MOTHERS' EXPERIENCES OF BARRIERS TO THE ELIMINATION OF MOTHER-TO-CHILD TRANSMISSION OF HIV IN SOUTH AFRICA

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DECLARATION

I declare that **MOTHERS' EXPERIENCES ON BARRIERS TO ELIMINATION OF MOTHER TO CHILD TRANSMISSION OF HIV IN SOUTH AFRICA** is my own work and that all the sources that I have quoted have been duly acknowledged by means of appropriate citing and referencing.

I further confirm that I submitted to originality checking software and that it falls within the accepted requirements for originality.

I further confirm that this work was not submitted previously for examination at UNISA for another qualification or at any other institution of higher learning.

22/01/2023

SIGNATURE DATE

MOTHERS' EXPERIENCES ON BARRIERS TO ELIMINATION OF MOTHERS TO CHILD TRANSMISSION OF HIV IN SOUTH AFRICA

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ABSTRACT

The prevalence of human immunodeficiency virus (HIV) infections in pregnant South African women is one of the highest in the world. Infants born to these women risk being exposed to and vertically infected with HIV. Since early 2001, the South African National Department of Health has made concerted efforts to prevent this mother-to-child transmission (MTCT) of HIV through its programme for the Prevention of mother-to-child transmission (PMTCT), in line with World Health Organization (WHO) and UNAIDS guidelines. The PMTCT program later translated to the elimination of mother-to-child transmission as the UNAIDS and UN bodies push for achieving the targets on ending HIV. (UNAIDS,2019) However, South Africa is yet to achieve the elimination target that the WHO set in 2011.

The purpose of this qualitative study was therefore to investigate HIV-positive mothers' experiences of the EMTCT programme, and the associated barriers, in Ehlanzeni district of Mpumalanga province, South Africa. An exploratory phenomenological research design was used with a purposive sample of 13 participants. The participants were mothers aged 18–35 whose infants had seroconverted before the age of 24 months after a negative birth PCR test. Qualitative data was collected through individual interviews with open ended questions and subjected to a thematic analysis.

The study showed that the guidelines are not implemented consistently to provide a comprehensive standardised service to mothers. The findings were grouped into highlighted five thematic areas compared to current policy and guidelines worldwide, namely: access to PMTCT services, experiences with disclosure and support, sexual and reproductive health, knowledge of the risks of MTCT, and proposed improvements to the EMTCT programme.

The following recommendations are proposed to strengthen South Africa's EMTCT programme: Women need to be empowered by giving them the right information and providing quality of sexual and reproductive health care. Healthcare providers should be capacitated to provide family-centered approach where men are included and encouraged to participate constructively in the sexual and reproductive health processes and decisions. More studies, quantitative and mixed method studies, need to be done to understand the subject further.

KEY CONCEPTS:

Barriers; HIV; seroconversion; mother-to-child transmission; elimination of mother-to-child transmission; prevention of mother-to-child transmission; HIV-positive mothers; HIV-positive infants.

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“Tshiwana ye e sa hweng e leta monono!”’ To you O Lord, I give glory and adoration. Narekele mo!

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- Dongamazi, your IT support anchored me, nana.

Dedication

I dedicate this study to my late grandmother,

Elizabeth Dongamazi Robinson, and my late mother,

Reilly Hlonipha Nchadi Robinson.

May your souls rest in perfect peace.

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
BANC	Basic Antenatal Care
CATI	Computer-administered Telephonic Interviews
CMV	Cytomegalovirus
CT	Counselling and Testing
DHIS	District Health Information System
EID	Early Infant Diagnosis
EMTCT	Elimination of Mother-to-child Transmission
EPI	Expanded Programme of Immunisation
GLOBAL PLAN	Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive
HAART	Highly Active Antiretroviral Therapy
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
IU	Intrauterine
MCH	Maternal and Child Health
MCWH	Mother, Child and Women's Health
MTCT	Mother-to-child transmission
NDoH	National Department of Health
NVP	Nevirapine
OECD	Organization for Economic Cooperation and Development
PACTG	Paediatric AIDS Clinical Trial Group
PAHO	Pan-American Health Organization
PCR	Polymerase Chain Reaction
PICT	Provider-initiated Counselling and Testing
PLHIV	People Living with HIV
PMTCT	Prevention of mother-to-child transmission
PrEP	Pre-exposure Prophylaxis

RNA	Ribonucleic Acid
RPR	Rapid Plasma Regime
SA	South Africa
SAMRC	South African Medical Research Council
SAMJ	South African Medical Journal
SAMR	South African Medical Research
SANAC	South African National AIDS Council
SANDoH	South African National Department of Health
SdNVP	Single-dose Nevirapine
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children’s Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION

South Africa (SA) has struggled for over three decades to contain the spread of the human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) that the virus causes. Both the South African National Department of Health (SANDoH) and the South African National AIDS Council (SANAC) have acknowledged that, when compared with other countries burdened by the HIV/AIDS pandemic, SA has one of the highest prevalence of HIV in pregnant women (Fomundam, Tesfay, Mushipe, Mosina, Boshielo, Nyambi, Larsen, Cheyip, Getahun & Pillay 2017). The Joint United Nations Programme on HIV/AIDS (UNAIDS) highlighted in its country report that SA has an incidence-prevalence ratio of 3.0–4.99 (UNAIDS 2018:1), and that between 1990 and 2015, the country had seen a steady rise from 0.7% to 30.8% HIV prevalence in mothers receiving antenatal care (ANC), posing a risk of vertical transmission to unborn infants and breastfed infants.

From as early as 2001, there were efforts to prevent mother-to-child transmission (MTCT) in many countries, including SA, and in 2011, UNAIDS in collaboration with other United Nations (UN) bodies, announced a global commitment to eliminating the transmission of HIV from mothers living with the disease to their unborn and breastfeeding infants, and keeping the mothers alive. This commitment was in the form of the *Global plan towards the elimination of new HIV infections among children and keeping their mothers alive* [the Global Plan] (UNAIDS 2011). UNAIDS (2018:1) presented data and scientific evidence that the rate of MTCT could be reduced to below 5% with effective interventions from pregnancy until the cessation of breastfeeding. In a 2017 technical brief, the World Health Organization (WHO) recommended that over and above the primary interventions (involving antiretroviral (ARV) treatment for the mother, a short course of ARV drugs for the infant, measures to prevent HIV during pregnancy, and appropriate breastfeeding practices), HIV-negative pregnant and breastfeeding women could be put on pre-exposure prophylaxis (PrEP) (WHO 2017:1).

Due to the country's high prevalence of ANC and paediatric HIV infections, in 2002 SA implemented a programme for the prevention of mother-to-child transmission (PMTCT) to reduce infections (Goga, Chirinda, Bhardwaj, Pillay, Sherman, Ng'oma, Doherty & Barron 2017:140). Roughly two decades since then, given its high HIV prevalence and the

complexities of HIV management, SA is considered to have made progress in reducing MTCT of HIV, but according to the country's UNAIDS factsheet (UNAIDS 2021), it is yet to meet the expected global elimination criterion.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

South Africa is one of many countries where HIV infections during pregnancy and the postnatal period remain a major contributor to perinatal morbidity and mortality. During pregnancy, the foetus may become infected because of maternal infection. Such infections may be picked up at birth, or may present later in life, usually within the first five years of life. The SANDoH identifies "HIV, syphilis, TB, HBV, Malaria, and most recently, Listeriosis" as "infections with significant impact on maternal and child health outcomes in SA" (SANDoH 2019).

To curb such infections, the SANDoH developed guidelines from 2002 to outline the minimum standards for the routine care for women of childbearing age and their families for (i) the prevention of new HIV cases, TB cases, Syphilis cases, and other infections, (ii) the prevention of unintended pregnancies, (iii) the prevention of mother-to-child transmission of HIV, syphilis, and other infections, and (iv) the care and treatment of the women living with HIV, syphilis and other infections, and their children who were exposed to infection (SANDoH 2019). These guidelines and standards were based on four pillars for the prevention of transmittable infections from mother to child, shown in Figure 1.1 below. These pillars were informed by the WHO's four PMTCT pillars for achieving the targets of zero HIV transmission from mothers to their infants and an HIV-free generation. Based on research and new development in HIV, these guidelines are reviewed and revised frequently to ensure effective interventions for the mothers and infants.

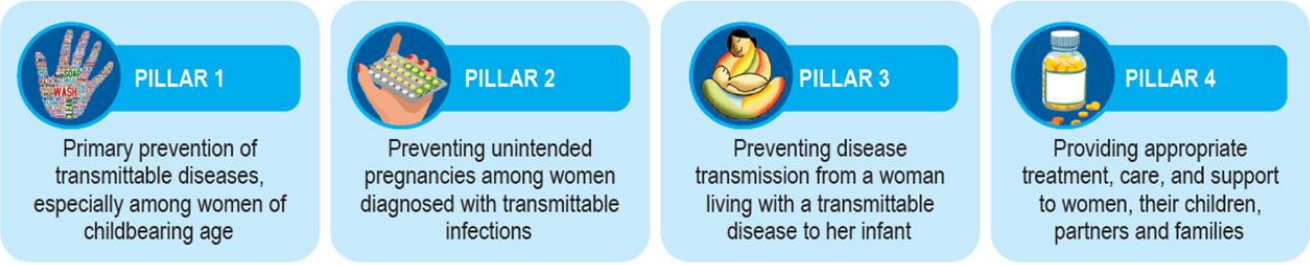

Figure 1.1: The four pillars for the prevention of transmittable infections from mother to child
Source: SANDoH 2019

In 2014, data from the SANDoH based on six weeks of PCR testing showed that prenatal infections had reduced significantly to almost 0.9% at birth (Feucht, Meyer & Kruger: 2014), but subsequent tests did not provide the required reassurance of eliminating MTCT by 2020. Therefore, in January 2015, the SANDoH launched PMTCT Option B+, which entailed initiating antiretroviral therapy (ART) for life in all pregnant and breastfeeding women, regardless of their CD4 count or clinical stage. A 2016 study conducted by the South African Medical Research Council (SAMRC) and the SANDoH to review the effectiveness of PMTCT from 2010 to 2015 in SA, indicated that national MTCT prevention strategies had brought the risk of infant HIV infection down from 8% in 2008 to 3.5% in 2010, 2.6% in 2012/13, and an estimated 1.4% in 2015 (SAMRC 2016). However, this achievement still did not translate into infants' lives saved, and the WHO set target for elimination (WHO 2017:1). For a country like South Africa where annually, over a million women give birth and 30% of them would be HIV positive, the estimated 1.4% translate to large numbers.

In 2017, Goga et al (2017:1) reported that biomedical interventions, as outlined in SA's PMTCT policy and guidelines, had been implemented as required to all the eligible mother/infant pairs, but that new infections were still being recorded in children at a rate far above the set limit of fewer than 50 cases per 100 000 live births. Given the high prevalence and complexities in HIV management, SA was however, considered to have made progress in reducing the MTCT of HIV from the inception of the PMTCT programme to date, but the country was yet to meet the expected global elimination criterion. According to the WHO (2017), countries should have achieved and maintained for at least one year, both (i) a population case rate of new paediatric HIV infections due to MTCT of ≤50 per 100 000 live births, and (ii) an HIV MTCT rate of <5% in breastfeeding countries or <2% in non-

breastfeeding countries. A 2018 report by the United Nations (UN) agencies (UNAIDS 2018) found that MTCTs were still occurring, with most occurring intrapartum and during breastfeeding, compared with the pre- and antenatal transmissions recorded before 2015.

Through its PMTCT programme, SA aimed to achieve the elimination targets outlined in the WHO's Last Mile Plan. Despite making significant progress in achieving these targets for the prevention of HIV infections in children, the SANDoH, through various reports produced by ministerial committees, has acknowledged that HIV remains a significant contributor to under-five deaths in SA (SANDoH 2019: 2). For this reason, managing the health of women living with HIV and preventing MTCT of HIV remains a critical intervention in ensuring that women and children survive and thrive in SA.

1.3 STATEMENT OF THE RESEARCH PROBLEM

The WHO expected South Africa, along with all other countries that promote breastfeeding, to reduce the number of new HIV infections in infants born to HIV-positive mothers to <5%, and the number of new paediatric HIV infections per 100 000 live births to ≤50 (WHO 2017:1). In 2018, Goga, Chirinda, Ngandu, Ng'oma, Bhardwaj, Feucht, Davies and Ntloana (2018:17) reported that the national intrauterine (IU) MTCT rate was 0.9% by 2016. This translated to an IU case rate of 245 HIV-positive neonates per one thousand live births. Provincial IU percentage MTCT risk ranged from 0.6% to 1.3%, with IU case rates ranging between 168 and 325 cases per 100 000 live births. District-level IU percentage MTCT risk ranged from 0.4% to 1.9% (Goga et al 2018:137). These figures indicated that the country was still experiencing high MTCT rates, and that there could be barriers to the elimination of HIV.

