

The recommendation for future research is to explore the knowledge and awareness level about MTCT among CHWs working in the PMTCT programmes. When CHWs are not well trained about HIV, MTCT and other PMTCT activities it may impact the reintegration and retention of HIV positive mothers in the PMTCT programmes. The study will look to explore the frequency of training and workshops about PMTCT trends. The information regarding PMTCT guidelines and policies is not well distributed among the healthcare workers especially on integrations of services that adopt new trends. The CHWs are often not informed about new developments or trends in the PMTCT guidelines or policies. For that reason, future research can explore the impact of poor knowledge and awareness of MTCT especially on the retention of HIV positive mothers.

This study recommends future research that addresses maternal feeding patterns that allow mothers to mix feed their infants in the early stage of motherhood. Motherhood patterns concerning infant feeding expose many social complexities related to family, gender dynamics, beliefs and healthcare systems. The study should also explore the relationship between health-seeking behaviour and knowledge or awareness about mix feeding opposing to recommended infant feeding methods. The study should investigate the association between LTFU and the promotion of recommended infant methods in settings where feeding methods are culturally rooted.

The future research should explore experiences and challenges faced by CHWs in the PMTCT programmes during tracing and retention processes: investigating the roles of CHWs in the PMTCT programmes and the relationship with other healthcare workers and HIV positive mothers. The study should emphasise the impact of CHWs and importantly the retention of HIV positive mothers and focus on the integration challenges as well as retention challenges. Investigating the influence of health care recording systems and data availability or completeness during tracking and tracing of HIV positive mothers who are LTFU or defaulters.

The influence of gender and family on HIV disclosures and non-disclosures on HIV treatment. The study should investigate the methods of disclosing HIV to family and sexual partners. The focus should be on the negative impact of HIV non-disclosure and integration of male or partner involvement and family to mitigate the fear of HIV disclosure. HIV disclosure to partners is important in the fight against the spread of HIV. Involving male partners exposed to HIV could save their lives through early initiations in ART. In consequence, it is important to understand the extent to which the fear of HIV disclosure impacts HIV targets. It is already hard to involve males to participate in HIV programmes. Therefore, snowballing of HIV exposed males through HIV positive mothers can assist with reaching the HIV targets if the male partners are involved in the programmes. Family and sexual partners could serve as treatment supporters if they are well counselled about HIV, MTCT and other PMTCT activities like infant feeding methods and adherence to Option B+ lifelong regimens.

The impact of social roles and responsibilities/obligations on LTFU and adherence to HIV treatment for HIV mothers enrolled in the PMTCT programmes. Social roles and commitment to daily life responsibilities may delay the initiation of ART. As a result, future studies should explore the extent to which social roles and responsibilities of HIV positive mothers impact service use and compliance.

The impact of mobility and self-transfer outcomes can be explored especially on patterns or reasons why HIV positive mothers self-transfer to other health facilities and whether they are transferred to reputable and sustainable health facilities. Mobility or self-transfers LTFU outcomes are a challenge for programme planners because of the constant movements of HIV positive mothers from one health facility to another and not alerting the health care workers. The study will inevitably explore the reasons and impact of not applying for transfer letters.

8.5. Limitations of the Study

The study was limited to only the Limpopo Province rural settings and the findings were generalised from a few local public clinics. Key respondents from the case and control groups where the subject matter was sensitive and retrospective and could have provided less detailed information. The participants who were LTFU were hard to trace due to wrong addresses/information and non-existing contact numbers. The study population for quantitative surveys with healthcare workers was small because of the staff shortages and a limited number of professional workers who work directly with HIV positive mothers. I was able to conduct surveys of a total population of the healthcare workers in five health facilities.

8.6. Conclusion

The study provided the social patterns or barriers concerning social institutions such as family, education, gender relations and healthcare systems. The reasons that influenced LTFU non-adherence are rooted in the mothers' guilt, fears and struggles with the disclosure of HIV to their sexual partners and family/parents. The other mothers self-transferred to nearby health facilities while a few experienced HIV medication barriers, delays and interruption of ART and health care systems factors. Though the mothers were LTFU, they showed impressive vigilance and concerns over their infants/baby's health to utilise HIV services. However, they lacked awareness and knowledge about MTCT during pregnancy, childbirth and after birth. The CHWs on the other hand were not aware of MTCT during pregnancy but were able to explain MTCT during childbirth and breastfeeding but expressed the need for training regarding PMTCT activities like MTCT. The mothers were mix-feeding their babies, this also confirmed by the CHWs. The mothers were aware that they are not allowed to mix feed, they were also aware of the HIV treatment prevention measures and their importance. The mix-feeding patterns of mothers were influenced by daily life activities and motherhood instincts to address their infants’ needs.

The research findings were drawn from multiple groups of HIV positive mothers and healthcare workers to address the existing gaps in the literature. The healthcare workers (nurses and lay counsellors and the CHWs) provided substantial complementary evidence from their experiences in the implementation of the PMTCT programmes and contributed to the understanding of the social patterns of LTFU and non-adherence of HIV positive mothers. The health facilities lack relevant resources such as test kits, medication, space and staff. The CHWs faces challenges like wrong addresses or contact information and lack of support. Additionally, the culture of healthcare accommodates healthcare workers’ needs rather than the health system accommodating the multiple daily life responsibilities of mothers.

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APPENDIX A

University of Johannesburg Ethical Clearance

UNIVERSITY
OF
JOHANNESBURG

FACULTY OF HUMANTIES

RESEARCH ETHICS COMMITTEE

02 October 2018

ETHICAL CLEARANCE NUMBER	**REC-02-00130-2018**
REVIEW OUTCOME	Approved with Minor Changes
APPLICANT	Ramoshaba, R
TITLE OF RESEARCH PROJECT	Social Patterns of Loss to Follow-Up and Non-Adherence in the Limpopo Province Prevention of Mother-to-Child Transmission Programmes
DEPARTMENT	Sociology
SUPERVISOR/S	Dr K Batisai Prof I Palmary

Dear Ramoshaba R;

The Faculty of Humanities Research Ethics Committee has scrutinised your research proposal and confirm that it complies with the approved ethical standards of the Faculty of Humanities; University of Johannesburg. We have made some recommendations, set out below, for your consideration in consultation with your supervisors.

Recommendations:

- Research Design – should consider qualitative.
- You have included the details of one counsellor in the letter: Will she be available to all the people in the two districts? Or should you not rather have different details for people in different places – accessible for the mothers where they are?
- Also, rather rephrase the inclusion to say something along the lines: "If this interview raises uncomfortable feelings and you would thus want to request counselling.
- You don't need to include the counsellor's details in the health workers' information letter.
- In the mothers' information letter, you write: "The study hopes to explore the reasons and associated factors that influenced your decision to no longer access or utilise PMTCT services" – However 50% of the mothers you intend to interview are actively participating in the services, right? Please edit.

- Consent form - It is unnecessary to include a second information letter (written in the same format as the information letter) in the consent form. What is needed here is the participant's declaration that you have as a second part of the consent form: "I ______ hereby…".
- Discussion of bias unclear -should be reflected on with supervisors.
- The student's discussion of bias is unclear. ("The instruments in this research will be given to participants who meet the eligible criteria by minimising selection bias."; "The reviews, interviews and questionnaires will be self-administered, minimizing risk of bias during data collection.") Something to reflect on with the supervisors.
- Question regarding access to health facilities: Will you get the permission from the health facilities in writing?

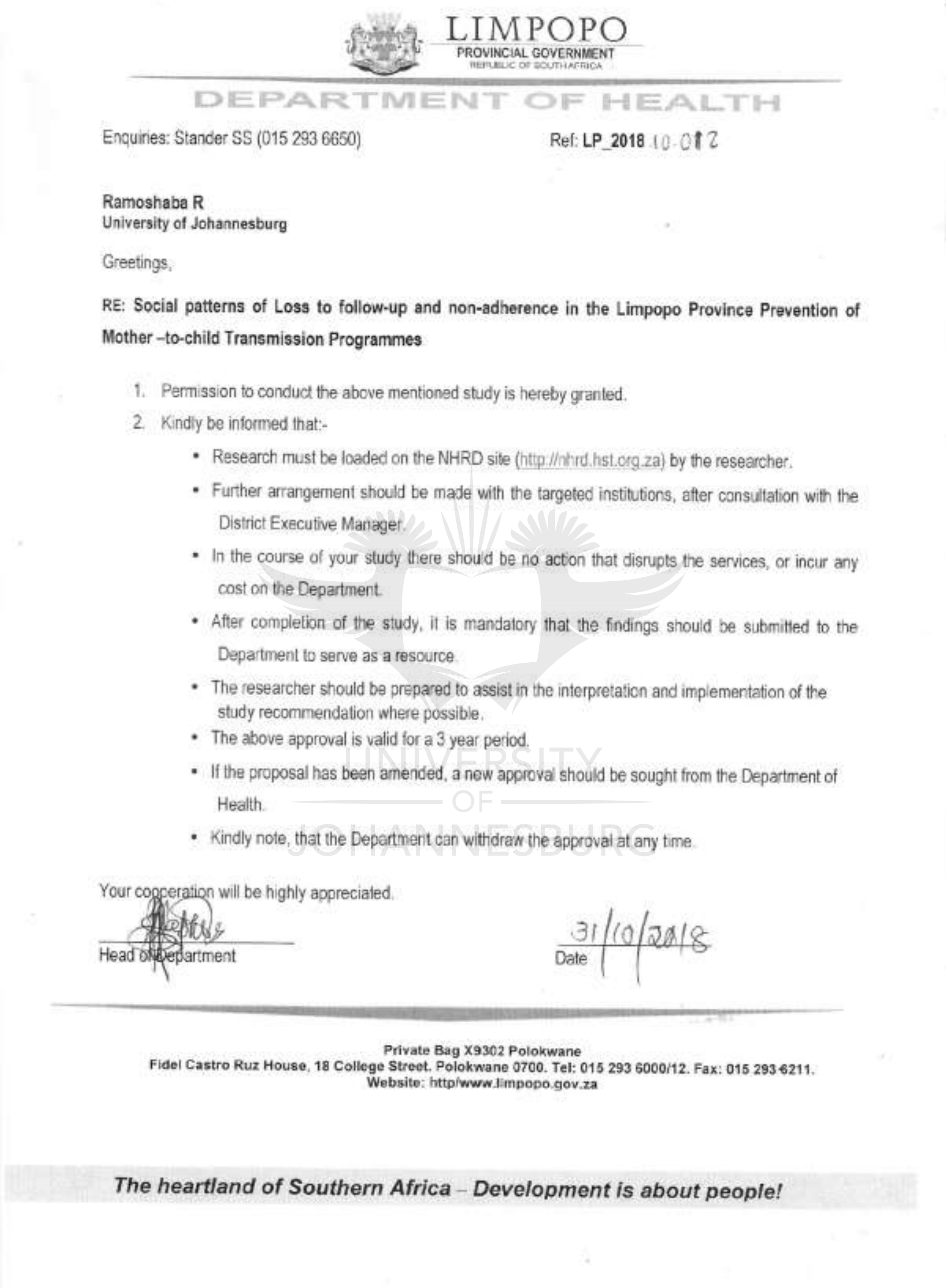
The REC would like to extend their best wishes to you with your postgraduate studies.