Despite having a robust, evidence-based PMTCT policy framework, SA's progress towards the elimination of mother-to-child transmission (EMTCT) of HIV has been challenged by a remarkably high maternal HIV prevalence (Woldesenbet, Kufa, Barron, Ayalew, Cheyip, Chirombo, Lombard, Manda, Pillay & Puren 2020:41), which is the highest risk for MTCT, as it leads to high rates of seroconversion during pregnancy and breastfeeding. According to the 2018 District Health Information System (DHIS) data reported from Ehlanzeni District, more than five hundred infants tested HIV positive using PCR tests, implying that their mothers had experienced barriers antenatally and postnatally ,which had made it difficult for them to adhere to the PMTCT guidelines until the cessation of breastfeeding, resulting in postnatal seroconversions (Massyn 2020: 393).

Based on the above, the researcher concluded that HIV-positive mothers play a significant role in their infant's HIV status. In a country where ANC services are free, where the uptake of the PMTCT programme stands at 95%, and where all interventions are implemented according to guidelines, the EMTCT of HIV should be possible and easily attained. However, as shown in the discussions above, the data from South Africa shows that the country is not anywhere near the EMTCT of HIV, with new infections leading to paediatric HIV and mortality (UNICEF 2019:1).

1.4 AIM OF THE STUDY

1.4.1 Study purpose

The purpose of the study was to investigate HIV-positive mothers' experiences of the barriers to the EMTCT in Ehlanzeni District.

1.4.2 Study objectives

The objectives of the study were therefore as follows:

1. To describe HIV-positive mothers' lived experiences in the implementation of the PMTCT programme.
2. To describe HIV-positive mothers' lived experiences of the barriers experienced in the EMTCT of HIV.
3. To formulate recommendations for the achievement of the EMTCT of HIV.

1.4.3 Study questions

In line with the study objectives of this study, the specific study questions that were formulated were as follows:

1. What are HIV-positive mothers' experiences in the implementation of the PMTCT programme?

2. What are HIV-positive mothers' experiences of the barriers experienced in EMTCT?

3. What recommendations can be made to achieve EMTCT?

1.5 SIGNIFICANCE OF THE STUDY

It was intended that the findings of this study would be able to inform personnel working in the field of PMTCT of HIV on the barriers to EMTCT. It was envisaged that the findings of the study would be able to contribute to modifying interventions to ensure the quality and effectiveness of the PMTCT programme.

1.6 STUDY SETTING

This study was conducted in Ehlanzeni, the largest of the three districts of Mpumalanga province in SA. As discussed in more detail in section 3.3.1, Ehlanzeni's geographic location makes it vulnerable to various health challenges. Ehlanzeni is bordering Limpopo Province, Mozambique and Swaziland, with three border gates, thus exposed to high influx of illegal immigrants, some expecting to share the district resources and services.

1.7 DEFINITION OF KEY CONCEPTS

1.7.1 Mother

A mother is defined in various ways as "a female parent", and to mother someone can mean either "to give birth to a child" or "to care for or protect (someone) like a mother" (The Britannica Dictionary 2022). In this study, mothers are defined as HIV-positive mothers who have given birth to their child.

1.7.2 Experiences

An experience can be described as "the act or process of directly perceiving events or reality", or a person's "direct observation of or participation in events" as a basis for practical knowledge (Merriam Webster Dictionary [s.a.]). In the nursing context, Grove, Burns and Gray (2013:10) have defined experiences as personal phenomena that enable one to gain the relevant skills to provide care to those require it. In this study, experiences refer to HIV-positive mothers' personal encounters with and knowledge of PMTCT.

1.7.3 Barriers

A barrier refers to a rule, law, policy or situation that results in a struggle to achieve what is intended to be realised (Collins English Dictionary [s.a.]). In this study, the researcher sought to establish the barriers to implementing PMTCT experienced by HIV-positive women during the period of breastfeeding their infants.

1.7.4 Mother-to-child transmission (MTCT)

Mother-to-child transmission (MTCT) refers to the transmission of HIV from an HIV-positive mother to her infant during pregnancy, delivery, or the breastfeeding period (World Health Organisation [s.a.]).

1.7.5 Human immunodeficiency virus (HIV)

The human immunodeficiency virus (HIV) is an infectious virus found in the blood of infected persons. The virus strikes and kills a specific group of cells that are essential in regulating the body's normal defences against contaminating organisms and other proteins (WHO 2022).

1.8. RESEARCH PARADIGM

Gray, Grove and Sutherland (2017:333) define a research paradigm as a set of philosophical or theoretical concepts that characterise a particular way of viewing the world. Tenny, Brannan, Brannan and Sharts-Hopko (2017), on the other hand, define research paradigms as the assumptions, norms, and standards that underpin different research approaches. Essentially, research paradigms reflect the general worldview that informs a research study. Unlike studies in the natural sciences, studies in the social sciences can follow either an interpretivist or critical realist paradigm.

In this qualitative study, an interpretivist approach was used to explore and describe HIV-positive mothers' lived experiences in relation to the barriers to implementing the PMTCT programme. The interpretivist paradigm relies on interaction between the researcher and the research subjects, during which they negotiate, collaborate, and develop a meaningful understanding of reality. Such understandings are specific to a particular time and context and cannot be generalised. Interpretivist approaches include interviews, observation, and textual analysis. This study employed an exploratory qualitative phenomenological approach where the women were encouraged to share their lived experiences to contribute to the researcher's investigation of the HIV-positive mothers' experiences of barriers to EMTCT in Ehlanzeni. In-depth interviews using a questionnaire with open ended questions was used. Furthermore, a reflexive journal captured the researcher's thoughts on the experiences of the mothers by putting herself in the shoes of the mothers. This was mainly from those participants who shared painful experiences and looked and sounded affected by the experiences shared.

1.9 RESEARCH DESIGN AND METHOD

This study employed a descriptive phenomenological research design of inquiry coming from psychology, (Creswell JW &Creswell JD:2018) which the researcher used to describe how mothers of infants who seroconverted had made sense of the existing PMTCT programme and the resources available to them, and how they had understood the prescribed guidelines to be followed. The researcher investigated the mother`s understanding of their role in ensuring e-MTCT. This approach was deemed useful for establishing insight into and understanding of their subjective lived experiences.

1.11 STEPS TO ENSURE TRUSTWORTHINESS

Trustworthiness, according to Polit and Beck (2017:747), is the degree of confidence in the authenticity and reliability of a research study. They identify the main elements of trustworthiness in qualitative research as credibility, confirmability, dependability, and transferability (Polit & Beck 2017). Similarly, Cypress (2017:258) stated that trustworthiness refers to the quality, authenticity, and truthfulness of the findings of qualitative research. As discussed in more detail in section 3.5, the researcher employed specific strategies to strengthen the trustworthiness of this study. These strategies included using a third-party translator to strengthen credibility, ensuring a detailed audit trail to strengthen dependability, engaging in written introspective activities to minimise researcher bias and ensure confirmability, purposively selecting participants to strengthen transferability, and staying as faithful as possible to the participants' voices to strengthen authenticity.

1.12. ETHICAL CONSIDERATIONS

The researcher adhered to the provisions of the National Health Act, which requires that proposals to conduct research be approved by an independent ethics committee before the research commences (Republic of South Africa 2003). The proposal to conduct this study was granted ethical clearance by UNISA's College of Human Sciences Research Ethics Review Committee (see Annexure 1) and the Mpumalanga Department of Health ethics committee (see Annexure 2). As discussed in more detail in section 3.3.4, all possible harm to the participants was avoided, and they were treated with respect. The researcher ensured that the participants' dignity, privacy and freedom of participation was maintained, and that their perspectives were faithfully captured with as little bias as possible.

1.13 STRUCTURE OF THE DISSERTATION

The structure of this dissertation is as follows:

- Chapter 1: Orientation to the study
- Chapter 2: Literature review
- Chapter 3: Study design and method
- Chapter 4: Presentation, analysis and description of the study findings
- Chapter 5: Discussion of findings, conclusions, and recommendations.

1.14 CONCLUSION

This chapter has provided an orientation to this investigation of HIV-positive mothers' experiences of the barriers to EMTCT in Ehlanzeni District. After introducing the research problem and presenting the relevant background to it, the purpose and objectives of the study were stated, and the significance of the study was explained. The study setting was defined, as were the key concepts used in the study, after which the general research design and methodology were described, and the research questions stated. The steps taken to strengthen the trustworthiness and ethical completion of the study were briefly described, and a chapter outline of the dissertation was presented.

The following chapter presents a review of the literature on EMTCT, focusing on the global legislative framework, a range of country perspectives, the theoretical implementation framework for EMTCT, and empirical research on seroconversion and barriers to EMTCT.

CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

The previous chapter introduced the foundational elements of this research study. In this chapter a detailed review of the literature on the EMTCT of HIV is presented. The chapter begins by discussing the global legislative framework for EMTCT, and by comparing various country perspectives. The theoretical framework for implementing EMTCT is then described, after which empirical research on seroconversion and barriers to EMTCT is presented.

2.2 LEGISLATIVE FRAMEWORK

2.2.1 Global perspective

The *Global plan towards the elimination of new HIV infections among children and keeping their mothers alive* [the Global Plan], was launched by UNAIDS in 2011. Included in this plan were strategies to be used to attain this goal, which were referred to as the EMTCT Plan. This EMTCT Plan included all low and medium-income countries and focused on 22 priority countries who had the highest number of HIV-positive pregnant women.

The EMTCT Plan placed great importance on enhancing the health outcomes of mother-infant pairs through shifting the focus from coverage of PMTCT to monitoring and evaluation of PMTCT services as stated in the" Last Mile Plan" of the UN bodies. (UNICEF:2020). The main goal of eliminating new paediatric infections by 2015 was placed within a wider vision of better HIV-free survival, maternal and child health (MCH) and sexual reproductive health (SRH). In addition, the elimination agenda was linked to the global obligation to attain the 2015 Millennium Development Goals and later the Sustainable Development Goals (WHO :2018).

According to the WHO (2017:10), the minimum EMTCT impact targets included the reduction of HIV to ≤50 new paediatric infections per 100 000 live births and a transmission rate of <5% in breastfeeding populations or, 2% in non-breastfeeding populations. The process targets on the other hand, were ≤95% antenatal coverage, ≤95% coverage of women testing positive to HIV and/or syphilis, and ≤90% ART coverage of pregnant women testing positive with HIV. Countries that had met the impact targets for one year and the process targets for two years, including the attainment of at least one of the lowermost sub-national levels, could apply for

validation of the EMTCT of HIV (WHO 2017:2). The targets and indicators of the Global Plan for EMTCT are shown in Figure 2.1 below.

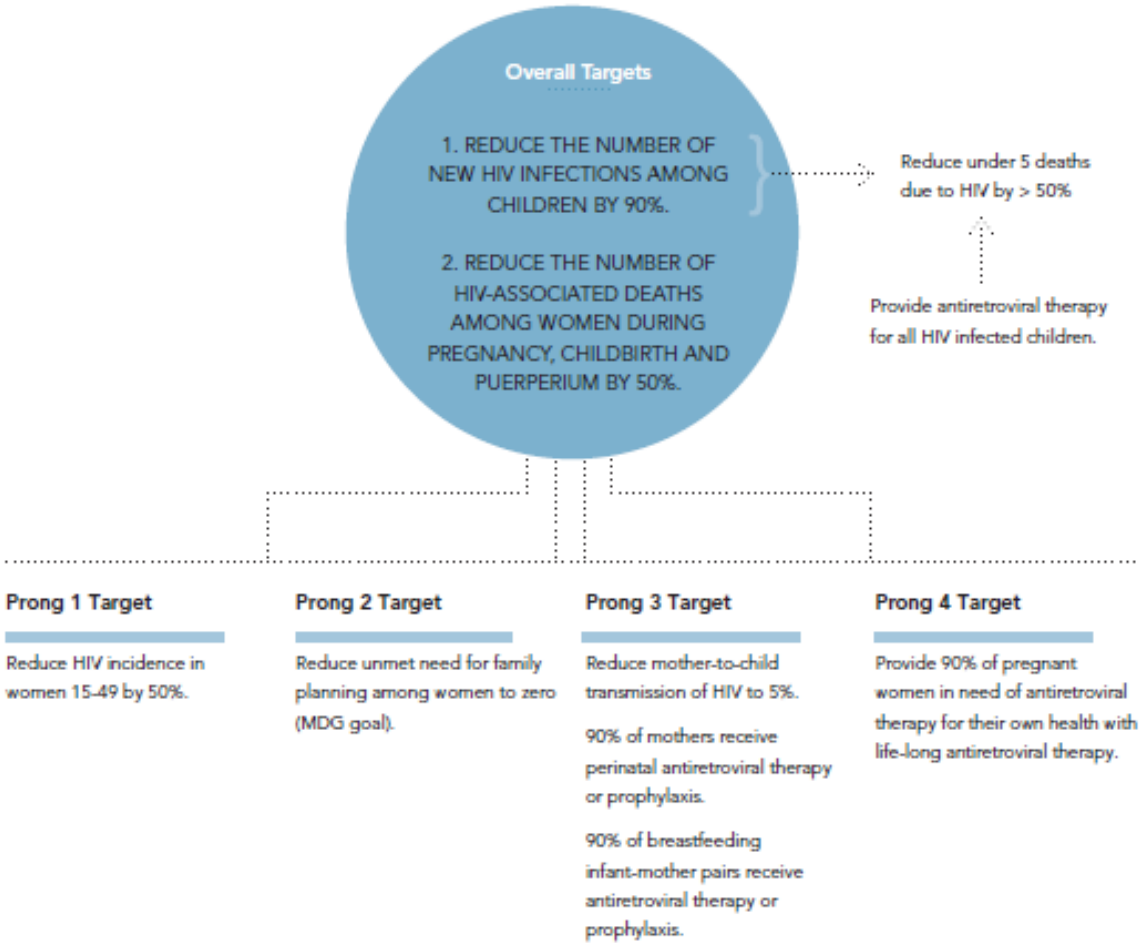

Figure 2.1: Global Plan for EMTCT targets and indicators

Source: WHO 2012

Figure 2.1 illustrates how the two overall targets of the Global Plan were intended to be achieved through a four-pronged approach. Target one was to reduce new paediatric HIV infections by 90%, while target two was to reduce the number of HIV-associated deaths of women during pregnancy, childbirth, and puerperium by 50%. Prong 1 of the Global Plan sought to reduce HIV incidents in women aged 15-49 years by 50%. Prong 2 aimed to reduce the unmet needs for family planning among women to zero. Prong 3 sought to (i) reduce MTCT of HIV to 5%, (ii) ensure that 90% of mothers receive perinatal ART or prophylaxis, and (iii) ensure that 90% of breastfeeding infant-mother pairs received ART or prophylaxis. Prong 4 sought to ensure that life-long ART was provided for 90% of pregnant women in need of

ART for their own health (WHO 2012:11). Figure 2.1 demonstrates the advancement and inventiveness of the Global Plan's comprehensive PMTCT programme. It also shows that to attain a 90% reduction of new infections in children, all four prongs of PMTCT should be adhered to, in order for the intervention to translate into effective EMTCT (BMC Infect Dis. 2018; 18: 566).

A Global Strategy for Women's and Children's Health was presented by UN Secretary-General Ban Ki-moon in 2010, with the goal of eliminating MTCT in member countries by 2015 (UN 2010). The key areas of the strategy were the improvement of funding, reinforcing policy, and enhancing service delivery for women and children. The significant strategy interventions comprised of exclusive breastfeeding practices and formula feeding to enhance child survival through nutrition and adherence to PMTCT.

Like the *Global Strategy*, the *Guidelines on HIV and infant feeding 2010* aimed to eliminate new paediatric infections and enhance the life and survival of HIV-positive women and their infants by 2015 (WHO 2017). The functional objectives of the strategy included (i) safeguarding and ensuring exclusive breastfeeding for six months, endorsed and reinforced with persistent breastfeeding up to two years or beyond, (ii) supporting opportune, sufficient, safe, and suitable complementary feeding, and (iii) affording assistance with feeding infants and young children in extremely challenging conditions, and with infants of HIV-positive mothers.

Given the above strategies, initiatives, and implementation criteria, one would assume that countries that had made strides in their EMTCT interventions would be declared MTCT free by 2015, with zero new infections by 2030. In their study titled "Postnatal HIV transmission in breastfed infants of HIV-infected women on ART: a systematic review and meta-analysis to review MTCT", Bispo, Chikhungu, Rollins, Siegfried and Newell (2017) reviewed the literature on MTCT at different stages of infants' lives. While they concluded that there was a lower risk of HIV MTCT in women who were on ART and virally suppressed, they did highlight the different transmission rates from 6 weeks to 18–24 months, with the latter showing a transmission rate of almost 4.1 from a study conducted in Kenya (Bispo et al 2017:20). However, this review did not identify the factors that may or may not have been supporting the adherence to ART by the HIV-positive mothers.

2.2.2 Country perspectives

2.2.2.1 Thailand

Like most countries, including SA, Thailand pledged its obligation to the 2011 Global Plan, which aimed to eliminate MTCT by 2015 while keeping mothers alive (UNAIDS 2016). Thailand managed to achieve this goal and was certified by the WHO in 2016 for the EMTCT of HIV and syphilis, becoming the second non-Organisation for Economic Co-operation and Development (OECD) country, following Cuba, to attain the goal of EMTCT. As early as 1980, Thailand had committed to addressing MTCT. By 1990–91, a few large hospitals had commenced routine screenings for HIV in their ANC clinics, and in 2001, the Thai government offered a universal PMTCT programme, which saw 94% of pregnant women receiving counselling and testing, and those testing positive receiving ART. By 2015, 99.6% of infants were receiving an ARV prophylaxis for HIV.

The WHO, together with its associates, presented guidance on the global progression and criteria for determining and validating the EMTCT of HIV and syphilis, and presented the indicators and targets to be met by member countries. In 2016, the WHO and international expects visited Thailand to evaluate and validate its EMTCT of HIV and syphilis. The validation team visited health centres, laboratories, and government offices, and conducted interviews with health officials and key role players. On the basis of the country's data and these inspections, Thailand then received validation from the WHO of its EMTCT of HIV and syphilis (UNAIDS 2016).

It is important to note that Thailand is considered a non-breastfeeding country in the context of MTCT of HIV. In 1992, the WHO/UNICEF issued a *Consensus statement on HIV transmission and breastfeeding*, stating that in situations in which pregnant women were HIV positive, they were to be counselled against breastfeeding in favour of using formula milk for their infants (Thisyakorn 2017). Bottle-feeding was considered safer than breastfeeding, as it was believed to reduce the risk of MTCT of HIV. The Thai government therefore offered free infant formula for the infants of HIV-positive mothers. This reduced the MTCT rate from 31% to 19% in 1997. Most households in Thailand had access to safe drinking water and good sanitation, and mothers were given good guidance on how to prepare their infants' formula (Thisyakorn 2017:4).

2.2.2.2 Cuba

In 2010, the Pan American Health Organisation (PAHO) member states officially adopted a dual target for the EMTCT of HIV and syphilis. The Regional Framework committed to reducing the rate of MTCT of HIV to 2% or less per year, reducing the incidence of MTCT to 0.3 cases per 1 000 live births, and reducing the incidence of congenital syphilis to 0.5 cases per 1 000 live births (PAHO 2015:13). Cuba came to be the first country to obtain validation from the WHO for the EMTCT of HIV and syphilis. Cuba's breakthrough in EMTCT was replicated by other countries within the Region of the Americas and around the world ,and was a milestone that marked the beginning of continuing validation of the end of epidemics in children (PAHO 2015).

Cuba had already started the process for the validation of EMTCT in 2013 by ensuring that they complied with all the requirements of the WHO and PAHO (Caffe, Perez, Kamb, de Leon, Alonso, Midy, Newman, Hayashi & Ghidinelli 2016). The validation team resolved that Cuba had adequate strategies set up to offer HIV and syphilis prevention, diagnosis and treatment services; that these were sustainable; and that they were not dependent on outside financing (Caffe et al 2016). There was evidence in the form of clinical records that showed that all pregnant women who attended ANC in the first trimester were offered HIV and syphilis testing on their first visit. The records also showed that close to 100% of mothers delivered in maternity hospitals, and that HIV and syphilis tests were repeated. It was also confirmed that Cuba had a sufficient laboratory network for HIV and syphilis diagnostic services (Caffe et al 2016).

The validation team noted that national norms and standards for operational protocols for HIV and syphilis were included in the national algorithm, and that testing was conducted in accordance with the normative framework. The vertical transmission of HIV and syphilis was not considered illegal, and the expert team observed that the Cuban laws and policies were non-discriminatory. Based on their evaluation of their findings, the validation team decided that the Cuba's dual EMTCT targets had been attained in accordance with the human rights deliberations (Caffe et al 2016).

Cuba's strategy for EMTCT was assumed sequentially and at different trimesters of pregnancy to delivery. Cuba is considered a non-breastfeeding country, and infant formula is commenced right after birth. The WHO stated in 2015 that the outstanding decrease in paediatric HIV infection rates was noted in developed countries when the Paediatric AIDS Clinical Trial Group (PACTG) Protocol 076 indicated the administration of a zidovudine

regimen to mothers from the fourteenth week of pregnancy and during labour, and to the newborn (WHO 2015a). This reduced the risk of MTCT by almost 70% when no breastfeeding took place, and when combined with elective Caesarean section, the regimen reduced the transmission rate to 2% or less in the non-breastfeeding population (WHO 2015a).

It was concluded that Cuba's success in the EMTCT was driven jointly by its government and the WHO (WHO 2015a).

2.2.2.3 Nigeria

In response to the World Health Organization's *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (WHO 2013), Nigeria's Federal Ministry of Health developed the 2014 *Integrated national guidelines for HIV prevention, treatment and care* (Federal Ministry of Health Nigeria 2014). This effort saw three previous sets of guidelines (the *National guidelines for HIV/AIDS treatment and care in adults and adolescents*, the *National guidelines for paediatric HIV/AIDS treatment and care*, and the *National guidelines for the prevention of mother-to-child transmission of HIV infection*) consolidated into one. The new set of guidelines provided general and specific guidance for the prevention and treatment of HIV infection in the country and underscored the Nigerian government's commitment to ensuring that all people living with HIV (PLHIV) in the country had access to high-quality HIV prevention and treatment services (Federal Ministry of Health Nigeria 2014).

The *National guidelines for the prevention of mother-to-child transmission of HIV infection* had been updated in 2010, after the release of the World Health Organization's (WHO) *Guidelines on antiretroviral drugs for treating pregnant women and preventing HIV infections in infants*, which was based on new global evidence and best practices. The 2010 national guidelines advocated breastfeeding as the preferred infant feeding option with ARVs being taken by either the mother or infant (Federal Ministry of Health Nigeria 2010). Because breastfeeding is practised in Nigeria, the national PMTCT guidelines advocated strongly in its favour.

In this regard, Nigeria's national PMTCT guidelines aimed to reduce the risk of MTCT to less than 2% through interventions that included the use of ARVs as either prophylaxis or therapy given to women during pregnancy, labour or breastfeeding. The guidelines stated that where a mother was not receiving ARVs during the breastfeeding period, the breastfed infant should receive ARV prophylaxis until one week after cessation of all breastfeeding. Where

breastfeeding was not possible however, the guidelines proposed the use of commercial infant formula as an alternative (Federal Ministry of Health Nigeria 2010). Nigeria, however, has not yet been declared MTCT free.

2.2.2.4 South Africa

South Africa began implementing its PMTCT programme in 2001 with two pilot sites in each of the nine provinces, which translated into 18 pilot sites employing nevirapine after its approval by the Medicines Control Council. A single dose of nevirapine (Sd-NVP) regimen was to be given to the mother in labour and to the infant within 72 hours of delivery. In addition, the PMTCT programme prescribed the implementation of certain changes in delivery practices, counselling mothers on infant feeding, and providing free infant formula to HIV-positive mothers who chose it. The PMTCT programme was rolled out in 2002 after the Constitutional Court ruled that the government was required to do so to fulfil the constitutional right of HIV-positive South Africans to treatment (Burton, Giddy & Stinson 2015:3).

In 2004, an all-inclusive package of care and treatment of HIV-positive persons was introduced by the SA government. This comprehensive care prescribed that all pregnant women with a CD4+T-cell count of 350 cells/mm^3, should be put on Option A, in line with the WHO guidelines (Barron, Pillay, Doherty, Sherman, Jackson, Bhardwaj, Robinson & Goga 2012:71). Prophylaxis treatment for infants born of HIV-infected mothers was daily nevirapine for six weeks, and in an attempt to reduce MTCT of HIV, all infants breastfed by mothers who were on highly active antiretroviral therapy (HAART) were given a daily dose of nevirapine (Barron et al 2012:71).

In 2008, the National Accelerated Plan (A-plan) was introduced, which intended to decrease MTCT of HIV from 12% in 2008 to less than 5% by 2011, in line with the National Strategic Plan 2008–2011 (Barron et al 2012:71). By 2010, the SANDoH had revised the PMTCT policy to incorporate lifelong HAART for HIV-infected women with CD4+T-cell counts ≤350 cells/mm^3, and dual ART from 14 weeks onwards in the pregnancy for HIV-positive women with a CD4+T-cell count >350 cells/mm^3, in accordance with Option A of the WHO guidelines (Barron et al 2012:71). Infant prophylaxis was daily nevirapine for 6 weeks for all infants breastfed by mothers not on HAART, to reduce MTCT of HIV (Barron et al 2012:71).

It was in 2011 that the South African Minister of Health, through the Tshwane Declaration, authorised an exclusive breastfeeding policy at all public facilities, and the phasing out of free

infant formula. In accordance with the call from global agencies, the SANDoH introduced a National Action Framework for EMTCT of HIV (Barron et al 2012:71), which was in response to the WHO's Global Plan (UNAIDS 2011).

In SA, breastfeeding is still the preferred method of infant feeding. Current breastfeeding recommendations include exclusive breastfeeding for the first six months, followed by the introduction of appropriate complementary foods, with breastfeeding continuing for two years or longer. It is therefore imperative that mothers receive support, for them to breastfeed their infants for the longest possible duration whilst maintaining viral suppression and reducing the risk of HIV transmission through breastmilk exposure (Wessels, Sherman, Bamford, Makua, Ntloana, Nuttall, Pillay, Goga & Feucht, 2020).