Yours sincerely,

Prof Grace Khunou
Chair: Faculty of Humanities REC
Tel: 011 559 3346
Email: gracek@uj.ac.za

APPENDIX B

Department of Health Provincial al Ethical Clearance



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: LP_2018 10-012

Ramoshaba R
University of Johannesburg

Greetings,

RE: Social patterns of Loss to follow-up and non-adherence in the Limpopo Province Prevention of Mother –to-child Transmission Programmes

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

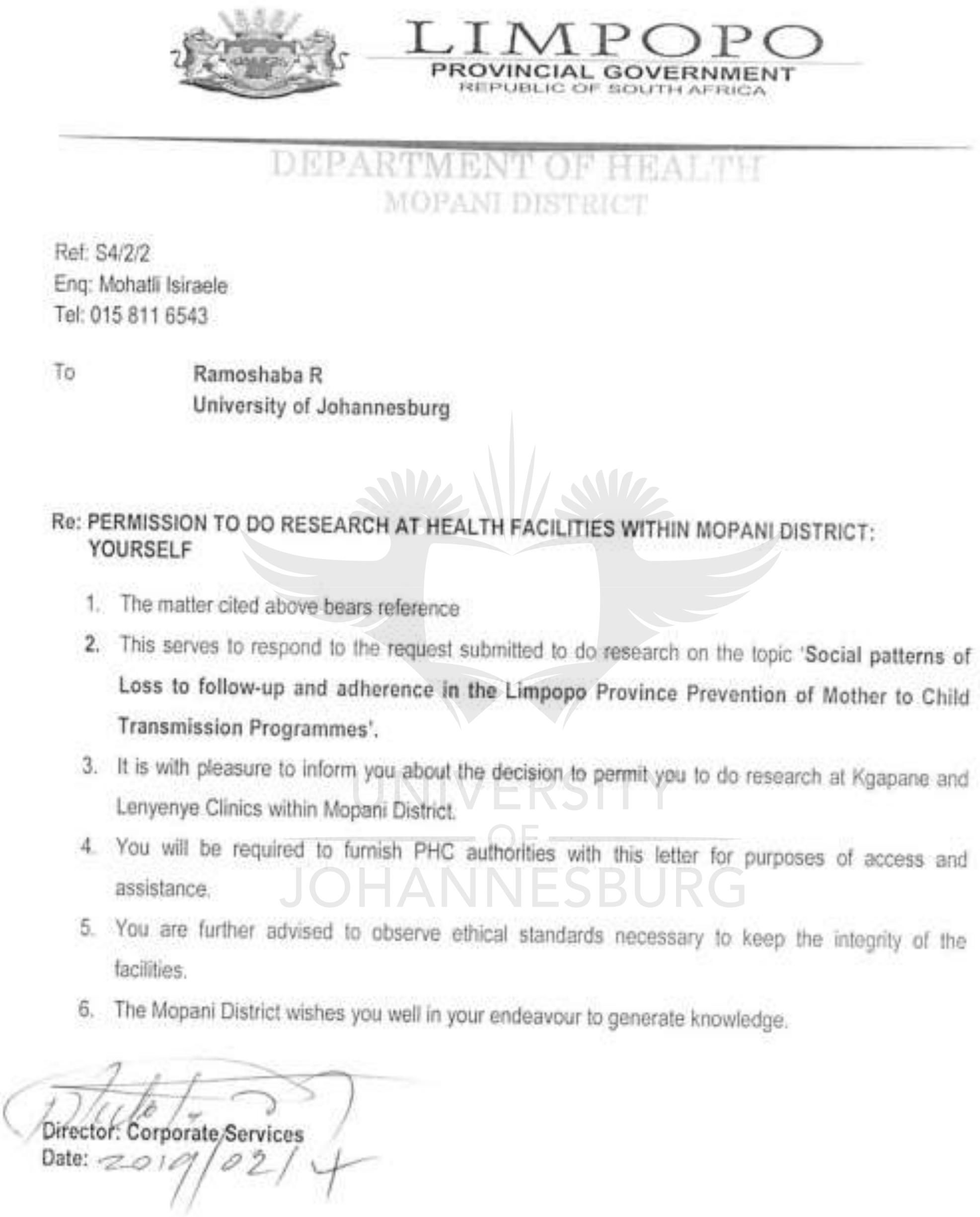
Your cooperation will be highly appreciated.

Head of Department

31/10/2018
Date

APPENDIX C

Permission to Conduct Research in Mopani District



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
MOPANI DISTRICT

Ref: S4/2/2
Enq: Mohatli Isiraele
Tel: 015 811 6543

To **Ramoshaba R**
University of Johannesburg

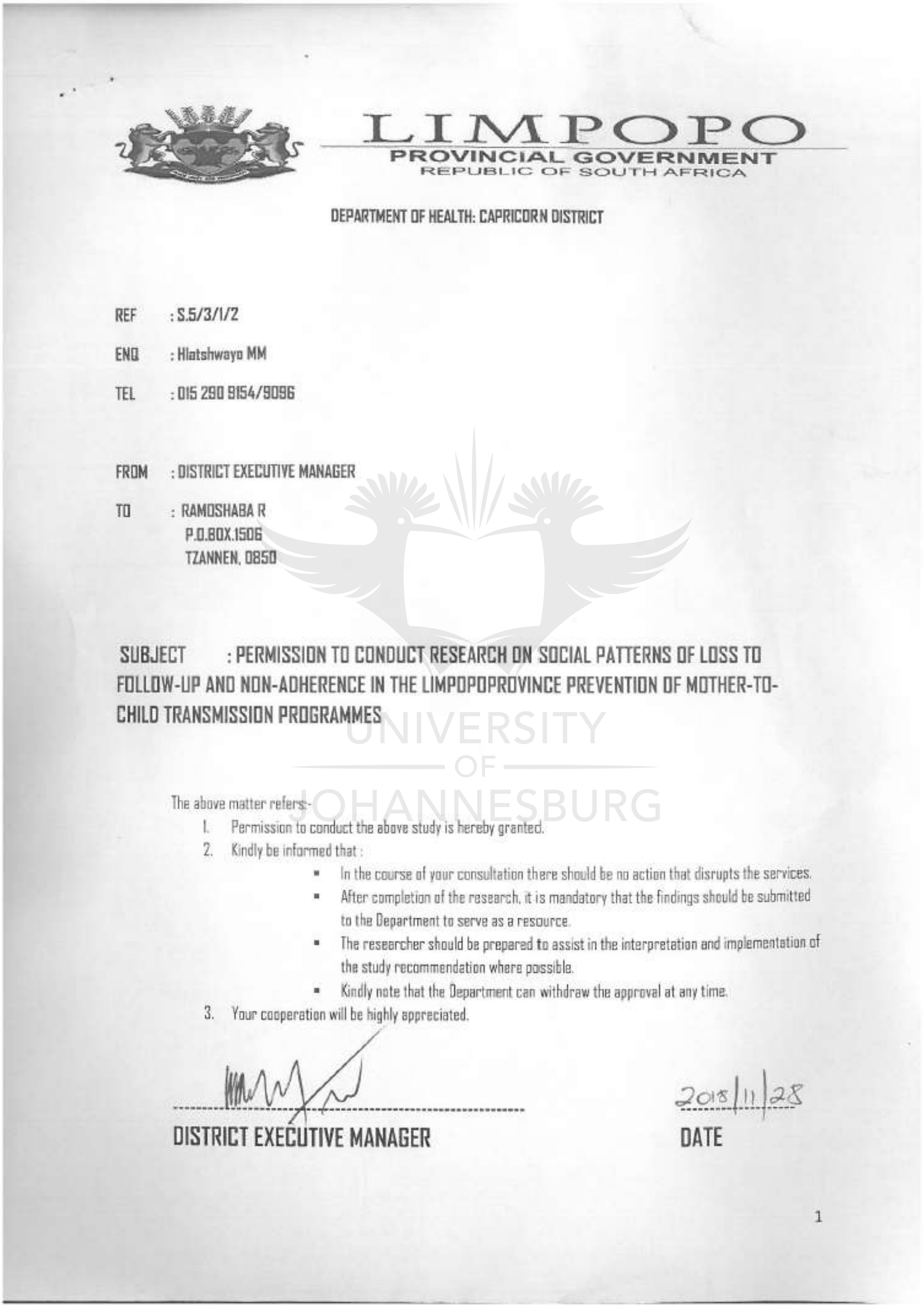
Re: PERMISSION TO DO RESEARCH AT HEALTH FACILITIES WITHIN MOPANI DISTRICT: YOURSELF

1. The matter cited above bears reference
2. This serves to respond to the request submitted to do research on the topic '**Social patterns of Loss to follow-up and adherence in the Limpopo Province Prevention of Mother to Child Transmission Programmes**'.
3. It is with pleasure to inform you about the decision to permit you to do research at Kgapane and Lenyenye Clinics within Mopani District.
4. You will be required to furnish PHC authorities with this letter for purposes of access and assistance.
5. You are further advised to observe ethical standards necessary to keep the integrity of the facilities.
6. The Mopani District wishes you well in your endeavour to generate knowledge.

Director: Corporate Services
Date: 2019/02/14

APPENDIX D

Permission to Conduct Research in Capricorn District



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH: CAPRICORN DISTRICT

REF : S.5/3/1/2
ENQ : Hlatshwayo MM
TEL : 015 290 9154/9096

FROM : DISTRICT EXECUTIVE MANAGER
TO : RAMOSHABA R
P.O.BOX.1506
TZANNEN, 0850

SUBJECT : PERMISSION TO CONDUCT RESEARCH ON SOCIAL PATTERNS OF LOSS TO FOLLOW-UP AND NON-ADHERENCE IN THE LIMPOPOPROVINCE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION PROGRAMMES

The above matter refers:-

1. Permission to conduct the above study is hereby granted.
2. Kindly be informed that :
    - In the course of your consultation there should be no action that disrupts the services.
    - After completion of the research, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    - Kindly note that the Department can withdraw the approval at any time.
3. Your cooperation will be highly appreciated.