The researcher has, however, noted that most women are not traceable during the postnatal period. Should they present to the facilities for any ailment, no reference is made to PMTCT guidelines, which prescribe screening mothers for risks, subsequent testing of mothers who tested negative, and monitoring of viral suppression and adherence to ART. The support required by these mothers and the monitoring of their viral load until cessation of breastfeeding is thus compromised. There may be multiple reasons for why this occurs, some of which this study aimed to identify.

In 2015, SA introduced the *National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults* (SANDoH 2015). These guidelines were based on the SABDoH's 10-point plan to create a well-functioning health system that would produce improved health outcomes. The seventh priority of the 10-point plan sought to accelerate the implementation of the HIV/AIDS plan and reduce mortality due to TB and other infectious diseases, in order to improve the quality of life and health outcomes of South Africans. In these guidelines, the eligibility criteria for ART initiation were revised in order to increase access to treatment. All HIV-positive pregnant and breastfeeding women, regardless of their CD4 count or WHO clinical stage, and children older than five years, adolescents and adults with CD4 counts of ≤500 cells/mm^3 would be initiated on ART (SANDoH 2015).

The 2015 guidelines also required that (i) HIV counselling and testing (HCT) be offered to all pregnant and breastfeeding women with unknown HIV status or those who tested HIV-negative three or more months previously; (ii) all pregnant and breastfeeding women be

screened for symptoms of TB using the screening tool at every visit to the clinic, irrespective of their HIV status; (iii) both first-time antenatal attendees and women attending follow-up antenatal visits should be given routine information about HIV testing and the PMTCT programme; and (iv) all pregnant women (suspected and confirmed) should be encouraged to book into antenatal care early and should be offered HCT at their first antenatal visit (SANDoH 2015).

A standalone guideline that SA developed focused on prevention of mother to child transmission of communicable infections. In these guidelines, Option B+ (lifelong ART for all pregnant and breastfeeding women, irrespective of their CD4 count or WHO clinical stage) and PCR testing at birth was implemented to reduce postpartum mother to child transmission. (SANDoH 2019). The guidelines provide guidance on (i) the strengthening of antenatal and postnatal care for both HIV-negative and HIV-positive mothers; (ii) the introduction of a dolutegravir-based ART regimen, which is more efficacious in reducing the risks of transmission of HIV; and (iii) the promotion of integrated management of the mother-infant pair by aligning PMTCT interventions with basic antenatal care (BANC) visits during the antenatal period and expanded programme of immunisation (EPI) visits during the postnatal period (SANDoH 2019). The aim of these guideline was to set out the minimum standards for the routine care of women aged 15–49 years and their families, in order to prevent new HIV cases and other infections, unintended pregnancies, and MTCT of HIV and other infections, and to provide care and treatment of women living with HIV, syphilis and other infections, and of their children exposed to these infections.

To strengthen the likelihood of reaching the target of zero MTCT of HIV and an HIV-free generation, the PMTCT programme adopted the four WHO pillars for the prevention of transmittable infections from mother to child (SANDoH 2019) described in section 1.2.

2.3 THEORETICAL FRAMEWORK FOR THE IMPLEMENTATION OF PMTCT

Figure 2.2 below illustrates Yah and Tambo's (2019) implementation framework for PMTCT.

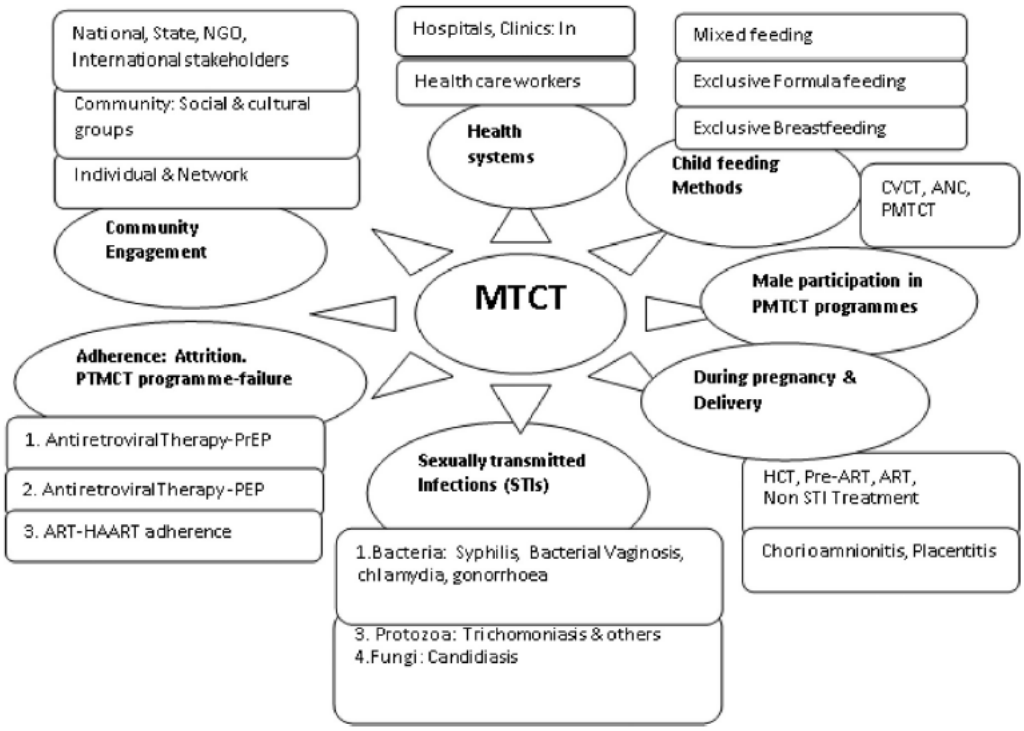

Figure 2.2: PMTCT implementation framework

Source: Yah & Tambo 2019

As shown in Figure 2.2, the determinants of the implementation of PMTCT include (i) health systems, (ii) child feeding methods, (iii) male participation in PMTCT programmes, (iv) pregnancy and delivery, (v) sexually transmitted infections (STIs), (vi) adherence, and (vii) community engagement (Yah & Tambo 2019). These determinants are discussed below.

2.3.1 Health systems

Mutabazi, Zarowsky and Trottier's (2017) Rwandan study found that underlying health system challenges, such as weak physical and human resource infrastructure, could negatively affect both PMTCT programmes and the health services with which these programmes interact. Similarly, a study titled" Workforce patterns in the prevention of mother to child transmission of HIV in Côte d'Ivoire: a qualitative model", published in the Human resources for Health journal (Rowan et al. 2018:16) found that hospital the workforce plays a major role in the quality of PMTCT services and the final outcomes. The same is observed from historical observations made by. Nguyen et al that suggested that the quality of PMTCT services could

be enhanced by improving the communication and other skills of health workers, by providing them with greater support, and by enhancing their motivation. Furthermore, a reduction of their workload was also found to be important in order for PMTCT to succeed.

In South Africa, the SANDoH integrated the PMTCT programme into the existing Maternal Child and Women's Health (MCWH) and Nutrition Strategic Plan in 2004 to improve on the vertically started programme, but the heavy workload and the struggling health care system does not provide that opportunity for quality services for HIV-positive pregnant mothers all through the continuum of care.

2.3.2 Child-feeding methods

Breastfeeding is regarded as one of the foundations of child health development and survival, especially where diarrhoea, pneumonia and undernutrition are common causes of mortality in children younger than five years. For these reasons, the WHO (2016) has recommended exclusive breastfeeding for the first six months of life, followed by continued breastfeeding with appropriate complementary foods for up to two years or beyond, as the preferred method of feeding infants. In their Kenyan study, Andare, Ochola and Chege (2019) concurred, regarding safe infant feeding practices as important determinants in PMTCT. They cautioned, however, that the decision to breastfeed or not is a very difficult one for mothers living with HIV. The mothers' lack of knowledge and various socio-economic factors may lead to non-adherence to safe infant feeding practices such as exclusive breastfeeding in virally suppressed conditions. In addition, socio-demographic factors such as age, education and occupation have already been established as important determinants of infant feeding practices among mothers living with HIV (Andare et al 2019). Nlend (2022) observed that transmission through breastfeeding still contributes to almost 50% of paediatric HIV infections recorded every year, and therefore hinders the achievement of EMTCT worldwide.

2.3.3 Male participation in PMTCT programmes

According to Makoni, Chemhuru, Chimbetete, Gombe, Bangure and Tshimanga (2016), the uptake of and adherence to PMTCT interventions in Zimbabwe are a challenge to most women when their male partner is not involved. The PMTCT programme in Kenya offers health authorities an opportunity to meet with pregnant women and their partners in order to discuss practices that will help prevent the transmission of HIV to the infant during pregnancy, labour and breastfeeding (The New Humanitarian 2012). In the Kenyan PMTCT programme,

it was found that HIV testing as a couple promoted communication, mutual disclosure, and mutual decision making on issues to do with safer sex, infant feeding and family planning. It was also found that support from a male partner improved a woman's adherence to PMTCT, and that male partner involvement in PMTCT may reduce the risk of MTCT by more than 40% (The New Humanitarian 2012).

Having worked in the private sector with antenatal women, the researcher assumed that where there was acceptance and positive support for HIV-positive women, the women would take their medication freely and would ensure that all precautions to protect their infant were taken.

2.3.4 MTCT during pregnancy and delivery

As already discussed previously, MTCT is a well-established mode of HIV transmission, and these infections may occur during pregnancy, labour, delivery and breastfeeding (Maputle & Jali 2008). Maputle and Jali (2008) have shown that breastfeeding increases the risk of MTCT by as much as 12–43%. They further argued that since breastfeeding is a significant and preventable mode of HIV transmission to infants, there is an urgent need to educate, counsel and support women and families to make informed decisions about how best to feed their infants in the context of HIV. The antenatal care offered to a pregnant HIV woman and the mode of delivery chosen have a direct impact on MTCT, with elective Caesarean section being associated with an 80% reduced risk of MTCT (Boer, England, Godfried & Thorne 2010). Similarly, ART for all women during pregnancy and breastfeeding is associated with an estimated low MTCT rate of 1.58% (Mugwaneza, Lyambabaje, Umubyeyi, Humuza, Tsague, Mwanyumba, Mutabazi, Nsanzimana, Ribakare, Irakoze, Mutaganzwa, Lombard & Jackson 2018).

2.3.5 Sexually transmitted infections

In their study on sexually transmitted infections (STIs) in pregnant women in sub-Saharan Africa, Ngobese and Abbai (2021) found that STIs present a major health problem, particularly in developing countries where the resources and technology to diagnose and treat them are limited. They also found that there is currently limited data on STIs and risk factors for these infections among pregnant women living with HIV, and that this is worse in sub-Saharan Africa (Ngobese & Abbai 2021). Untreated STIs account for certain adverse outcomes during pregnancy, including stillbirth, preterm labour and delivery, and low birth weight. They have

also been shown to increase the risk of HIV acquisition and MTCT, with the risk being highest in women with multiple STIs (Ngobese & Abbai 2021).

STIs can include Chlamydia Trachomatis, Neisseria Gonorrhoeae, Treponema Pallidum, and Cytomegalovirus (CMV). These may lead to adverse pregnancy and infant outcomes (Adachi, Xu, Yeganeh, Camarca, Morgado, Watts, Mofenson, Veloso, Pilotto, Joao & Gray 2018). According to Adachi et al (2018), HIV-infected pregnant women identified during labour are at high-risk for STIs, and co-infection with STIs, including Cytomegalovirus, nearly doubles the risk of HIV MTCT. CMV infection appears to confer the largest risk of HIV MTCT. Despite the large burden and risk to maternal and infant health posed by STIs, routine antenatal testing for STIs is not offered in most countries, resulting in suboptimal diagnosis and treatment of these conditions (Wynn, Bristow, Cristillo, Murphy, van den Broek, Muzny, Kallapur, Cohen, Ingalls, Wiesenfeld & Litch 2020). In this regard, Adachi et al (2018) suggest that STI screening be included as part of routine prenatal care, especially for high-risk pregnant women, such as those who are young and infected with HIV.

2.3.6 Adherence: attrition and PMTCT programme failure

The interventions aimed at PMTCT of HIV are extremely effective if they are used. However, they remain underutilised in several countries, for various reasons. Yacobson, Malkin and Lebetkin (2016) stated that the economic barriers to PMTCT experienced by pregnant women with HIV are well documented and include the time and cost of frequent travel to their local health facility, the distance to the facilities, and lack of transportation. Yacobson et al (2016) proposed that addressing these economic barriers could potentially improve PMTCT utilisation and further reduce MTCT of HIV. Numerous studies have identified food insecurity as a factor that affects access to services and adherence to treatment. Ebuy, Yebyo and Alemayehu (2015) conducted a study to assess the level of adherence and predictors of adherence to the Option B+ PMTCT program in Tigray, northern Ethiopia. They found that counselling on medication and HIV status disclosure were positive predictors of adherence to Option B+ PMTCT drugs, but that where counselling was inadequate and HIV status was not revealed, the PMTCT programme would fail (Ebuy et al 2015).

2.3.7 Community engagement

In 2011, various countries committed to work towards the elimination of new HIV infections among children by 2015 and the reduction of AIDS-related maternal mortality. This was to be

accomplished through the implementation of the new WHO Global Plan for scaling up comprehensive PMTCT programmes (UNAIDS 2011). The Global Plan called for out-of-the-box thinking and action, both within and outside the usual health care delivery system. An important feature of the plan was its emphasis on community engagement as an integral part of the scale-up strategy (UNAIDS 2012). Three primary modes of community engagement were recommended:

Improving the supply of PMTCT services

a. by extending the workforce through employing community cadres (e.g., community health workers, mentor mothers, lay counsellors, traditional birth attendants),
b. by strengthening linkages with community and faith-based organisations to promote and provide PMTCT services, and
c. by monitoring PMTCT programmes through civic participation using a rights-based approach.

2. Increasing the uptake of PMTCT services

a. by empowering communities to lead social and behaviour change communication around PMTCT,
b. by providing peer support through individual counsellors and in support groups, and
c. by engaging communities to maximise their assets and address financial barriers to PMTCT.

3. Creating an enabling environment for PMTCT scale-up

a. by advocating and supporting activism for PMTCT and the right to health, and
b. by promoting policies and strategies that support PMTCT and community engagement.

However, despite the widely recognised features of the Global Plan, much of the PMTCT guidance focused on ARV drug prophylaxis during pregnancy, facility-based interventions, and post-natal ART and breastfeeding practices (UNAIDS 2012).

From the theoretical PMTCT implementation framework above, the researcher deduced that all seven factors might be contributing to the seroconversion of the infants in Ehlanzeni. To establish the reasons for this more decisively, it was important to explore the mothers' perceptions of each factor. The design of the data collection instrument (in-person interviews, informed by an interview guide) therefore had to include these seven determinants of the implementation of PMTCT shown in this theoretical framework.

2.4 EMPIRICAL RESEARCH

2.4.1 Seroconversion

Ratini (2021) defines HIV seroconversion as the progression from HIV exposure (where the HIV test remains negative) to HIV infection, where antibodies are developed and are detectable by a positive HIV antibody test. This transition can take few weeks and is commonly referred to as the window period. Seroconversion takes place within three weeks in most infected individuals (Weatherspoon & Eske 2018).

This study focused on HIV-negative infants born to HIV-infected mothers, who seroconverted within the first 24 months of life. Tsehay (2019) found that home delivery, mixed feeding, episiotomy, and ARV prophylaxis at birth were factors that influenced the HIV sero-status of HIV-exposed infants in Ethiopia. Of these factors, mixed feeding was significantly associated with MTCT of HIV. Tsehay's (2019) findings confirmed those of Lussiana, Clemente, Ghelardi, Lonardi, Pulido Tarquino, Floridia and Vermund (2012), who had conducted a similar study in Angola, in which exposure to HIV-infected maternal milk before the age of six months was associated with a five-fold increased risk of HIV for infants born to HIV-positive mothers.

2.4.2 Barriers to EMTCT

In 2015, the World Health Organization (2015b) stated that Europe and central Asia had the highest ARV prophylaxis coverage for pregnant HIV-infected women and their infants when compared with other low- and middle-income countries. In most European countries, HIV testing is conducted routinely during ANC and involves a number of strategies, including intrapartum testing of women with unknown status and repeat testing of women in their third trimester of pregnancy. These strategies have been employed in order to clearly establish the HIV status of pregnant women, as such knowledge is essential to the efforts surrounding PMTCT. The World Health Organization (2015b) has highlighted late diagnosis of (or failure

to diagnose) women, barriers to ANC, the late initiation of ART in women, and treatment failure due to drug resistance or poor medication adherence as significant barriers to EMTCT that need to be addressed. Fortunately, opportunities exist in Europe and central Asia to address these issues effectively and to further decrease MTCT of HIV and the number of new infections among children.

During the first year of implementing the PMTCT programme in Kenya, it was found that 43% of women who had tested HIV positive at their first ANC visit were lost to follow up. Thomson, Telfer, Opondo Awiti, Munge, Ngunga and Reid (2018) conducted a qualitative study to establish the barriers to enrolling and retaining women in PMTCT services throughout the pregnancy and postpartum periods. From the data analysis, five themes emerged that were thought to influence attrition from PMTCT service in the setting: (i) HIV in the context of Kibera (the neighbourhood in Nairobi where the study was conducted), (ii) knowledge of HIV status, (iii) knowledge of PMTCT, (iv) disclosure of HIV status, and (v) male partner support for PMTCT services.

According to Thomson et al's (2018) study, every new HIV diagnosis during pregnancy required an immediate and ongoing risk assessment of perceived barriers to participation in PMTCT services that could occur in the pregnant woman's home, community, and clinic environments. The presence or absence of male partners was a major influence on this risk assessment, but the male partners were generally unaware of PMTCT services. Before enrolling for the programme, the women had to continuously weigh the risks and benefits of PMTCT services and interventions in order to preserve their relationships with their male partners, meet community expectations of womanhood, and maintain confidentiality while following the recommendations of health care providers.

To overcome these barriers, and to therefore improve the uptake of care and retention in care, and to optimise the benefits of PMTCT interventions for HIV prevention, Thomson et al (2018) recommended community-based HIV testing and PMTCT education, male involvement in antenatal care, and customised counselling to assist each woman in her own unique risk assessment.

In a critical literature review, Okoli and Lansdown (2014) explored the reasons for the inadequacy and failure of PMTCT in both Malawi and Nigeria. The findings indicated that socioeconomic and sociocultural factors were the most significant barriers to the successful

implementation of the PMTCT programmes. Other significant factors included (i) limited male involvement, (ii) the organisation of PMTCT, and (iii) health workers' inefficiencies (Okoli & Lansdown 2014). The researchers concluded that PMTCT programmes would remain inefficient unless these factors were addressed by the respective governments through collaborative strategic efforts to ensure high PMTCT programme uptake in both countries, and thus the elimination of HIV/AIDS in children (Okoli & Lansdown 2014).

Since MTCT of HIV continued to be a challenge in Nigeria, as a result of persistently poor use of PMTCT services by pregnant women, Anigilaje, Ageda and Nweke (2016) conducted a follow-up study on 52 mothers of vertically infected HIV-seropositive infants in order to explore barriers throughout the chain of PMTCT services. The 2016 study confirmed the findings of their earlier 2013 study (Anigilaje, Dabit, Ageda, Hwande & Bitto 2013), and identified the following major barriers that prevented the use of PMTCT services: (i) non-involvement of male partners, (ii) stigma and discrimination experienced by HIV-seropositive mothers, (iii) financial constraints on couples, (iv) the involvement of traditional birth attendants in antenatal care and delivery of HIV-infected women, (v) lack of awareness of HIV-seropositive status on the part of pregnant women, (vi) a poor health system, and (vii) the lack of funding for PMTCT services at private and rural health facilities. To overcome some of these barriers, Anigilaje et al (2016) recommended strong political and financial commitments.

Despite its scaled-up response for PMTCT, in 2019 Nigeria still accounted for the greatest number of infants infected with HIV globally. In a review of policy documents and research papers that also drew on their personal knowledge, Olakunde, Adeyinka, Olawepo, Pharr, Ozigbu, Wakdok, Oladele and Ezeanolue (2019) explored the achievements and challenges in the Nigerian EMTCT programme using the WHO's health systems framework. Their evaluation found that Nigeria had (i) increased the number of PMTCT sites, (ii) decentralised and integrated PMTCT care for expanded service delivery, (iii) adopted task-shifting to address the shortage of skilled health care providers, (iv) explored alternative sources of domestic funding to bridge the funding gap, and (v) harmonised the health management information system to improve data quality (Olakunde et al 2019). Despite these interventions, however, their assessment found that the following challenges still existed: (a) low uptake of antenatal care, (b) interrupted supplies of medical commodities, (c) knowledge gaps among health care workers, and (d) lack of a national unique identifying system to enhance data quality. Olakunde et al (2019) strongly suggested to the Nigerian government that successful

EMTCT in Nigeria required the implementation of feasible, culturally acceptable, and sustainable interventions.

To understand the perspectives of pregnant and postpartum women living with HIV in Mozambique, in relation to barriers to following PMTCT strategies, Buleza Lamucene, Bernales, Irarrázabal Vargas and Ferrer Lagunas (2022) conducted a qualitative study between October 2020 and March 2021. They found that barriers to EMTCT included social stigma associated with an HIV-positive status and the associated fear of discrimination, side effects of medications, economic barriers, and denial of diagnosis/treatment (Buleza et al 2022). Buleza et al (2022) recommended that the community should receive more education about HIV.

In 2017, a systematic review of existing literature on barriers to the implementation of the PMTCT programme in China was conducted by Peng, Wang, Xu and Wang (2017). Their study identified eighteen barriers to the successful implementation of the PMTCT programme and emphasised the importance of the government's role in the coordination, acceptability, and accessibility of PMTCT services (Peng et al 2017). The barriers were grouped into four themes: (i) *social and political constraints*, which included a lack of supporting policy, stigma, ethnic minority status, and negative family attitudes towards HIV; (ii) *recipients of care*, which included lack of knowledge of PMTCT, lack of confidence in PMTCT, hesitation regarding child-rearing, and lack of awareness of susceptibility to HIV; (iii) *providers of care*, which included lack of technical training and discrimination towards recipients; and (iv) *health care system*, which featured the problems of limited transportation in mountainous areas, the economic burden of institutional birth, delays in HIV testing, poor communication between health care providers and pregnant women, no informed consent for ART, lack of communication among health service providers, lack of occupational stability for service providers, and the lack of capability of the PMTCT services at public and private service sites (Peng et al 2017).

EMTCT implementation has also faced significant challenges in Uganda, where the HIV infection rate of the roughly 130 000 Ugandans living in fishing communities is 3–4 times higher than the reported national average of 7.3% (UNICEF 2016). According to the 2016 UNICEF study, a high degree of mobility and a lack of HIV/AIDS services are major contributors to the high HIV/AIDS prevalence rates among these communities. Other contributing factors included cultural norms, knowledge and attitudes, service quality, and

engagement of pregnant mothers and their partners. Barriers to the effective implementation of EMTCT programmes in Uganda were identified as (i) social barriers and lack of family support (stigma regarding the woman's HIV status, and fear of disclosure and victimisation affected the programme uptake); (ii) high mobility and migrant labour, which resulted in a loss of follow up; (iii) long distances to health facilities; (iv) poor health services; and (v) understaffing (UNICEF 2016).

As in other low- and middle-income countries, HIV-positive pregnant women in Zambia are less likely to start and remain on ART throughout pregnancy and after delivery (Kanguya, Koyuncu, Sharma, Kusanathan, Mubanga, Chi, Vinikoor & Mubiana-Mbewe 2022). In their qualitative study conducted among pregnant women to explore barriers to PMTCT implementation in Zambia, Kanguya et al (2022) found disclosure and partner support to be crucial factors in ART initiation and adherence.

According to (Mnyani, Simango, Murphy, Chersich & McIntyre (2014) SA is still confronted with the problem of a lack of adherence to the policies and implementation guidelines for PMTCT, highlighting the need for an exploration of the barriers to the implementation of the country's PMTCT programme. For this reason, Mnyani et al (2014) conducted an integrated literature review that focused on exploring and synthesising the barriers to PMTCT in rural SA. Their study identified (i) institutional (ii) patient-related, and (iii) socio-economic factors as the most significant barriers to the management of HIV-exposed children in the rural areas of SA, and concluded that intervention strategies were required improve the implementation of EMTCT policy guidelines (Mnyani et al 2014).

A case-control study among HIV-infected women with HIV-infected (cases) and uninfected (controls) infants diagnosed at around six weeks of age, was undertaken by Buthelezi, Modeste and Phetlhu (2021). Their study aimed to identify key patient factors for MTCT in a high HIV prevalence setting in Johannesburg, SA. The most significant patient-related risk factors for MTCT were identified as (i) undiagnosed maternal HIV infection prior to conception, (ii) unplanned pregnancies, (iii) delays in accessing antenatal care, and (iv) low levels of education. Buthelezi et al (2021) observed that while there has been an emphasis on increasing the availability and coverage of efficacious ART regimens, and on strengthening the health systems within EMTCT initiatives in SA, there is also a need to also address patient-related factors if SA is to achieve its EMTCT goal (Buthelezi et al 2021).

In Chapter 4, the findings from this study's investigation of HIV-positive mothers' experiences of the barriers to the EMTCT in Ehlanzeni District will be presented in relation to the barriers to EMTCT discussed above, and will thus contribute further to the existing body of knowledge on barriers to EMTCT in South Africa. The findings on the mother's experiences will identify patient-related factors that need attention, and will also address ways in which the mothers failed to access and utilise PMTCT services optimally. Recommendations for revisions to policies and guidelines that could improve the quality, acceptability and availability of PMTCT services will be based on the mothers' experiences, thus allowing them to make a significant contribution to the outcomes of the PMTCT programme.