DISTRICT EXECUTIVE MANAGER

2018/11/28
DATE

APPENDIX E

Consent Form

Informed Consent Form

Formal acknowledgement of consent

I……………………………………………..hereby voluntary consent to participate in the following project: **Social patterns of loss to follow up and Non-adherence in the Limpopo province PMTCT programmes**. I understand that I will be asked questions regarding my experiences in the Limpopo province PMTCT programmes. I acknowledge that my participation is voluntary and I am aware that I do not have to take part in the project and that I may voluntarily withdraw at any stage. I hereby consent to the tape recording of my participation in the interviews. Under these conditions, I am willing to participate in the project.

Signature of participant…………………Date……………………….

APPENDIX F

Information Letter for HIV positive Mothers

Information Sheet /Letter for Semi-structed Interviews with HIV Positive Mothers)

Dear Prospective participants

My name is Refilwe Ramoshaba, I am a Sociology Doctoral student from the University of Johannesburg. I am conducting an academic study: **Social Patterns of Loss to Follow-Up and Non-Adherence in the Limpopo Province Prevention of Mother-to-Child Transmission Programmes**. The study and its procedures have been approved by the University of Johannesburg Ethic committee and by the Limpopo provincial Department of Health (DoH). I been granted permission by the health facilities authorities to carry out the study.

The purpose of the study is to determine patterns of loss to follow up and adherence in the Limpopo province PMTCT programmes, and the explore reasons, associated factors, retention challenges and strategies to improve care, treatment and service utilisation. You are being requested to participate in this research study because it is felt that you have the relevant experience as a community health worker who has implemented the PMTCT programme to contribute to your understanding and knowledge of health care practices within the PMTCT context.

The information you provide will be treated with the utmost confidentiality and will only be used for the purposes of this study. Some of the questions will be very personal and sensitive and to assure your anonymity; your name will not appear on the written report, the study will only take place in the health facility (the researcher will be allocated a secure office in the facility to adhere anonymity and confidentiality). The information you provide will not be used against you (the information will only be used for academic purposes). The study findings of this study will be public and published but your name will not be linked with the report/findings. Your name or identity or any information about you will represented with a code (e.g.; p1, R1). All data will be collected by the researcher, stored in a secure place, and not shared with any other person without your permission. The soft copies of the research data will be stored in the researcher`s password protected and secured laptop and backed in the researcher`s password protected external hard drive.

The interviews will take approximately 45 minutes or less to complete. Your participation in the study is purely voluntary; you are under no obligation to participate. If you choose not to participate, I assure you that you will not lose your job because of the study, nothing will change. You are free or have a right to withdraw from the study at any time and your relationship with health care team will not be compromised.

You are free to ask any questions pertaining to the study or about being a research participant and you may contact me. My contact details are as follows: Mr R Ramoshaba on +2782 703 8721. Email address: refilweramoshaba@gmail.com. You may also contact my supervisors: Prof Kezia Batisai (keziab@uj.ac.za/ 011 559 3438) or Prof Ingrid Palmary (ipalmary@uj.ac.za/ 011 559 2975). If you request counselling, the contact details and name of a person who will provide free counselling is; Mrs Genes Mafokwane, cell number: 0732691738, work number: 011 933 0000. I am therefore requesting your permission to participate in this study by completing and signing the consent form below.

Thank You

Yours Faithfully

APPENDIX G

Information Letter for Nurse and Lay counsellors

Information Sheet /Letter for Questionnaires with Nurses and Lay Counsellors

Dear Prospective participants

My name is Refilwe Ramoshaba, I am a Sociology Doctoral student from the University of Johannesburg. I am conducting an academic study: **Social Patterns of Loss to Follow-Up and Non-Adherence in the Limpopo Province Prevention of Mother-to-Child Transmission Programmes**. The study and its procedures have been approved by the University of Johannesburg Ethic committee and by the Limpopo provincial Department of Health (DoH). I been granted permission by the health facilities authorities to carry out the study.

The purpose of the study is to determine patterns of loss to follow up and adherence in the Limpopo province PMTCT programmes, and the explore reasons, associated factors, retention challenges and strategies to improve care, treatment and service utilisation. You are being requested to participate in this research study because it is felt that you have the relevant experience as a community health worker who has implemented the PMTCT programme to contribute to your understanding and knowledge of health care practices within the PMTCT context.

The information you provide will be treated with the utmost confidentiality and will only be used for the purposes of this study. Some of the questions will be very personal and sensitive and to assure your anonymity; your name will not appear on the written report, the study will only take place in the health facility (the researcher will be allocated a secure office in the facility to adhere anonymity and confidentiality). The information you provide will not be used against you (the information will only be used for academic purposes). The study findings of this study will be public and published but your name will not be linked with the report/findings. Your name or identity or any information about you will represented with a code (e.g.; p1, R1). All data will be collected by the researcher, stored in a secure place, and not shared with any other person without your permission. The soft copies of the research data will be stored in the researcher`s password protected and secured laptop and backed in the researcher`s password protected external hard drive.

The survey will take approximately 15 minutes or less to complete. Your participation in the study is purely voluntary; you are under no obligation to participate. If you choose not to participate, I assure you that you will not lose your job because of the study, nothing will change. You are free or have a right to withdraw from the study at any time and your relationship with health care team will not be compromised.

You are free to ask any questions pertaining to the study or about being a research participant and you may contact me. My contact details are as follows: Mr R Ramoshaba on +2782 703 8721. Email address: refilweramoshaba@gmail.com. You may also contact my supervisors: Prof Kezia Batisai (keziab@uj.ac.za/ 011 559 3438) or Prof Ingrid Palmary (ipalmary@uj.ac.za/ 011 559 2975). If you request counselling, the contact details and name of a person who will provide free counselling is; Mrs Genes Mafokwane, cell number: 0732691738, work number: 011 933 0000. I am therefore requesting your permission to participate in this study by completing and signing the consent form below.

Thank You

Yours Faithfully
Ramoshaba R

APPENDIX H

Information Letter for Community Health Workers (CHWs)

Dear Prospective participants

My name is Refilwe Ramoshaba, I am a Sociology Doctoral student from the University of Johannesburg. I am conducting an academic study: **Social Patterns of Loss to Follow-Up and Non-Adherence in the Limpopo Province Prevention of Mother-to-Child Transmission Programmes**. The study and its procedures have been approved by the University of Johannesburg Ethic committee and by the Limpopo provincial Department of Health (DoH). I been granted permission by the health facilities authorities to carry out the study.

The purpose of the study is to determine patterns of loss to follow up and adherence in the Limpopo province PMTCT programmes, and the explore reasons, associated factors, retention challenges and strategies to improve care, treatment and service utilisation. You are being requested to participate in this research study because it is felt that you have the relevant experience as a community health worker who has implemented the PMTCT programme to contribute to your understanding and knowledge of health care practices within the PMTCT context.

The information you provide will be treated with the utmost confidentiality and will only be used for the purposes of this study. Some of the questions will be very personal and sensitive and to assure your anonymity; your name will not appear on the written report, the study will only take place in the health facility (the researcher will be allocated a secure office in the facility to adhere anonymity and confidentiality). The information you provide will not be used against you (the information will only be used for academic purposes). The study findings of this study will be public and published but your name will not be linked with the report/findings. Your name or identity or any information about you will represented with a code (e.g.; p1, R1). All data will be collected by the researcher, stored in a secure place, and not shared with any other person without your permission. The soft copies of the research data will be stored in the researcher`s password protected and secured laptop and backed in the researcher`s password protected external hard drive.

The Focus Group Discussion will take approximately 45 minutes or less to complete. Your participation in the study is purely voluntary; you are under no obligation to participate. If you choose not to participate, I assure you that you will not lose your job because of the study, nothing will change. You are free or have a right to withdraw from the study at any time and your relationship with health care team will not be compromised.

You are free to ask any questions pertaining to the study or about being a research participant and you may contact me. My contact details are as follows: Mr R Ramoshaba on +2782 703 8721. Email address: refilweramoshaba@gmail.com. You may also contact my supervisors: Prof Kezia Batisai (keziab@uj.ac.za/ 011 559 3438) or Prof Ingrid Palmary (ipalmary@uj.ac.za/ 011 559 2975). If you request counselling, the contact details and name of a person who will provide free counselling is; Mrs Genes Mafokwane, cell number: 0732691738, work number: 011 933 0000. I am therefore requesting your permission to participate in this study by completing and signing the consent form below.

Yours Faithfully

Ramoshaba R

APPENDIX I

Interview Guide with HIV positive Mothers in the Case Group (LTFU)

APPENDIX A **Form#** ☐☐☐☐

SEMI-STRUCTURED INTERVIEWS WITH HIV POSITIVE MOTHERS (LOSS TO FOLLOW-UP)

SECTION A: DEMOGRAPHIC INFORMATION

Facility Information

Name of researcher ______________________________

Date of data collection ______________________________

Country ______________________________

Province ______________________________

District ______________________________

Sub-district ______________________________

Name of health facility ______________________________

Participant's Information

1. Age

18-21	1
22-25	2
26-30	3
31-35	4
36-40	5
41-45	6
46-50	7
Others (specify)	8

2. Marital status

Never Married	1
Married	2
Divorced	3
Separated	4
Co-habiting	5
Others (specify)	6

3. Race

Black	1
White	2
Coloured	3
Indian	4
Asian	5
Others (specify)	6

4. Are you employed?

Yes	1
No	2

5. If yes, please specify below the category you belong

Teacher	1
Bank teller	2
Police	3
Nurse	4
Others (specify)	5

6**.** Please specify the salary/stipend/ grand allowance you receive per month?