2.5 CHAPTER SUMMARY

In this chapter the researcher has presented a detailed review of the existing literature on the legislative framework for the PMTCT programme, from a global perspective and from the perspectives of selected countries. In this regard, applicable global guidelines and policies that emanate from the WHO, UNAIDS and UNICEF were outlined. The second area that the chapter covered was the theoretical framework for the implementation of PMTCT, which identified and described seven primary factors that influence it. The final section of the chapter focused on empirical research on seroconversion and on barriers to the successful implementation of PMTCT/ EMTCT. In this regard, studies from a range of countries that highlighted specific barriers to the implementation of PMTCT in those countries were reviewed. Most of these studies were qualitative in design and used interviews to generate data.

The following chapter will focus on the research methodology employed in this study, and will explain the research design, the population and sampling, the methods of data collection and data analysis, and the measures taken by the researcher to strengthen the trustworthiness of the study.

CHAPTER 3
RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

In Chapter 2, the researcher presented a detailed review of the literature on the EMTCT of HIV, which included literature on the legislative framework for EMTCT from a global perspective and from the perspective of various countries, as well as a description of the theoretical framework for implementing EMTCT and a discussion of empirical research on seroconversion and barriers to EMTCT. Most of these were qualitative, empirical studies that used interviews, focus groups and document reviews as data collection instruments.

In this chapter, the research methodology employed in this study on the experiences of HIV-positive mothers of the barriers to EMTCT in Ehlanzeni district, Mpumalanga is presented. The research design is explained, after which the specific research methods employed in sampling, data collection and data analysis are described. After describing how trustworthiness was strengthened in the study, the chapter concludes with a summary.

3.2 RESEARCH DESIGN

This study was a descriptive phenomenological study whose purpose was to investigate how HIV-positive mothers of HIV-positive infants who had seroconverted experienced the existing PMTCT programme, and how and why they used or failed to use the resources available to them. The mothers' subjective experiences provided insight and understanding of the problem of continuing barriers to EMTCT in SA.

3.2.1 Research approach

There are three approaches that researchers may choose from when undertaking a research study: qualitative, quantitative, or mixed methods. When conducting qualitative research, the researcher describes a research problem that can best be understood by exploring a concept or phenomenon, while in quantitative research the problem is best addressed by understanding what factors or variables influence an outcome (Creswell & Creswell 2017). Quantitative research is defined by Creswell (2014:247) as "a means for testing objective theories by examining the relationship among variables". Qualitative studies consider the

natural context in which individuals or groups function to provide an in-depth understanding of real-world problems (Korstjens & Moser 2017:274). Qualitative studies also focus on meaning and understanding, and often involve purposeful sampling, data generation via interviews and observations, and data analysis that is inductive and comparative, where the findings are descriptive and are presented as themes/categories (Merriam & Tisdell ,2016:42).

Creswell and Creswell (2017) describe mixed methods research as a method of addressing complex social and health science problems that cannot be adequately addressed by using only a qualitative or a quantitative approach. Mixed methods research employs a combination of both qualitative and quantitative approaches (Creswell & Creswell 2017:203). Mixed methods research, according to Ngulube and Ngulube (2015), can provide richer results for certain fields of study, and allows researchers to obtain a comprehensive picture of the phenomenon under investigation.

For this study on the experiences of HIV-positive mothers of the barriers to EMTCT in Ehlanzeni district, the researcher chose to conduct a qualitative study, because qualitative studies take into account the natural context in which individuals or groups function to provide an in-depth understanding of real-world problems (Korstjens & Moser 2017:274). A qualitative approach to the study assisted with investigating how the individual women made sense of the PMTCT programme, and how and why they engaged or did not engage with the available resources. A qualitative research design also enabled the researcher to interview participants using open-ended questions and to probe further when the answers were not clear.

3.2.1 Research design

There are several types of qualitative research designs. Tenny et al (2017) posit that before qualitative researchers commence with an enquiry, they must choose one of several approaches: ethnography, grounded theory, phenomenology, or narrative research.

Ethnographic research designs have their origins in social and cultural anthropology and require researchers to directly immerse themselves in the participants' environment, before emerging from it with accounts of actions, behaviours, and events understood through the eyes of the participants (Tenny et al 2017).

In grounded theory, researchers generate a theoretical model by observing the study population and developing a comparative analysis of their speech and behaviour, to understand the participants' social interactions or experiences (Tenny et al 2017). Narrative research focuses on the ability of the participants to tell a story, often from their own perspective.

Phenomenology, on the other hand, is regarded as the study of the meaning of phenomena. Phenomenology investigates experiences from the perspective of the participants. For this study, investigating HIV-positive mothers' experiences of the barriers to EMTCT, the researcher employed a descriptive phenomenological approach that prioritised the participants' communication of their own lived experiences with the PMTCT programme to address the research questions.

3.2.2 Descriptive phenomenology

Phenomenology can be described as the philosophy of experience, as it is a perspective and a method that concentrates on individuals' existence in their own world and within their own social context (Horrigan-Kelly, Millar & Dowling 2016: 7). This approach to research describes phenomena according to how people experience them in their daily lives (Polit & Beck 2017:471). (Alhazmi & Kaufmann 2022) describes phenomenology as a tool allowing the researcher to engage in flexible activities that can describe and help to understand complex phenomena, such as human social experience. According to Brink and van Rensburg (2022:124), phenomenological studies involve exploring human experience by relying on descriptions provided by the individuals involved, aiming to address the fundamental question: "What does it feel like to undergo this particular experience?"

Because phenomenological research focuses on the lived experiences of the participants, it is often descriptive. When researchers observe, define, and document aspects of people's experiences as they naturally transpire (Hunter, McCallum & Howes 2019:11), rich, emic information about the situation and how the participants see the world is generated (Bradshaw, Atkinson & Doody 2017:5).

This study therefore adopted a descriptive phenomenological design that relied primarily on detailed- in-depth interviews with people (mothers) who had lived experience and knowledge of the research problem (the seroconversion of infants who had been born HIV negative, despite having gone through the PMTCT programme in South Africa). Polit & Beck (2020),

explains this as a phenomenological researcher asking the questions:" what is the essence of this phenomenon as experienced by these people? Or what is the meaning of the phenomenon to those who experienced it?". Phenomenology as a qualitative practice was used to document and examine the experiences of the infants' mothers, to understand why the seroconversion of their infants occurred.

The researcher gathered descriptive information on the mothers' lived experiences in relation to PMTCT from them during face-to-face interviews. In the process, the researcher tried to elicit detailed explanations from the mothers, by probing their answers and encouraging their deeper engagement with the questions posed. These interviews were recorded and transcribed to facilitate analysis and were supplemented by field notes that the researcher took during the interviews. This descriptive phenomenological research design encouraged the researcher to listen to the mothers as they related their lived experiences of the PMTCT programme during the interviews (Polit & Beck 2017: 473).

A descriptive phenomenological design often contains four steps: bracketing, intuiting, analysing and describing. These steps are briefly explained below.

3.2.4.1 Bracketing

Tufford and Newman (2010:80) describe bracketing as "a method used in qualitative research to mitigate the potentially deleterious effects of preconceptions that may taint the research process". Bracketing requires researchers to suspend their own defined ideas and judgements about the phenomenon under study, and to set aside their existing information and preconceptions, to avoid influencing the collection and analysis of data (Streubert & Carpenter 2011:77). The researcher's goal is therefore to achieve what Lopez and Willis (2004) call "transcendental subjectivity", which they describe as a state where "the impact of the researcher on the inquiry is constantly assessed and biases and preconceptions neutralized, so that they do not influence the object of study" (Lopez & Willis 2004:728). Bracketing is therefore an ideal method that can never be achieved totally, but that does help researchers to be as objective as possible by being mindful of their preconceptions. In this way, researchers can focus more closely on the participants' descriptions of their own lived experiences.

In this study, the researcher strove to focus on what the participants had to say about their experiences of the PMTCT programme. The researcher faithfully recorded and transcribed

their comments and drew verbatim excerpts from the transcriptions to support the interpretations formed during the analysis of this data.

3.2.4.2 Intuiting

Streubert and Carpenter (2011: 76) indicate that after bracketing has been achieved, the researcher needs to stay alert and focused on the participants' descriptions and remain open to the participants' own interpretations of their first-hand experiences in relation to the phenomenon. Dahlberg, Dahlberg and Nyström (2008) note that this openness involves the researcher being observant, attentive and sensitive to how the participants express their experiences. This focused, receptive mindset assisted the researcher to identify and understand the various aspects of what the mothers had to say about their experiences with the PMTCT programme, in order to better understand the phenomenon of the seroconversion of their children.

3.2.4.3 Analysing

After the process of data collection, during which bracketing and intuition are ideally heavily employed, the researcher begins the process of data analysis. For descriptive phenomenological studies, thematic analysis and a process of coding themes is generally involved. Phenomenological researchers examine the data cautiously and deliberately, by reading and re-reading information, whilst checking for meanings and clarity (Brink, van der Walt & van Rensburg 2012:122). This process involves identifying the relevant data that addresses the research phenomenon (Streubert & Carpenter 2011: 80). For this research study, the primary database comprised of a set of transcriptions from the recorded qualitative interviews. The researcher examined these transcribed interviews in detail in order to identify and code relevant themes that would enable deeper insight into the research problem.

3.2.4.4 Describing

This final stage in the process of conducting descriptive phenomenological research involves the researcher's written descriptions of the lived experiences communicated by the participants. The researcher organises the themes into patterns and describes them in relation to the aims and objectives of the study, to address the research questions. Sundler, Lindberg, Nilsson and Palmér (2019) note that when these findings are reported, they are described "conversely", by "starting with the themes and the descriptive text, illustrated with quotes". In

this study, the researcher used verbatim quotes from the mothers to illustrate their experiences with the PMTCT programme.

3.3 RESEARCH METHOD

3.3.1 Research setting

The research setting is the physical, social, or experimental context within which a study is conducted (Atkinson, Delamont, Cernat, Sakshaug & Williams 2021). This study was conducted in Ehlanzeni district, within its four sub-districts (Nkomazi, Bushbuckridge, Thaba Chweu and City of Mbombela). The Ehlanzeni District Municipality is one of the three district municipalities in the Mpumalanga Province situated in the north-eastern part of the province bordered by Mozambique and Swaziland in the east consisting of approximately 27 895 km^2 of land with a population of 1856 753 people in 2019 according to the COGTA report (2020: 5) Figure 3.1 below shows Ehlanzeni district in Mpumalanga province. The research was conducted in four high volume community health centres in Ehlanzeni, each with more than 1000 patients on ART, and one clinic with less than 1000 patients on ART. The headcounts for 20 years and older were 20 424 patients with the lowest being 1 540 and the highest being 6149 among the chosen facilities where a total of 558 deliveries over the age of 20 occurred from July 2022 to February 2023 (DHIS:2023).

Figure 3.1: Study setting: Ehlanzeni district in Mpumalanga province.

Source: www.municipalities.co.za

Ehlanzeni is the largest of the three districts found in Mpumalanga province, and its geographic location makes it vulnerable to various health challenges. The district features three border gates to both Swaziland and Mozambique (Matsamo, Komatipoort and Mananga border gates) and, therefore, movement of people from neighbouring countries into the district, and from Gauteng to either Swaziland or Mozambique, creates a catalyst for the economic life of the area. (COGTA report (2020). The 2015 ANC seroprevalence survey showed that at 38.1%, Ehlanzeni had the highest HIV prevalence in pregnant women after the KwaZulu-Natal districts (SANDoH 2015), with adolescents and young women most affected. DHIS data for 2017/18 showed that 3.6% of the children aged 19 months to 14 years in the district tested positive for HIV, compared with the provincial and national rate of 3.2% and 2.2%, respectively (Massyn 2020: 393). The research study was conducted at five health care institutions in Ehlanzeni district.

3.3.2 Population

A population is a group of individuals sharing similar characteristics (Momoh 2022). They are generally defined according to their demographic characteristics and their location boundaries. For this study, the population consisted of HIV-positive mothers above the age of eighteen years, whose infants tested positive for HIV after a negative birth PCR test at Ehlanzeni district, Mpumalanga between January 2018 and December 2020.

3.3.3 Sampling

A study sample is a smaller sub-group of the population that the researcher intends to interview for the purpose of the research, that is representative of the larger group (Dingwall & Staniland 2021:126). A researcher's sampling strategy refers to their method of selecting a sample of participants from the available population, their criteria for including and excluding certain participants, and their decisions on the final sample size (Omona 2013; Robinson 2014). Researchers should ensure that sample sizes and sample strategies are compatible with their research purposes, and the more representative the sample is, the more likely the researcher will be able to encompass the varying factors at play (Tenny et al 2017).

A non-probability sample was used which cannot be generalized to the rest of the population. The following are examples of non-probability participant sampling and selection relevant to qualitative research: (i) purposive sampling, where the selection of participants is based on the researcher's judgement of who would be the most informative; (ii) criterion sampling, where the selection is based on pre-determined factors; (iii) convenience sampling, where participant selection is based on their accessibility and availability; (iv) snowball sampling, where participant selection is through referral from other participants or people who know potential participants; (v) extreme case sampling, where rare cases are targeted; and (vi) typical case sampling, where the selection of participants is based on the researcher's judgement of who would be an average or typical participant (Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood 2015: 533-544).