____

7. Educational Level

Never went to school	1
Primary level	2
Secondary level	3
Tertiary level	4
Others (specify)	5

8. What is your Religion?

Christianity	1
African traditional	2
Islam	3
Buddhism	4
Others (specify)	5

9. How many children do you have?

Zero	1
One	2
Two	3
Three	4
Others (specify)	5

10. How old is your current children?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
10-12 months (41-49 weeks)	4
Others (specify)	5

11. When did you start post-natal care?

____

12. How long have your child been on post-natal care?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
Others (specify)	4

13. What is the HIV Status of your child?

HIV positive	1
HIV negative	2
I don`t know	3

Knowledge and attitude towards the MTCT, PMTCT programme

14. Can an HIV-positive mother transmit HIV to her baby?

Yes	1
No	2
I don’t know	3

15. Pleases support your answer with reasons, why?

____
____
______

16. How can a mother transmit HIV to her child after birth?

____
____
______

17. At what stage could a mother transmit HIV to her child?

During pregnancy	Yes	1	Pleases support your answer ______________________________________
	No	2	
During delivery or labour	Yes	3	Pleases support your answer ______________________________________
	No	4	
During breastfeeding	Yes	5	Pleases support your answer ______________________________________
	No	6	

18. How can Mother-to-Child Transmission of HIV be prevented?

____
____
______

19. Are you aware of any intervention that helps women to prevent mother-to-child transmission of HIV?

Yes	1
No	2

20. If yes, please identify and explain what the intervention entails?

____
____
______

21. Does the use of anti-HIV drugs prevent mother-to-child transmission of HIV?

Yes	1
No	2
I don’t know	3

22. Pleases support your answer with reasons

____
____
______

23. Which feeding method are you following?

Breastfeeding	1
Exclusive breastfeeding	2
Formula feeding	3
Mix feeding	4

24. Pleases support your answer, give reasons for the feeding choice, and is it challenging?

____
____
______

25. Do you think HIV positive women should breastfeed their babies?

Yes	1
No	2

26. Pleases support your answer with reasons, why?

____
____
______

27. If yes, how long can HIV positive mothers breastfeed her baby and why?

____
____
______

Need for health services

28. How would you describe the service provided to you in the PMTCT programme?

Good	1
Bad	2
Moderate	3

29. Please support your answer

____

____

____

30. Is there a need for you to use PMTCT post-natal services?

Yes	1
No	2

31. Please support your answer

____

____

____

32. Do you think PMTCT post-natal follow-up services are important in reducing the spread of HIV? Especially from a mother to child.

Yes	1
No	2

33. Please support your answer with reasons.

____

____

____

34. Will you recommend anyone to use PMTCT follow-up services?

Yes	1
No	2

35. Please support your answer with reasons

____

____

____

Loss to Follow-Up

36. What was the reason/s for missing a scheduled post-natal follow-up visit? Please explain why?

____

____

37. What is the reason/s you are loss to follow-up at this clinic?

Too ill/weak to come to the clinic	1
Self-Transferred to another clinic	2
Fear of what other people will say	3
Have not disclosed HIV status partner/family	4
Religious or cultural beliefs	5
Distance	6
Travelling costs	7
Others (specify)	8

38. Please explain why?

____

____

______

39. How long have you been loss to follow-up?

____

___

40. How many post-natal visits have you missed since birth?

1 visit	1
2 visits	2
3 visits	3
Others (specify)	4

41. Please explain why?

____

____

______

42. What is the reason/s you allowed your child to missed scheduled visits? Please explain why?

____

____

______

43. Did you want your child to continue missing scheduled visits at this clinic? Please explain why?

____

44. What challenges did you or have you encountered that contributed or influenced your decision to discontinue HIV treatment or services at this clinic? Please explain why?

____

45. When did you miss your first PMTCT post-natal follow-up visit, what was the reason/s then?

____

46. What did you do when you missed a scheduled appointment?

____

47. How is your current health situation after you discontinued PMTCT post-natal services?

____

48. How is your child`s current health after you discontinued follow-up services? Please explain.

____

49. Did you receive any communication or visit from the clinic personnel after you where loss to follow-up?

Yes	1
No	2

50. If yes, please explain what the health personnel discussed with you on the phone or during the visit?

____
____
____

51. How where you treated by the health personnel who called you or visited you?

____
____
____

52. Do you want to restart PMTCT services with this clinic?

Yes	1
No	2

53. Please explain why?

____
____
____

54. If no, what is the reason and what needs to happen for you to restart?

____
____
____

Non-adherence of Treatment

55. Are you on ART now?

Yes	1
No	2

56. Explain why?

____
____
_____

57. If no, when did you stop taking HIV medications and why?

____
____
_____

58. How many times have you collected ARV since you started ART at this clinic?

1 visit	1
2 visits	2
3 visits	3
Others (specify)	4

59. Explain why?

____
____
_____

60. If you are on ART, how long have you been on ART?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
Others (specify)	4

61. What is the number of HIV pills you swallow every day?

0	1
1	2
2	3
3	4
4	5
5	6
If other specify _____	7

62. What is the name of this HIV pill/s? How can you confirm that they are HIV pills.

____
____
______

63. Where you consistently taking this pill everyday as instructed?

Yes	1
No	2

64. Please explain why?

____
____
______

65. If no, how long did you continue with treatment interruption?

____
____
____

66. What was the reason for interrupting treatment?

____
____
______

67. If you are currently on HIV treatment, where are you receiving HIV medication? Please explain why?

____
____
____

68. Do you want to receive HIV treatment anywhere else other than this clinic?

Yes	1
No	2

69. Please explain why?

____
____
____

70. Did you receive counselling on treatment adherence?

Yes	1
No	2

71. If yes, what did you learn and what instructions did you receive from the treatment counselling?

____
____
______

72. For how long did the treatment counselling last and where you satisfied? Please support your answer with reasons.

____
____
______

73. Have you experienced any adverse reactions (side effects) of ART?

Yes	1
No	2

74. If yes, please explain these reactions and are these side effects the reason you not taking HIV medication as instructed.

____
____
______

75. Do you adhere to treatment schedule when you aren’t feeling well?

Yes	1
No	2

76. Pleases support your answer with reasons.

____
____
____

77. Would you confidently say that you are adhering to treatment?

Yes	1
No	2
Not sure	3

78. Pleases support your answer with reasons

____
____
____

79. How do you adhere to HIV treatment after giving birth?

____
____
____

80. What where the barriers or challenges to treatment adherence after birth?

____
____
____

81. Where you on HIV treatment while feeding your child?

Yes	1
No	2

82. Please explain why?

____
____
____

83. What would you say have been the challenges of adhering to treatment for you personally?

____
____
____

84. Do you have a treatment supporter presently?

Yes	1
No	2

85. Please explain and if yes, what is the role or significance of this treatment supporter?

____

Disclosure, Stigma and discrimination

81. Have you disclosed your HIV status to anyone?

Yes	1
No	2

82. Please explain why?

____

83. How do you feel about disclosing your HIV status?

____

84. Who did you disclose your HIV status to and why?

____

85. How did the first person that you disclosed to react?

____

86. How are people living with HIV treated in your community?

87. Are you satisfied with the anonymity, privacy and confidentiality practice at your clinic?

Yes	1
No	2

88. Please explain why?

89. If no is lack of anonymity, privacy and confidentiality in the Clinic the reason you discontinued service?

Yes	1
No	2

90. Please explain why?

91. Are you using another clinic that is not from the community you belong?

Yes	1
No	2

92. Please explain why?

93. Are you worried about using the clinic at your community because you fear that your status will be revealed?

Yes	1
No	2

94. Please support your answer with reasons

____
____
______

95. Have you ever experienced stigmatisation or/and discrimination because of your HIV status?

Yes	1
No	2

96. If yes, please explain where, by who and what happened?

____
____
______

97. How did you deal with the stigmatisation or/and discrimination?

____
____
______

98. If you experienced stigma and discrimination, did the experience influenced your adherence to PMTCT post-natal services?

Yes	1
No	2

99. Please explain why?

____
____
______

100. Does your experience with stigmatisation or/and discrimination because of your status influence your decision to not use HIV medications?

Yes	1
No	2

101. Please explain why?

____
____
______

Gender inequality and male involvement

102. What role does a partner play in the PMTCT programme and why?

____
___

103. Did you disclose your HIV status to your partner?

Yes	1
No	2

104. Please explain why?

____
____
______

105. Did you invite your partner for support and to be involved in PMTCT post-natal activities?

Yes	1
No	2

106. Please explain why?

____
____
______

107. Did you invite your partner to get tested and counselling for HIV/AIDS?

Yes	1
No	2

108. Please explain why?

____
____
______

109. Is your partners tested for HIV?

Yes	1
No	2
I don’t know	3

110. Please explain why?

____

111. Is your partner often violent towards you?

Yes	1
No	2

112. Please explain why?

____

113. Do you fear that he might be violent when you use HIV-related services?

Yes	1
No	2

114. Please explain why?

____

115. Do you fear that your partner might leave you because of your HIV status or if you use HIV-related services?

Yes	1
No	2

116. Please explain why?

____

117. Do you find it easy to negotiate for safer sex practices?

Yes	1
No	2

119. Please explain why?

____

____

______

120. Is your HIV status affecting your marriage or relationship?

Yes	1
No	2

121. Please explain why?

____

____

______

122. Did your partner influence you to discontinued services at this clinic?

Yes	1
No	2

123. Please explain why?

____

____

______

124. Is your partner the reason you don’t use or adhere to HIV treatment?

Yes	1
No	2

125. Please support your answer

____

____

______

126. How does your partner feel about your feeding choice? Does he support you?

____

____

______

Cultural and religious factors

127. Does your religion allow you to use PMTCT services?

Yes	1
No	2

128. Please explain why?

____

129. Which methods are you using to treat HIV?

African Traditional medicines	1
Western medicines (e.g., ARV)	2
Prayers and anointed water	3
Both African Traditional and western medicines	4
Prayers and Western medicines (e.g., ARV)	5
Both African traditional medicines and prayers	6
Herbals	7
Other (specify)	4

130. Please explain why?

____

131. Is it safer to use traditional medicines as HIV treatment?

Yes	1
No	2

132. Please explain why?

____

133. Who do you believe can manage HIV better?

Traditional healer	1
Medical doctor	2
Priest	3
Other (specify)	4

134. Please explain why?

----

135. Please explain why? What is your family cultural or religious practices or beliefs in terms of feeding a baby?

____
____
____

136. Does your culture or religion allow use of feeding practices (such as exclusive breastfeeding or exclusive formula feeding) instructed by health workers?

Yes	1
No	2

137. Please explain why?

Accessibility and Socio-economic factors

138. What are the obstacles to accessing PMTCT follow-up services?

Transportation cost	1
Lack of Financial support	2
Distance of the Clinics	3
Others…specify	4

139. Please explain why?

____
____
____

140. What are the obstacles to accessing or collecting PMTCT medication or treatments?

Transportation cost	1
Lack of Financial support	2
Distance of the Clinics	3
Others…specify	4

141. Please explain why?

____

____

______

Social Support

142. Does your family support you to use PMTCT follow-up services?

Yes	1
No	2

143. Please explain why?

____

____

_

144. Are you supported by your family in terms of your feeding practice that you are currently using? Please support your answer

____

____

______

Health Care System Factors

145. Do you think PMTCT service providers know how to tackle loss to follow-up of babies?

Yes	1
No	2

146. Please explain why?

____

____

______

147. Do you think current PMTCT guidelines and policies are effective in combating HIV from a mother to her baby?

Yes	1
No	2

148. Please explain why?

149. Do you think current PMTCT guidelines and policies are they effective in preventing loss to follow-up of HIV positive mothers and their babies?

Yes	1
No	2

150. Please explain why?

151. Is the government doing enough to promote the use of PMTCT follow-up services by mothers?

Yes	1
No	2

152. Please explain why?

153. Were you well treated at the health facility by health workers?

Yes	1
No	2

154. Please explain why?

155. Were you well treated at the health facility by other patients or visitors?

Yes	1
No	2

156. Please support your answer. If yes, explain what happened.

____
____
______

157. Were you well informed about PMTCT follow-up services at the health facility?

Yes	1
No	2

158. Please support your answer

____
____
______

159. In your opinion do you think health care personnel are well informed/knowledgeable about PMTCT follow- up activities?

Yes	1
No	2

160. Please explain why?

____
____
______

161. Are you satisfied with the waiting period at the clinic?

Yes	1
No	2

162. Please support your answer with reasons

____
____
______

163. Do you think the healthcare system has relevant resources (staff, space, medication, and testing kits) to provide PMTCT services?

Yes	1
No	2

164. Please explain why? If yes, which resources are lacking?

____
____
______

165. Which of the following Healthcare factors are reasons you are loss to follow-up at the clinic? Select all applicable.

Long waiting periods	1
Poor conditions (infrastructure)	2
Lack of space for privacy and confidentiality	3
Health workers` attitude	4
Lack of health workers	5
Lack of medications	6
Lack of professionalism by health workers	7
Lack of anonymity and confidentiality	8
Others….Specify here	9

166. Please explain why?

____

____

______

167. Which of the following Healthcare factors are reasons you are not collecting HIV medication? Select all applicable.

Long waiting periods	1
Lack of space for privacy and confidentiality	2
Health workers` attitude	3
Lack of health workers (staff)	4
Lack of medications	5
Lack of professionalism by health workers	6
Lack of privacy, anonymity and confidentiality	7
Others….Specify here	8

168 Please explain why?

____

____

______

169. Specify any strategies to improve PMTCT follow-up services for the future. How would you improve on the services?

____

____

______

170. Specify any strategies that can motivate you to use and continue with PMTCT follow-up services and to adhere to treatment in the future.

____

THANK YOU FOR YOUR TIME AND PARTICIPATION

APPENDIX J

Interview Guide with HIV positive Mothers in the Control Group (CIC)

APPENDIX B **Form#** ☐☐☐☐

SEMI-STRUCTURED WITH HIV POSITIVE MOTHERS (CURRENTLY ATTENDING PMTCT SERVICES)

SECTION A: DEMOGRAPHIC INFORMATION

Facility Information

Name of researcher ______________________________

Date of data collection ______________________________

Country ______________________________

Province ______________________________

District ______________________________

Sub-district ______________________________

Name of health facility ______________________________

Participant's Information

1. Age

18-21	1
22-25	2
26-30	3
31-35	4
36-40	5
41-45	6
46-50	7
Others (specify)	8

2. Marital status

Never Married	1
Married	2
Divorced	3
Separated	4
Co-habiting	5
Others (specify)	6

3. Race

Black	1
White	2
Coloured	3
Indian	4
Asian	5
Others (specify)	6

4. Are you employed?

Yes	1
No	2

5. If yes, please specify below the category you belong

Teacher	1
Bank teller	2
Police	3
Nurse	4
Others (specify)	5

6. Please specify the salary/stipend/ grand allowance you receive per month.

____

7. Educational Level

Never went to school	1
Primary level	2
Secondary level	3
Tertiary level	4
Others (specify)	5

8. What is your Religion?

Christianity	1
African traditional	2
Islam	3
Buddhism	4
Others (specify)	5

9. How many children do you have?

Zero	1
One	2
Two	3
Three	4
Others (specify)	5

10. How old is your current child?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
10-12 months (41-49 weeks)	4
Others (specify)	5

11. When did you start PMTCT post-natal care?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
Others (specify)	4

12. How long have your child been on post-natal care?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
Others (specify)	4

13. What is the HIV Status of your child?

HIV positive	1
HIV negative	2
I don`t know	3

Knowledge and attitude towards the MTCT, PMTCT programme

14. Can an HIV-positive mother transmit HIV to her baby?

Yes	1
No	2
I don’t know	3

15. Pleases support your answer with reasons, why?

____

____

______

16. How can a mother transmit HIV to her child after birth?

____
____
______

17. At what stage could a mother transmit HIV to her child?

During pregnancy	Yes	1	Pleases support your answer ____________________
	No	2	
During delivery or labour	Yes	3	Pleases support your answer ____________________
	No	4	
During breastfeeding	Yes	5	Pleases support your answer ____________________
	No	6	

18. How can Mother-to-Child Transmission of HIV be prevented?

____
____
______

19. Are you aware of any intervention that helps women to prevent mother-to-child transmission of HIV?

Yes	1
No	2

20. If yes, please identify and explain what the intervention entails?

____
____
______

21. Does the use of anti-HIV drugs prevent mother-to-child transmission of HIV?

Yes	1
No	2
I don’t know	3

22. Pleases support your answer with reasons

23. Which feeding method are you following?

Breastfeeding	1
Exclusive breastfeeding	2
Formula feeding	3
Mix feeding	4

24. Pleases support your answer, give reasons for the feeding choice, and is it challenging?

25. Do you think HIV positive women should breastfeed their babies?

Yes	1
No	2

26. Pleases support your answer with reasons, why?

27. If yes, how long can HIV positive mothers breastfeed her baby and why?

Need for health services

28. How would you describe the service provided to you in the PMTCT programme?

Good	1
Bad	2
Moderate	3

29. Please support your answer

____
____
____

30. Is there a need for you to use PMTCT post-natal services?

Yes	1
No	2

31. Please support your answer

____
____
____

32. Do you think PMTCT post-natal follow-up services are important in reducing the spread of HIV? Especially from a mother to child.

Yes	1
No	2

33. Please support your answer with reasons.

____
____
____

34. Will you recommend anyone to use PMTCT follow-up services?

Yes	1
No	2

35. Please support your answer with reasons

____
____
____

Loss to Follow-Up

36. What are the reason/s that influence HIV mothers and their babies to miss a scheduled post-natal follow-up visit? Please explain why?

____
____

37. What do you think is the reason/s they are loss to follow-up at this clinic?

Too ill/weak to come to the clinic	1
Self-Transferred to another clinic	2
Fear of what other people will say	3
Have not disclosed HIV status partner/family	4
Religious or cultural beliefs	5
Distance	6
Travelling costs	7
Others (specify)	8

38. Please explain why?

____
____
______

39. How many post-natal visits have you missed since birth?

1 visit	1
2 visits	2
3 visits	3
Others (specify)	4

40. Please explain why?

____
____
______

41. Do you want your child to miss scheduled visits at this clinic? Please explain why?

____
____
______

42. What challenges did you or have you encountered that can contribute or influence your decision to discontinue HIV treatment or services at this clinic? Please explain why?

____
____
______

43 when was did you first miss a scheduled visit? What was the reason/s then?

____
____
______

44. What did you do when you missed a scheduled appointment?

____
____
______

45. How is your current health situation?

____
____
____

46. How is your child`s current health? Please explain.

____
____
______

47. Did you receive any communication or visit from the clinic personnel after you missed a scheduled visit?

Yes	1
No	2

48. If yes, please explain what the health personnel discussed with you on the phone or during the visit?

____
____
______

49. How where you treated by the health personnel who called you or visited you?

____
____
______

50. Do you want to continue with the PMTCT services with this clinic?

Yes	1
No	2

51. Please explain why?

____

____

____

52. If no, what is the reason and what needs to happen for you to continue?

____

____

____

Non-adherence of Treatment

53. Are you on ART now?

Yes	1
No	2

54. Explain why?

____

____

____

55. If no, when did you stop taking HIV medications and why?

____

____

____

56. How many times have you collected ARV since you started ART at this clinic?

1 visit	1
2 visits	2
3 visits	3
Others (specify)	4

57. Explain why?

____

____

____

58. If you are on ART, how long have you been on ART?

1-3 months (1-13 weeks)	1
4-6 months (14-26 weeks)	2
7-9 months (27-40 weeks)	3
Others (specify)	4

59. What is the number of HIV pills you swallow every day?

0	1
1	2
2	3
3	4
4	5
5	6
If other specify _____	7

60. What is the name of this HIV pill/s?

____
____
______

61. Are you consistently taking this pill as instructed?

Yes	1
No	2

62. Please explain why?

____
____
______

63. If no, how long did you continue with treatment interruption?

____
____
____

64. What was the reason for interrupting treatment?

____
____
______

65. Do you want to receive HIV treatment anywhere else other than this clinic?

Yes	1
No	2

66. Please explain why?

____
____
____

67. Did you receive counselling on treatment adherence?

Yes		1
No		2

68. If yes, what did you learn and what instructions did you receive from the treatment counselling?

____
____
______

69. For how long did the treatment counselling last and where you satisfied? Please support your answer with reasons.

____
____
______

70. Have you experienced any adverse reactions (side effects) of ART?

Yes	1
No	2

71. If yes, please explain these reactions. Can these side effects be the reason you not taking HIV medication as instructed?