For this study, purposive sampling was used to select participants based on the researcher's judgement of those who would be most informative (Polit & Beck 2017:741). According to this sampling method, participants are selected according to specific identified criteria of importance (Korstjens & Moser 2018:1).

3.3.3.1 Criteria for inclusion and exclusion

The inclusion criteria for participants in this study were: (i) mothers whose infants seroconverted after a negative birth PCR test, as identified from the PCR registers at the facility; (ii) mothers aged 18 years and above, as they were not minors and did not require parental/guardian assent to participate in the study; and (iii) mothers of infants aged 18 to 24 months.

The following were excluded from the study: (i) mothers with children older than 24 months, (ii) mothers who refused to take part in the study, (iii) mothers who did not speak English or iSiSwati, and (iv) mothers under the age of 18 years, as they are legally regarded as minors in SA and cannot therefore sign consent without parental support. Section 35, 1(a) of the Health Act 61 (Republic of South Africa, 2003) requires that a parent or guardian must formally provide permission for information to be collected from a child, where the latter is defined as a person under the age of 18 years.

3.3.3.2 The sample

The sample of participants was selected from the study population on a first-come, first-selected basis in accordance with the inclusion criteria. The sample size was based on the researcher's informational needs, where the guiding principle was data saturation. In this regard, Sacks and Allsop (2019:1) posit that data saturation is reached when no or little additional information is obtained from collecting additional data. In this study, the sample size was estimated at 10 participants, but data saturation was achieved after 13 participants had been interviewed.

3.3.3.3 Ethical considerations related to sampling

After permission to conduct this study had been granted by UNISA's College of Human Sciences Research Ethics Review Committee (see Annexure 1), the Mpumalanga Department of Health HAST Chief Director (see Annexure 2), and the Ehlanzeni District Manager, the researcher made an appointment with the operational managers or facility managers in each sub-district to discuss the possibility of conducting this study. The approval letter from the ethics committee and the letters granting permission from the provincial and district leaders to conduct the study were shown to these managers who in turn provided permission for the researcher to conduct the study in that the selected facility.

3.4 DATA COLLECTION AND ANALYSIS

Data collection refers to the gathering of information from participants using a data collection tool. The information is gathered in order to understand a problem and come up with recommendations to solve it (Alase 2017:14).

3.4.1 Data collection instrument

Face-to-face, in-depth interviews were conducted with 13 participants at five health care institutions in Ehlanzeni district to collect relevant information for this study. These interviews were guided by an interview schedule (see Annexure 6).

3.4.1.1 Individual, face-to-face, in-depth interviews

In-depth, face-to-face, individual interviews were conducted with each of the 13 participants in order to understand their experiences of the barriers to EMTCT in South Africa. Each interview took approximately 45-60minutes depending on openness of the participant. While individual interviews can be costly and time consuming (Creswell & Creswell 2017:218), they are ideal for encouraging participants to talk freely and openly. According to Taylor, Bogdan and De Vault (2016:102), in-depth interviews are also useful for when a researcher wishes to study past events that cannot be observed by the researcher, in order to reconstruct these events. Studies employing interviews as a data collection tool can usually be completed in a shorter time period than those based on the observation of participants.

Furthermore, according to Taylor et al (2016:104), when a researcher is interested in understanding a broad range of people or settings, interviewing multiple participants lends itself to building general theories about the nature of social phenomena. This was applied in this study, where the aim was to elicit the participants' experiences, perceptions, thoughts, and feelings in relation to the seroconversion of their infants (Korstjens & Moser 2018:1). According to Oleribe, Enenche, Udofia, Ekom, Osita-Oleribe, Kim and Taylor-Robinson (2018:102), in-depth interviewing seems especially well suited where researchers have a clear sense of their interests and the kinds of questions they wish to pursue.

The advantages of in-depth interviews are: the interviewer can observe the participants' mannerisms and gestures; the interviewer has the chance to probe further where an answer needs further clarity; open-ended questions enable interviews to probe answers further; interviewers are able to obtain insights from the participants; and the participants' level of

education does not hinder the interview; the results of in-depth interviews are rated more highly in terms of the quality of the responses than questionnaires.

The disadvantages of in-depth interviews are that they take a lot of time and are costly; interviewers need proper training to standardise the interviewing process; sensitive issues may be challenging; and there may be interviewer/interpreter bias in the process.

To reduce the risk of these disadvantages, the researcher allocated sufficient time to each participant, and had a clear understanding of the interview guide and process. The researcher also conducted interviews with consideration for the sensitivity of certain issues, and the participants were reassured that if they did not feel comfortable with a question or statement, they could choose not to answer. Most of the participants understood English as the medium used, and where a native language was used, the researcher understood that language.

3.4.1.2 Interview schedule

The objectives of this study were (i) to explore and describe HIV-positive mothers' lived experiences in PMTCT programme implementation, (ii) to explore and describe HIV-positive mothers' experiences of the barriers to EMTCT, and (iii) to make recommendations for the improvement of EMTCT. An interview schedule (Annexure 6) was created to support the face-to-face interviews by guiding the researcher through the relevant questions.

Three main research questions were asked of each participant in this regard:

1. What is your experience in PMTCT program implementation?
2. What barriers did you experience regarding PMTCT?
3. What recommendations can be made to improve PMTCT?

The data collection guide consisted of four sections:

Section 1: Participant biographical and demographic data, which consisted of age, race, marital status, level of education, employment status and parity.
Section 2: PMTCT programme implementation.
Section 3: Barriers experienced to EMTCT.
Section 4: Knowledge of the PMTCT.
Section 5: Recommendations for improvement of EMTCT.

Each section had open-ended sub-questions that were used during the interview (see Annexure 6).

3.4.2 Data collection process

3.4.2.1 Gaining access to the institution

The researcher was able to gain access to the five study sites after being granted permission by the gatekeepers. These are four high volume community health care centres and one clinic. Singh and Wassenaar (2016) described gatekeepers as people who ensure that their facilities cannot be accessed without permission, and who function as access providers to certain parts or services of the facilities. Gatekeepers are usually influential people or people in authority.

A discussion between the researcher and the health facility operational managers (gatekeeper) took place when potential participants whose infants had seroconverted had been identified. The UNISA ethical clearance certificate (Annexure 1) and the approval letter from the Mpumalanga Department of Health (Annexure 2) were given to the gatekeepers. Each operational manager ensured compliance with the Protection of Personal Information (POPI) Act 4 of the Republic of South Africa (Republic of South Africa, 2013) by providing potential participants with a participation information sheet (see Annexure 4) and by obtaining informed consent from potential participants to share information with the researcher. In this regard, the operational manager compiled a list of all participants who fitted the inclusion criteria, with their appropriate contact details, and supplied it to the researcher, who approached the potential participants telephonically and made appointments accordingly.

The participants were asked to sign the consent form for the study (see Annexure 5) after reading the information letter (see Annexure 4) that described the nature and goals of the study and assured the participants that their information would be kept confidential. The data provided by the participants was maintained on a secure server. The participants were reminded of their freedom to withdraw from participating in the study at any given time, without explanation or penalty. Confidentiality risks were mitigated by informing the participants that the analyses of the study results would be presented in aggregate in any technical reports or manuscripts submitted for presentations, posters, and publication in scientific journals.

3.4.2.2 The interview process

1. Preparation for the interviews

Prior to the interviews, the researcher made appointments with potential participants telephonically to determine the most convenient date and time for them for an interview. The participants were informed that no incentive would be provided other than a travel reimbursement and lunch on the day of the interviews.

The dates of the appointments were discussed with the operational managers of the sites to ensure the availability of a space that was comfortable and suitable for confidential discussions. Given the Covid-19 prevention protocols in place at the time of data collection, the participants were allocated different time slots to avoid being in the same place, and a well-ventilated secluded area was provided by each facility for the researcher to use. The researcher also ensured that all relevant and required forms and documents were available and were sanitised before being shared with the participants.

Systems like computer-administered telephonic interviews (CATI) were explored, where the conversation could be recorded. In practice, however, this proved to be inaccessible and impractical because the anticipated load shedding at the interview sites prevented the researcher from using a CATI system. It was therefore decided that the interviews would be recorded using the voice recorder from a Samsung cell phone.

2. Introduction to the interviews

Information about the objectives of the interview and overall study was provided to each participant before the session could commence, and the participants' rights to confidentiality and anonymity were explained and emphasised before each interview. Informed consent was obtained from each participant prior to conducting the in-depth interviews, and each participant granted consent to be recorded using a digital recorder. The researcher reminded the participants that they were free to withdraw from the study at any time if they felt uncomfortable.

3. During the interviews

The researcher conducted one-on-one sessions in a private room after consent had been obtained from the participant and the process explained. Covid-19 prevention protocols were

implemented during the interviews, such as wearing face masks, hand sanitising, and social distancing. These protocols had been explained when the appointment was arranged.

The researcher conducted the interview using the interview schedule as a guide and took detailed notes during the interview in a diary. Where participants sometimes volunteered information, the researcher did not adhere strictly to the guide. Audio recordings were only started after the participants had given consent. Pre-determined participant identification numbers were used on the data collection forms (topic guide and notes) to assist in protecting confidentiality. The identification numbers were noted down with the participants' contact details and kept separately from the audio recordings in order to validate whether the researchers' interpretations were a true reflection of what had been said.

All notes and audio files were always kept on the person of the researcher during visits to the facilities. Neither participants nor non-participants were ever allowed to view the notes, and the content of the interviews was not revealed to anyone else, as confidentiality was strictly applied.

4. Recording interviews

The interviews were digitally recorded using a cell phone, and the researcher made notes on the participants' responses and any non-verbal behaviour during the interviews, as well as notes on the setting and atmosphere of each interview. The latter context enabled the researcher to gain deeper insight into the participants' responses.

5. After the interviews: summary, transcription and storage

The researcher typed detailed field notes after each interview, as they assisted in quality assurance. A contact summary form was captured on the file after the interview, where it was labelled with the responded unique number of the interviewee. The contact summaries were used for reference purposes and assisted in determining preliminary findings that fed into the overall study design, enabling the researcher to reflect on challenges with the interview guide and to keep a reflexive journal to improve memory recall.

The researcher transcribed the interviews after each in-depth interviews to enable memory recall and to compile and compare notes and then to reflect on the notes to develop relevant themes. A data capture, re-capture methodology was followed to ensure data quality and to provide backup. The relevant transcript and audio files were linked to each case. Audio

recordings were then transcribed into Microsoft OneNote and Microsoft Word version 365 ready for coding and analysis. The audio recordings of those participants who had responded in their home language, namely iSiSwati, were also translated after the event. The researcher made use of an iSiswati interpreter to translate interviews delivered in iSiswati into English. The short summaries of field work observations and each interview were also transcribed and stored. A standardized layout was applied to all transcripts to facilitate comparison of data at the analysis stage.

Transcriptions with verbatim records, paused and incomplete sentences were marked according to a set of notations according to standards. The transcription was checked against the audio file by both the researcher and translator to check for accuracy, identity and missed or misheard words and clarify any areas of confusion or unclear terminology. All queries and changes were made using track changes in MS Word. The cross-checked cleaned transcript was used to validate whether this was indeed a trustworthy reflection of the interview.

All typed records, forms, consent forms and other notes were kept on a password-protected computer on a password-protected drive. The files were backed up regularly and were only shared amongst the researcher, supervisor and teams that were doing the translation.

3.4.3 Ethical considerations related to data collection

The Belmont Report, which outlines the ethical principles to be followed when conducting research that involves humans, requires that such research should adhere to three ethical principles: beneficence, justice and respect for human dignity (Polit & Beck 2012:1). The principle of beneficence imposes the need to be cautious and avoid any harm to the participants, whilst maximising benefits to them (Taylor 2019:8). Accordingly, the potential benefits to the individual and society should outweigh the potential risks to the individual participants. The principle of justice imposes an ethical obligation on the researcher to treat each person in accordance with what is right and proper. According to Taylor (2019:9), there are two ways of ensuring social justice, namely, by designing public health research to identify barriers, and by prioritising the public health needs of the most disadvantaged. This is in line with primarily distributive justice, whereby there is equitable distribution of both burdens and benefits to participants (Health Professions Council of South Africa 2016:3). The principle of respect for human dignity implies the right to full disclosure and self-determination. In this

regard, participants should be given the right to voluntarily take part and be given a full explanation of the study, objectives, and processes.

In this study, the researcher focused on participants from diverse language groups and ensured that potentially disadvantaged mothers were included in the study. The participants' privacy was respected throughout the study. Data collection was kept confidential, and upon completion of the study, computer files and any data collection forms containing study data will be safely stored and then destroyed after five years, as per UNISA policy. The researcher used this information from the participants to improve existing PMTCT interventions, whilst minimising any possibility of harm to the participants through accidental disclosure of their data. In order to mitigate any potential risk of disclosure due to use of translators, translators were asked to enter into confidentiality agreements with the researcher (see Annexure 7). Through the informed consent process, the participants were treated as autonomous and were given freedom of participation. Participants were not compensated other than by having their travel and lunch reimbursed, as per the district policy for face-to-face interviews.