____
____
______

72. Do you adhere to treatment schedule when you aren’t feeling well?

Yes	1

No	2

73. Pleases support your answer with reasons.

____
____
____

74. Would you confidently say that you are adhering to treatment?

Yes	1
No	2
Not sure	3

75. Pleases support your answer with reasons

____
____
____

76. How do you adhere to HIV treatment after giving birth?

____
____
____

77. What where the barriers or challenges to treatment adherence after birth?

____
____
____

78. Where you or are you on HIV treatment while feeding your child?

Yes	1
No	2

79. Please explain why?

____
____
____

80. What would you say have been the challenges of adhering to treatment for you personally?

____

____

______

81. Do you have a treatment supporter presently?

Yes	1
No	2

82. Please explain and if yes, what is the role or significance of this treatment supporter?

____

____

______

Disclosure, Stigma and discrimination

83. Have you disclosed your HIV status to anyone?

Yes	1
No	2

84. Please explain why?

____

____

______

84. How do you feel about disclosing your HIV status?

____

____

______

85. Who did you disclose your HIV status to and why?

____

____

______

86. How did the first person that you disclosed to react?

____

____

______

87. How are people living with HIV treated in your community?

____

____

______

88. Are you satisfied with the anonymity, privacy and confidentiality practice at your clinic?

Yes	1
No	2

89. Please explain why?

____

____

______

90. If no is lack of anonymity, privacy and confidentiality in the Clinic the reason you discontinued service?

Yes	1
No	2

91. Please explain why?

____

____

______

92. Are you using another clinic that is not from the community you belong?

Yes	1
No	2

93. Please explain why?

____

____

______

94. Are you worried about using the clinic at your community because you fear that your status will be revealed?

Yes	1

No	2

95. Please support your answer with reasons

____
____
____

96. Have you ever experienced stigmatisation or/and discrimination because of your HIV status?

Yes	1
No	2

97. If yes, please explain where, by who and what happened?

____
____
____

98. How did you deal with the stigmatisation or/and discrimination?

____
____
____

99. If you experienced stigma and discrimination, did the experience influenced your adherence to PMTCT post-natal services?

Yes	1
No	2

100. Please explain why?

____
____
____

101. Does your experience with stigmatisation or/and discrimination because of your status influence your decision to not use HIV medications?

Yes	1
No	2

102. Please explain why?

Gender inequality and male involvement

103. What role does a partner play in the PMTCT programme and why?

104. Did you disclose your HIV status to your partner?

Yes	1
No	2

105. Please explain why?

106. Did you invite your partner for support and to be involved in PMTCT post-natal activities?

Yes	1
No	2

107. Please explain why?

108. Did you invite your partner to get tested and counselling for HIV/AIDS?

Yes	1
No	2

109. Please explain why?

110. Is your partners tested for HIV?

Yes	1
No	2
I don’t know	3

111. Please explain why?

112. Is your partner often violent towards you?

Yes	1
No	2

113. Please explain why?

114. Do you fear that he might be violent when you use HIV-related services?

Yes	1
No	2

115. Please explain why?

116. Do you fear that your partner might leave you because of your HIV status or if you use HIV-related services?

Yes	1
No	2

117. Please explain why?

118. Do you find it easy to negotiate for safer sex practices?

Yes	1
No	2

119. Please explain why?

____
____
______

120. Is your HIV status affecting your marriage or relationship?

Yes	1
No	2

121. Please explain why?

____
____
______

122. Did your partner influence you to discontinued services at this clinic?

Yes	1
No	2

123. Please explain why?

____
____
______

124. Is your partner the reason you don’t use or adhere to HIV treatment?

Yes	1
No	2

125. Please support your answer

____
____
______

126. How does your partner feel about your feeding choice? Does he support you?

____

____

______

Cultural and religious factors

127. Does your religion allow you to use PMTCT services?

Yes	1
No	2

128. Please explain why?

____

____

______

129. Which methods are you using to treat HIV?

African Traditional medicines	1
Western medicines (e.g., ARV)	2
Prayers and anointed water	3
Both African Traditional and western medicines	4
Prayers and Western medicines (e.g., ARV)	5
Both African traditional medicines and prayers	6
Herbals	7
Other (specify)	4

130. Please explain why?

____

____

______

131. Is it safer to use traditional medicines as HIV treatment?

Yes	1
No	2

132. Please explain why?

____

____

______

133. Who do you believe can manage HIV better?

Traditional healer	1
Medical doctor	2
Priest	3
Other (specify)	4

134. Please explain why?

----

135. What is your family cultural or religious practices or beliefs in terms of feeding a baby?

____

136. Does your culture or religion allow use of feeding practices (such as exclusive breastfeeding or exclusive formula feeding) instructed by health workers?

Yes	1
No	2

137. Please explain why?

Accessibility and Socio-economic factors

138. What are the obstacles to accessing PMTCT follow-up services?

Transportation cost	1
Lack of Financial support	2
Distance of the Clinics	3
Others…specify	4

139. Please explain why?

____

140. What are the obstacles to accessing or collecting PMTCT medication or treatments?

Transportation cost	1
Lack of Financial support	2

Distance of the Clinics	3
Others…specify	4

141. Please explain why?

____
____
______

Social Support

142. Does your family support you to use PMTCT follow-up services?

Yes	1
No	2

143. Please explain why?

____
____
_

144. Are you supported by your family in terms of your feeding practice that you are currently using? Please support your answer

____
____
______

Health Care System Factors

145. Do you think PMTCT service providers know how to tackle loss to follow-up of babies?

Yes	1
No	2

146. Please explain why?

____
____
______

147. Do you think current PMTCT guidelines and policies are effective in combating HIV from a mother to her baby?

Yes	1
No	2

148. Please explain why?

____
____
______

149. Do you think current PMTCT guidelines and policies are they effective in preventing loss to follow-up of HIV positive mothers and their babies?

Yes	1
No	2

150. Please explain why?

____
____
______

151. Is the government doing enough to promote the use of PMTCT follow-up services by mothers?

Yes	1
No	2

152. Please explain why?

____
____
_____

153. Were you well treated at the health facility by health workers?

Yes	1
No	2

154. Please explain why?

____
____
______

155. Were you well treated at the health facility by other patients or visitors?

Yes	1
No	2

156. Please support your answer. If yes, explain what happened.

____

____

______

157. Were you well informed about PMTCT follow-up services at the health facility?

Yes	1
No	2

158. Please support your answer

____

____

______

159. In your opinion do you think health care personnel are well informed/knowledgeable about PMTCT follow- up activities?

Yes	1
No	2

160. Please explain why?

____

____

______

161. Are you satisfied with the waiting period at the clinic?

Yes	1
No	2

162. Please support your answer with reasons

____

____

______

163. Do you think the healthcare system has relevant resources (staff, space, medication, and testing kits) to provide PMTCT services?

Yes	1
No	2

164. Please explain why? If yes, which resources are lacking?

____
____
______

165. Which of the following Healthcare factors can be the reasons you are loss to follow-up at the clinic? Select all applicable.

Long waiting periods	1
Poor conditions (infrastructure)	2
Lack of space for privacy and confidentiality	3
Health workers` attitude	4
Lack of health workers	5
Lack of medications	6
Lack of professionalism by health workers	7
Lack of anonymity and confidentiality	8
Others….Specify here	9

166. Please explain why?

____
____
______

167. Which of the following Healthcare factors can be the reasons you are not collecting HIV medication? Select all applicable.

Long waiting periods	1
Lack of space for privacy and confidentiality	2
Health workers` attitude	3
Lack of health workers (staff)	4
Lack of medications	5
Lack of professionalism by health workers	6
Lack of privacy, anonymity and confidentiality	7
Others….Specify here	8

168 Please explain why?

____
____
______

169. Specify any strategies to improve PMTCT follow-up services for the future. How would you improve on the services?

____
____
____

170. Specify any strategies that can motivate you to use and continue with PMTCT follow-up services and to adhere to treatment in the future.

____
____
____

THANK YOU FOR YOUR TIME AND PARTICIPATION

APPENDIX K
Interview Guide with Community Health Workers (CHWs)

APPENDIX D **Form#** ☐☐☐

IN-DEPTH INTERVIEWS WITH FOCUS GROUP DISCUSSION (WITH COMMUNITY HEALTH WORKERS)

Facility Information

Name of researcher ______________________________

Date of data collection ______________________________

Country ______________________________

Province ______________________________

District ______________________________

Sub-district ______________________________

Name of health facility ______________________________

Demographic Information

1. Sex

Male	1
Female	2

2. Age

15-17	1
18-21	2
22-25	3
26-30	4
31-35	5
36-40	6
41-45	7
46-50	8
Others (specify)	9

3. Race

African	1
White	2
Coloured	3

Asian	4
Indian	5
Others (specify)	6

4. What is your occupation?

Voluntary worker	1
Community health worker	2
Others specify	3

. 5. What is your highest level of qualification?

Metric	1
Certificate	2
Diploma	3
Degree	4
Other (specify)	5

6. How many years of work experience do you have in the PMTCT program

____

7. Which HIV and AIDS training have you received? (Tick all applicable)

HIV Counselling and Testing	1
Treatment Adherence counselling	2
PMTCT	3
HIV/TB collaboration	4
STI's management	5
Home Community Based Care	6
HCT training	7
Other (specify)	7

8. How many hours per week do you work at the facility?

____

Implementation of the Prevention of Mother-to-Child Transmission of HIV outreach programme

9. Can you please describe, in much detail as possible, what your job entails as CHW?

10. How does the Community and clients perceive ORWs?

11. How do you convince mothers to continue ART?

12. What are the benefits and opportunities of been an outreach worker?

Patient-related challenges

13. Can you please describe, in much detail as possible, the reasons for loss to follow-up (LTFU) and non-adherence of mothers in the PMTCT at your facility during and after tracing sessions?

14. In your experience with clients, how does the following associated factors influence loss to follow-up (LTFU) and non-adherence of treatment of mothers in the PMTCT programme at your clinic? Please explain

- Lack of knowledge, awareness and attitude
- The need to continue ART
- Disclosure, Stigma and discrimination
- Lack of social support (from family and health workers)
- Gander inequality and lack of male involvement
- Infant feeding
- Cultural and religious beliefs
- Geographical location/ distance
- Financial support/ transport cost
- Health care factors (such as long waiting periods, lack of space/waiting areas)

Challenges faced by outreach worker

15. What are the challenges that you face when tracing patients who are LTFU?

16. What are reasons for unsuccessful tracing of patients who are LTFU?

17. How effective are the following system below for tracing clients, which ones are highly utilised and what are the advantages and disadvantages?

- SMS
- Phone calls
- Home visits
- Focal person

18. Specify any strategies to improve PMTCT follow-up services and adherence for the future. How would you improve on the services?

19. What are strategies that you are currently implementing to motivate clients to use and continue with PMTCT follow-up services and to adhere to treatment?

THANK YOU FOR YOUR TIME AND PARTICIPATION

APPENDIX L

Questionnaire Guide with Health Workers (Nurses and Lay Counsellors)

APPENDIX C **Form#**

QUESTIONNAIRES WITH HEALTH WORKERS (NURSES AND LAY COUNSELLORS)

Facility Information

Name of researcher ______________________________

Date of data collection ______________________________

Country ______________________________

Province ______________________________

District ______________________________

Sub-district ______________________________

Name of health facility ______________________________

Demographic information

(Check with an **X)**

1. Sex

Male	1
Female	2

2. Age

15=17	1
18-21	2
22-25	3
26-30	4
31-35	5
36-40	6
41-45	7
46-50	8
Others (specify)	9

3. Race

African	1
White	2
Coloured	3
Asian	4
Indian	5
Others (specify)	6

4. What is your occupation?

Nurse	1
Lay counsellor	2
Community health worker	3
Others (specify)	4

5. What is your highest level of qualification?

Metric	1
Certificate	2
Diploma	3
Degree	4
Other (specify)	5

6. How many years of work experience do you have in the PMTCT program

____

7. Which HIV and AIDS training have you received? (Tick all applicable)

HIV Counselling and Testing	1
Treatment Adherence	2
PMTCT	3
HIV/TB Collaboration	4
STI's management	5
Home Community Based Care	6
Other (specify)	7

8. How many hours per week do you work at the facility?

____

Knowledge and attitude towards the PMTCT programme

9. Can an HIV-positive mother transmit HIV to her baby?

Yes	1
No	2
I don't know	3

10. At what stage could a mother transmit HIV to her child?

During pregnancy	Yes	1
	No	2
	I do not know	3
During delivery or labour	Yes	1
	No	2
	I do not know	3
During breastfeeding	Yes	1
	No	2
	I do not know	3

11. Do all babies born to HIV positive mothers always become infected with HIV?

Yes	1
No	2
I don’t know	3

12. Can Mother-to-Child Transmission of HIV be prevented?

Yes	1
No	2
I don’t know	3

13. Does the use of anti-HIV drugs prevent mother-to-child transmission of HIV?

Yes	1
No	2
I don’t know	3

14. Do you think of their babies?

Yes	1
No	2
I don’t know	3

PMTCT and Prevention Services

15. Which HIV-related services does your facility provide (Tick all that apply)

ART for adults	1
ART for children	2
HCT	3
PMTCT	4
Home and Community Based Care	5
Support group of PLHA’s	6
Treatment Adherence Counselling	7
Couple Counselling	8
Other, please specify	9

16. Do you routinely perform PCR HIV test for infants during post-natal visits?

Yes	1
No	2

17. Is CD4 testing for mothers routinely done on facility?

Yes	1
No	2

18. How often is CD4 testing routinely done at the facility?

Every Day	1
3 times a week	2
Once a week	3
Other (specify)	4

Need for health services

19. Do you think HIV positive mothers feel the need to use PMTCT follow-up services at you clinic?

Yes	1
No	2

20. Do you think HIV positive mothers feel the need to bring their babies for PMTCT post-natal follow-up visits?

Yes	1
No	2

21. Do they have faith in PMTCT post-natal services?

Yes	1

No	2

22. Do they believe that the PMTCT services are important in reducing the spread of HIV?

Yes	1
No	2

23. In your experience with HIV positive mothers, do you think ignorance and lack of understanding of the importance of PMTCT services are the reasons clients are loss to follow-up?

Yes	1
No	2

Loss to Follow-Up and Adherence

24. Who is authorized to collect treatment for the client (HIV positive mother) on ART? (Tick all that apply)

Client	1
Treatment supporter	2
Any family member	3
Home Based Carer	4
Don’t know	5
Other please describe	6

25. How frequently are the following data available in the records for each clinic visit of HIV positive mothers and their babies at this facility? (Tick the items applicable)

TYPE OF DATA	ALWAYS	USUALLY	SOMETIMES	NEVER
Dosing schedule for ART				
Names of other medications taken by clients				
Reported side effects				
Client self-report of recent adherence				
Health Care Worker’s written findings from client medication calendar				
Pill counts of medicine in client’s possession				

Health Care Worker's assessment of recent client adherence				
Number of ART pills dispensed				
Expected day's supply of ART dispensed				
Date of next scheduled clinic visit				
How close was actual visit to scheduled visit				
Was the client referred for adherence counselling				
Did the client receive adherence counselling				
Reported reasons for non-adherence				
Reported reasons for loss to follow-up				
Does the client have Treatment Supporter				
Did the Treatment Supporter receive adherence counselling				

26. How is HIV positive mothers` adherence to ART monitored in this health facility? (Tick the items applicable)

ADHERENCE MEASURE	**BY CLINIC STAFF**	**BY PHARMACY STAFF**	**NOT USED**
Dosing schedule for ART			
Names of other medications taken by Clients			
Reported side effects			
Client self-report of recent adherence			
Health Care Worker's written findings from client medication calendar			
Pill counts of medicine in client's Possession			
Health Care Worker's assessment of recent client adherence			
Number of ART pills dispensed			

Expected day’s supply of ART dispensed			
Date of next scheduled clinic visit			
How close was actual visit to scheduled Visit			
Was the client referred for adherence Counselling			
Did the client receive adherence Counselling			
Reported reasons for non-adherence			
Reported reasons for loss to follow-up			
Does the client have Treatment Supporter			
Did the Treatment Supporter receive adherence counselling			

27. In your opinion, what are the reasons HIV positive mothers fail to use or adhere to HIV treatments? (Tick all that apply)

Side effects	1
Stigma and discrimination	2
Change of health facilities	3
Issues of privacy, confidentiality and anonymity	4
Poor services	5
Lack of social support the family	6
Religious and cultural beliefs	7
Distance to health facility	8
Lack of resources (e.g.: medication, space and testing kits)	9
Waiting hours	10
Other, please specify	11

28. In your opinion, what are the reasons that HIV positive mothers are loss to follow-up at your facility? (Tick all that apply)

Cost of Transportation to the facility	1
Stigma and discrimination	2
Lack of Knowledge and awareness	3
Change of health facilities	4
Issues of privacy, confidentiality and anonymity	5
Poor services	6
Lack of Social support	7
Religious and cultural beliefs	8
Distance to health facility	9
Poor treatment from Health workers	10
Lack of resources (e.g.: medication, space and testing kits)	11
Waiting hours	12
Other, please specify	13

29. Does the facility routinely offer the following services or support to HIV mothers and their infants who do not adhere to HIV treatment? (Tick all that apply)

Transport reimbursement	1
Link to home-based care	2
Telephone reminders	3
HIV education/health talk for both patient and supporter	4
Follow-up with defaulter tracing	5
Social support	6
A designated friend/family member/support group member as adherence supporter	7
Other, please specify	8

30. In your opinion, what are the associated factors that influence loss to follow-up of HIV positive mothers in the PMTCT programme at your clinic? (Tick all applicable)

Health workers' attitude	1
Health care systems problems	2
Poor PMTCT services	3
Financial problems	4
Geographical location	5
Stigma and discrimination	6
Lack of confidentiality and anonymity	7
Lack of social support	8
Gander inequality and lack of male involvement	9
switching of Health facilities	10
Cultural and religious beliefs	11
Other, specify	12

31. Does the facility routinely offer the following services or support to HIV mothers and their infants who are loss to follow-up? (Tick all that apply)

Transport reimbursement	1
Link to home-based care	2
Telephone reminders	3
HIV education/health talk for both patient and supporter	4
Follow-up with defaulter tracing	5
Social support	6
A designated friend/family member/support group member as adherence supporter	7
Other, please specify	8

32. Does the facility routinely provide on-facility HIV-related adherence counseling for mothers (either group or individual)?

Yes	1

No	2

33. Do you have a formal system in place to monitor whether HIV positive mothers and their babies adhere to ART?

Yes	1
No	2

34. If yes, which systems are in use? (Tick all that apply)

Appointment book	1
Electronic follow-up system	2
Patient Diary	3
Improvised books	4
ART Register	5
Other (specified)	6

35. From the answer above, are these systems working successfully?

Yes	1
No	2
I don`t know	3

36. Are clients given scheduled appointments for their next attendance?

Yes	1
No	2

37. Do you have a recognised system in place to monitor whether HIV positive mothers receiving ART attend scheduled appointments?

Yes	1
No	2

38. If yes, which systems are in use? (Tick all that apply)

Appointment book	1
Electronic follow-up system	2
Patient Diary	3
Improvised books	4
ART Register	5
Other (specified)	6

39. Do you have a formal system in place to monitor whether HIV exposed infants attend scheduled appointments?

Yes	1
No	2

40. If a client does not attend a scheduled visit, do you know if they are ill, have died or have dropped out?

Yes	1
No	2
I don’t know	3

41. Are there systems in place at this facility for following up with PMTCT clients who do not appear for an appointment?

Yes	1
No	2
I don`t know	3

42. From question 41, which systems are in use but ineffective (Tick all that are applicable?)

SMS	1
Phone calls	2
Village Health Workers	3
Patient Tracking tool	4
Focal person	5
Support group member	6
Other, specify______	7

43. Is patient tracking routinely conducted at this facility?

Yes	1
No	2

44. At what point is a client considered a PMTCT drop-out or defaulter? (Tick the item applicable)

After failing to attend for a certain length of time, specify how long_______	1
After missing a certain number of scheduled appointments, specify how	2

many __________	
Clients are never counted as dropouts or defaulters	3
Other, please specify	4

45. At what point is a client considered loss to follow-up? (Tick all items applicable)

After failing to attend for a certain length of time, specify how long________	1
After missing a certain number of scheduled appointments, specify how many __________	2
Clients are never counted as dropouts or defaulters	3
Other, please specify	4

46. Which interventions do you currently use or plan to use at this clinic to promote client adherence to ART and use of PMTCT post-natal services? (Tick all that are applicable)

TYPE OF INTERVENTION	**ALREADY IN USE**	**PLAN TO USE**
Patient counselling before starting ART		
On-going counselling after starting ART		
Home/community Based carers/volunteers		
Require a treatment supporter to observe treatment		
Social support (food parcels, food supplements, day care)		
Fast track service at health facility		
Use devices to promote adherence (Diary, pill box, alarm, reminder phone calls)		
Other interventions (please describe)		

47. Do you use any interventions to improve the health provider's motivation to promote better client adherence?

Yes	1
No	2

48. Have you carried out any evaluation of your intervention approaches to improve adherence to ART at this facility?

Yes	1
No	2

49. Are you receiving sufficient support from the Department of Health?

Yes	1
No	2

50. What do you think would be some useful (recommended) intervention approaches to improve PMTCT adherence rates at your facility? (Tick all applicable)

INTERVENTION	**RECOMMENDED**	**NOT RECOMMENDED**
Social support		
Psychological Support		
Health Care Facility Location		
Health Care Provider capacity and Motivation		
Use reminders for patient adherence		
Improved adherence monitoring		
Improved patient counselling and Communication		
Other, please specify		

51. What do you think would be some useful intervention approaches to improve PMTCT follow-up rates at your facility? (Tick all applicable)

INTERVENTION	**RECOMMENDED**	**NOT RECOMMENDED**
Social support		
Psychological Support		
Health Care Facility Location		
Health Care Provider capacity and Motivation		
Use reminders for patient adherence		
Improved adherence monitoring		
Improved patient counselling and Communication		
Improve clients privacy, confidentiality and anonymity		
Monitor stigma and discrimination		
Other, please specify		

52. Do you monitor rates of adherence to ART at the health facility level (that is, adherence rates averaged across multiple clients?

Yes	1
No	2

53. If you do not monitor adherence at facility level, what are the reasons for not doing so? _______________________________

54. What source of data is used to calculate this ART adherence rate at the health facility? (Tick all that apply)

Records from individual clients' routine adherence monitoring	1
Special survey conducted to monitor adherence	2
Not known	3

Stigma and discrimination

55. Are HIV positive mothers experiencing Stigma and discrimination at the clinic?

Yes	1
No	2

56. Have you ever witnessed stigmatisation and discrimination against an HIV positive mother at the clinic?

Yes	1
No	2

57. If yes, did you report the matter?

Yes	1
No	2

58. From the category below who stigmatise or discriminate clients at the Facility? (Tick all applicable)

Colleagues	1
Other patients	2
Visitors	
Family of clients	3
Partner of clients	4
Community members	5
Other, specify	6

59. Which system do you have to monitor stigma and discrimination? (Tick all applicable)

Report system	1
Social support and Counselling	2
Other, specify	3

60. Does your facility have an active stigma and discrimination report system?

Yes	1
No	2

61. If yes, does it work?

Yes	1
No	2

62. In your experience with clients, do you think stigma and discrimination are the reasons HIV positive mothers and their babies fail to adhere to ART?

Yes	1
No	2

63. In your experience with clients, do you think stigma and discrimination are the reasons HIV positive mothers and their babies are loss to follow-up?

Yes	1
No	2

Gender inequality and Male involvement

64. Does the facility provide male partners HIV testing and counselling?

Yes	1
No	2

65. Do you routinely ask clients to involve their partners?

Yes	1
No	2

66. Does HIV positive mothers involve their partners in the utilising PMTCT services?

Yes	1
No	2

67. Are clients supported by their partners when utilising PMTCT services?

Yes	1
No	2

68. Did your client report domestic violence from their partner?

Yes	1
No	2

69. Do you provide HIV testing and counselling for partners of HIV positive mothers?

Yes	1
No	2

70. Do you invite partners of HIV positive mothers for HIV testing and counselling?

Yes	1
No	2

71. If yes, are partners of HIV-positive mothers counselled and tested for HIV?

Yes	1
No	2

72. Usually in PMTCT a mother is supposed to either breastfeed the child exclusively for 6-12 mouths. Are HIV positive mothers following these instructions?

Yes	1
No	2

73. In your experience with clients, do you think gender inequalities and lack of male involvement are the reasons HIV positive mothers are loss to follow-up?

Yes	1
No	2

Cultural and religious factors

74. Do cultural and religion beliefs affect the use PMTCT services?

Yes	1
No	2

75. Does cultural and religious beliefs influence loss to follow-up at your facility?

Yes	1
No	2

76. If yes, select from the options below, how does cultural and religion beliefs influence loss to follow up at your facility? (Tick the items applicable).

They promote beliefs that traditional medicines are effectives more than western medicines	1
They promote beliefs prayers/anointed water can cure or reduce the spread of for HIV	2
Promote non-adherence to western medicine (ARV)	3
Promote fear and stigmatisation	4
Other (specify)	5

77. Is it safer for HIV positive mothers to use traditional medicines than western HIV medicines (ARV)?

Yes	1
No	2

78. If No, select from the options below, how? (Tick the items applicable).

Traditional medicines impact negatively on the patients human system	1
Increases the viral load of HIV	2
Promote non-adherence to western medication (ARV)	3
Increases the risk HIV-related death	3
Only drugs HIV (ARVs) drugs have been shown to substantially reduce HIV viral load	
Make patients more sick	
Other (specify)	4

79. Are the clients who follow religious or cultural beliefs at your facility adhere to the western HIV treatment provided by health workers?

Yes	1
No	2

80. Who do you think clients believe can manage HIV better? (Tick all applicable)

Traditional healer	1
Medical doctor	2
Priest	3
Other (specify)	4

81. In your experience with clients, do you think religious and cultural beliefs are the reasons HIV positive mothers and their infants are loss to follow-up?

Yes	1
No	2

Accessibility and Socio-economic factors

82. Are clients struggling to access PMTCT follow-up services?

Yes	1
No	2

83. Do you consider your facility accessible for everyone in the community?

Yes	1
No	2

84. Which of the obstacles below prevent clients from accessing PMTCT follow-up services? (Tick all applicable)

Transportation cost	1
Lack of Financial support	2
Distance of the Clinics	3
Others…specify	4

85. Which of the obstacles below prevent clients from collecting HIV medication? (Tick all applicable)

Transportation cost	1
Lack of Financial support	2
Distance of the Clinics	3
Others…specify	4

Social Support

86. Which of the following psychosocial services does the facility routinely provide to mothers with HIV?

Support groups	1
Supportive counselling	2
Other (specify)	3

87. Are there services to support disclosure?

Yes	1
No	2

88. In your experience with clients, do you think lack of social support are the reasons clients are lost to follow-up?

Yes	1
No	2

Infant Feeding

89. Which feeding methods do you recommend for HIV positive mothers?

Breastfeeding	1
Exclusive breastfeeding	2
Formula feeding	3

Mix-feeding	4
Other, specify ___	5

90. Which feeding method is most used by HIV positive mothers?

Breastfeeding	1
Exclusive breastfeeding	2
Formula feeding	3
Mix-feeding	4
Other, specify ___	5

91. Usually in PMTCT a mother is supposed to either breastfeed the child exclusively while on treatment for only 6-12 months, what sort of challenges do clients face in terms of exclusive breastfeeding? (Tick all applicable)

Non-adherence to treatment	1
Mix-feeding	2
Non-adherence to exclusive breastfeeding practice	3
Confusion and lack of knowledge	4
Other, specify ___	5

92. The WHO has recommended that mothers are supposed to breastfeed their infants exclusively while on treatment for only 6-12 months, do you provide counselling and support for clients in terms their feeding options?

Yes	1
No	2

93. Do you think the community support mothers with their feeding options advised at facility?

Yes	1
No	2

94. In your experience with clients, do you think endorsing the use of infants feeding methods (such as exclusive breastfeeding and exclusive formula feeding) instructed by health workers at the health facility is the reason HIV positive mothers and their babies are loss to follow-up?

Yes	1
No	2

Health Care System Factors

95. Which of the challenges do you experience when implementing the PMTCT programme? (Tick all applicable)

Clients' attitude	1
Poor PMTCT guidelines and policies	2
Poor support from the government	3
Lack of Resources	4
Poor systems	
Other, specify	5

96. How would you describe the working conditions in the PMTCT programme?

Good	1
Bad	2
Moderate	3

97. Will you recommend anyone to continue using PMTCT services at this facility?

Yes	1
No	2

98. Do you think your colleagues in the PMTCT programme know how to deal with non-adherences of ART by HIV positive mothers and their babies?

Yes	1
No	2

99. Do you think your colleagues PMTCT programme providers know how to deal with loss to follow-up of HIV positive mothers and their babies?

Yes	1
No	2

100. Do you think current PMTCT guidelines and policies are effective in dealing with non-adherence of ART?

Yes	1
No	2

101. Do you think current PMTCT guidelines and policies are effective in dealing with loss to follow-up of mothers and their babies?

Yes	1
No	2

102. Specify any strategies to improve PMTCT follow-up services for the future

103. Is the government doing enough to promote the use of PMTCT follow-up services by mothers?

Yes	1
No	2

104. In your opinion do you think other health care personnel know enough about PMTCT follow- up activities?

Yes	1
No	2

105. In your opinion, do you think your colleagues are doing enough to promote PMTCT activities?

Yes	1
No	2

106. In your opinion, do you think your colleagues are doing enough to prevent loss to follow-up of HIV positive mothers and their babies to attend PMTCT services?

Yes	1
No	2

107. Do you think the healthcare system has relevant resources to provide PMTCT services and care?

Yes	1
No	2

108. Which resources are needed at the facility to improve adherence and follow-up attendance (Tick all applicable)

Staff	1
Testing Kits	2
Telephones (for tracking patients)	3
HIV drugs	4
Infrastructure (rooms)	5
Other, specify	6

109. Has the health facility experienced any stock-outs of HIV drugs in the past 3 months**?**

Yes	1
No	2

110. If yes, were these stock outs of:

Adult CTX	1
Paediatric CTX	2
Others (specify)	3

111. Does this facility have any stock of expired ARV now?

Yes	1
No	2

112. Do health care providers routinely recommend HIV testing and counselling as part of the standard of care to all mothers?

Yes	1
No	2

113. Do health care providers routinely recommend HIV testing and counselling as part of the standard of care to all HIV exposed infants and children with symptoms?

Yes	1
No	2

Implementation support and approaches

114. Does the facility have an active quality improvement programme?

Yes	1
No	2

115. Does the facility receive any mentorship visits on PMTCT & HIV?

Yes	1
No	2

116. If yes which kind of mentoring? (Tick what is applicable)

Individual mentoring	1
Group Mentoring	2
Both	3

117. How often do you receive mentoring?

Once a month	1

Once a quarter	2
Every six months	3
Once a year	4
Other, please specify	5

118. Is there a suggestion box for patients to provide feedback on quality of care?

Yes	1
No	2

119. If yes, have the suggestions from patients been reviewed in the last three months?

Yes	1
No	2

120. Does the facility receive any supportive supervision visits on PMTCT & HIV?

Yes	1
No	2

121. Does the facility need any specific technical/training support?

Yes	1
No	2

122. If yes, please specify the main areas of technical support needed (Tick all applicable)

PMTCT training	1
Telephonic consult	2
Mentorship (Adult ART)	3
Mentorship (Paediatric ART)	4
Paediatric training	5
Other specify	6

123. Please specify challenges that you face when implementing the PMTCT programme

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THANK YOU FOR PARTICIPATING