3.4.4 Data analysis

A thematic data analysis was conducted to determine if the data told a convincing story that answered the research questions, as postulated by Braun, Clarke and Rance (2015:188). Neuendorf (2019) posits that thematic analysis assumes that the recorded messages themselves are the data, and codes are developed by the researcher during a close examination of the texts as salient themes emerge inductively from them. The researcher conducted a thematic analysis of the data using the process described by Braun and Clark (2006), whereby the data is coded and then closely reviewed to search for themes.

Reflexive Thematic Analysis needs to be implemented with theoretical knowingness and transparency where the researcher strives to be fully aware of the philosophical sensibility and theoretical assumptions informing their use of Thematic Analyses. During this coding process, the researcher found herself constantly questioning and querying the assumptions that she was making in interpreting and coding the data. Themes emerged from the analytic *outputs* developed through and from the coding. Themes reflected analysis that is *actively* created by the researcher at the intersection of data, analytic process, and subjectivity. This was to align the analysis with the statement by Nowell, Norris, White and Moules(2017),that a rigorous thematic analysis approach brings out insightful and trustworthy findings.

The study focused on making sense of the lived experiences of the mothers by using their feedback about what they know, feel, emotions they experienced and their experience in the PMTCT programme. The researchers' analysis was driven by the research question and was thus more top-down than bottom-up. Even though the researcher used a top-down approach, she reflected constantly on what the respondents said and what she observed during the interviews compared to her own experiences in the PMTCT programme to understand and enrich the findings

Looking back at the questions to be answered, the researcher started to look for themes from coded information and identifying which area of the interventions, systems and policy are the themes relating to, then a run through and taking out the weak thematic links was done. The researcher reviewed the transcribed data several times to immerse herself in the data collected and reflect on the themes (Dawadi 2020) and the themes were given headings with categories and finally a report was generated in relation to the thematic areas. Below are the steps followed in the analysis of the data:

Step one: **Getting familiar with the data**

The first step in any qualitative analysis is reading and re-reading the transcripts. The researcher ensured that the data collected is fully understood and internalised for it to make sense in answering the research questions. The researcher used the responses recorded, the notes on the questionnaire and on the diary book, read them and repeatedly looked at the questions topic it was meant to cover and listened to the recordings again to ensure that the data captured is addressing what was asked. The researcher made more notes, taking into consideration some noted gestures, emotion and recorded her own feelings regarding the information and the analysis. The researcher made notes in a different colour, capturing all interesting responses and information in a draft table with the questions and how each participant responded to it. As per Byrne`s (2021:1398) guidance the interviewer's and participant's inflections, breaks, pauses, tones, etc., were orthographically transcribed

Step two: Generate initial codes.

During the first step of data analysis, the researcher organized the data in a meaningful and systematic way to enable comparison with the research questions and how lived experiences of the women compared or contrasted to what the researcher knows and experienced in the PMTCT program. The transcriptions were read and reread to obtain chunks of meaning or

information of interest that related to the key research questions as well as the PMTCT guidelines. The approach was thus more theoretical rather than inductive. The researcher used an open coding process as she worked through the coding process. The researcher looked and listened to each data point and look up the relationship between the codes and grouped them into themes in the next step..

Step three: *developing themes*

As defined earlier, a theme is a pattern that captures something significant or interesting about the data and/or research question. As described by Braun and Clarke (2006) developing themes starts with a long list of codes that the researcher identified from the data set. This step then assisted the researcher to identify some patterns and relationships across the collected data as stated by Chamberlain (2015). This was the most challenging step in that the researcher had to read, reread, and compare some of the interesting pieces from the data set with what she read from literature reviews and came up with several themes which finally had to be refined to fewer themes.

Step four: examining prospective themes

During the review phase, the researcher modified and developed the preliminary themes that were identified in Step 3 to examine whether they made sense. Braun and Clarke (2006) suggests that the themes must be verified for differentiating them and checking if there is consistency in the themes. All the themes were re-evaluated to form one predominant theme where possible. The researcher read the data associated with each theme and considered whether the data really did support the research questions or whether it differed to the extent that a new theme had to be formulated considering our overarching framework, namely the PMTCT guidelines and research questions. A helpful framework of questions was taken from Moira Maguire & Brid Delahunt (2022): Do the themes make sense? Does the data support the themes? Am I trying to fit too much into a theme? If themes overlap, are they really separate themes? Are there themes within themes (subthemes)? Are there other themes within the data?

Step five: Identifying themes and giving them names

Themes were refined to '. identify the 'essence' of what each theme is about.'. (Braun & Clarke, 2006, p.92). The researcher was aiming ensuring that the themes that were refined actually tells the story of the lived experiences, each pinning a specific area that the question aimed to answer. The researcher then looked at inclusiveness and comprehensiveness of the thematic framework, with a potential interaction between the themes and how it related to the main theme .This emerged from those themes found to be common throughout the dataset. The researcher defined the themes and the sub theme which were later categorised. The dataset and goals of the study was then tabled according to each topic and subcategory. Names of themes were then clearer and were finalised, with thorough analysis of what the theme was saying. A high-level description of what participants stated, or an illustration of the data was then offered (Byrne 2022). The researcher also considered what has been considered as significant in the participants' statements and used the interpretation in the perspective of the existing body of literature. The researcher endeavored to ensure that the names of the topics are succinct, informative, and enduring as suggested by Byrne, (2021:1407)

Step six: **Writing up the results of the analysis.**

The results of the analysis were captured as results and presented as this report. Great effort was taken to provide a concise and coherent report on the findings using the themes. This is aimed at ensuring that the researcher is able to communicate the findings and point they make in an accurate and reliable manner.

3.5 RIGOUR OF THE STUDY

According to Morse (2015), rigour is defined as the measure of the strength of the research design and the appropriateness of the research methods for answering the questions and entails that the research be reliable and valid. Cypress (2017:257), on the other hand, defines rigour as "the quality or state of being very exact, careful, or with strict precision or the quality of being thorough and accurate". During the design and implementation of this study, the researcher ensured that all data was reliable and could be validated at any given time by peers.

3.5.1 Trustworthiness

Trustworthiness refers to the quality, authenticity, and truthfulness of the findings of qualitative research (Cypress 2017:258). Denzin and Lincoln (2018:1373) state that inter-rater reliability

is appropriate with semi-structured interviews, where all the participants have been asked the same questions, in the same order, and all data has been coded at once at the end of the data collection period. To ensure inter-rater reliability in this study, an interview schedule was developed to guide the individual interviews of the selected participants. The inter-rater reliability was ensured by asking the supervisor to check the categories and themes as well as consensus agreement with the independent coder as this would enhance transferability and consistency of the research. The researcher ensured trustworthiness by following similar processes and standards. Furthermore, trustworthiness was established by strengthening the credibility, dependability, confirmability, transferability, and authenticity of the study, as follows.

3.5.1.1 Credibility

Credibility is the assurance of the truth of the data and the interpretations thereof (Polit & Beck 2017:559; Loh 2013:5) and should be ensured during data collection and report writing. Credibility ensures that the study measures what it is intended to measure and that it is a true reflection of the social reality of the participants. In this study the researcher ensured that notes and voice recordings were used to compare the transcribed data and written report with the data sources. In this regard, the researcher avoided translating the participants' statements into what sounded like her own understanding. The use of a translator also enhanced credibility. In addition, the researcher's notes and a reflective journal were used to cross-check the transcribed data with the digital recordings.

3.5.1.2 Dependability

The findings of an inquiry should be repeatable for them to be considered dependable (Polit & Beck 2017:564). Dependability requires that the data and reports remain consistent when a similar study is conducted with similar participants. During the interviews, the researcher ensured that the participants understood the importance of sharing their lived experiences and asked relevant questions that sought to answer the research questions. Dependability requires that the research process be described in sufficient detail to enable another researcher to repeat the work. A detailed audit trail was ensured in this regard. An audit trail is a collection of documents that would allow an independent coder to reach the same conclusions about the data (Polit & Beck 2017:564). The supervisor and an independent coder assisted in reviewing the transcribed and categorised material.

3.5.1.3 Confirmability

Confirmability refers to minimising investigator bias by acknowledging a researcher's predispositions (Polit & Beck 2017:567), and by ensuring objective reporting (i.e., making sure that the data reported by the researcher is what the participants reported). The researcher avoided applying her own bias, motivations and perspectives to this study, and the study findings reflect the participants' voices and their lived experiences of the implementation of the PMTCT programme. The researcher kept notes and documented her introspections daily on aspects that would be beneficial and pertinent during the study.

3.5.1.4 Transferability

Transferability refers to the ability of the findings to be transferred to other settings or contexts. Qualitative research is said to be specific to a particular context, and thus a "thick" description of the research context must be provided to enable the reader to assess whether it is transferrable or not (Polit & Beck 2017). In this study, transferability was enhanced by using a purposive sampling method, by providing a "thick" description, and by generating robust data with a wide range of information through the detailed and accurate descriptions of the participants, and by continuously returning to the texts generated by these descriptions. After the data was coded and the researcher was able to make sense of the transcribed data, all efforts were exhausted to illuminate themes associated with the barriers to PMTCT experienced by the participants.

3.5.1.5 Authenticity

Authenticity refers to the extent to which a researcher engages with a range of realities in an honest, faithful, and fair manner (Polit & Beck 2017). This was achieved by preserving the tone of the participants' lived experiences, with an emphasis on their mood and feelings. The researcher therefore used verbatim quotes from the participants when reporting the data. The researcher also selected a diverse sample of participants to ensure authenticity. In order to mitigate any potential risk of disclosure due to use of translators, translators were asked to enter into confidentiality agreements with the researcher (see Annexure 7).

3.6 CHAPTER SUMMARY

Chapter 3 has mapped out the selected research design and methods employed in this descriptive, phenomenological qualitative study which aimed to explore the barriers to EMTCT experienced by HIV-positive mothers in Ehlanzeni, Mpumalanga, whose infants seroconverted during the first two years of their lives. The research setting and strategy for sampling the 13 participants were described, after which the procedures for data collection and analysis were explained. The procedures for the face-to-face, in-depth interviews were explained, as was the process of thematic data analysis. This chapter has also presented the ethical considerations that were taken into account by the researcher, as well as measures that were taken by the researcher to strengthen the trustworthiness of the study findings.

Chapter 4 presents, analyses, and describes the study findings.

CHAPTER 4
PRESENTATION, ANALYSIS AND DESCRIPTION OF THE STUDY FINDINGS

4.1 INTRODUCTION

Chapter 3 presented the research design and methods used to collect data from the 13 mothers from five health care facilities in Ehlanzeni district, who met the criteria set for participation in this study. In this chapter, the findings of the study are presented. The purpose of the study was to investigate HIV-positive mothers' experiences of the barriers to the EMTCT of HIV in Ehlanzeni, Mpumalanga province. These mothers were aged 18 and above, and their infants, who were 18–24 months old, had seroconverted after a negative birth PCR test.

The researcher used an interview schedule to guide the in-depth interviews with open ended questions to collect the data from the 13 participants. This interview schedule consisted of the following four sections:

- Participant biographical and demographic data
- PMTCT Programme implementation
- Perceived barriers to e-MTCT
- Recommendations for improvement of e-MTCT.

4.2 DATA MANAGEMENT AND ANALYSIS

Scrutinising and making statements out of data by logically organising it, is defined by Polit and Beck as managing and analysing the research data (2017:725). Analysis follows a process where information is collected and properly saved to avoid breach of confidentiality and loss before it is analysed to provide a reflection or story about the subject studied.

The data from this study was analysed after the transcription of interviews using descriptive, qualitative approaches. A reflective journal was also kept capturing the insights from each participant. While the researcher had planned to interview ten participants, data saturation was reached with the thirteenth participant, according to Hancock, Amankwaa, Revell and Mueller's (2016) explanation that thematic saturation is reached when no new information is noted in the responses.

The participants were located at five high-volume health care facilities in the district. Throughout the study, the researcher ensured the confidentiality of the participants by keeping audio recordings and field notes locked safely in a briefcase. The recordings were saved as password-protected electronic files to ensure that no one could access them. The recordings were transcribed verbatim, and the researcher ensured that the verbatim transcripts were correctly and accurately captured before analysis. This involved repeated reading and analysis of the transcriptions of the audio recordings of the participants' responses as documented in the themes and categories in Table 4.2 below.

4.3 BIOGRAPHICAL AND DEMOGRAPHIC DATA

Table 4.1 below presents the biographical and demographic data of the participants.

Table 4.1: Biographical and demographic data

BIOGRAPHICAL/ DEMOGRAPHIC	CATEGORIES	PARTICIPANTS #	PARTICIPANTS %
AGE (YEARS)	18–24	4	31
	25–30	5	38
	31–35	4	31
NATIONALITY	South Africans	9	69
	Non-South Africans	4	31
RACE	Black (African)	13	100
	Indians	0	0
	Coloured	0	0
	White	0	0
MARITAL STATUS	Married	1	8
	Single	11	84
	Divorced	1	8
FEEDING	Breastfeeding from birth	13	100
HIGHEST EDUCATION LEVEL	Tertiary	2	15
	High School	10	77
	Primary School	1	8
	No formal schooling	0	0
EMPLOYMENT STATUS	Employed	4	31
	Self-employed	0	0

	Unemployed	9	69
PARITY	1 pregnancy	3	23
	2 pregnancies	7	54
	3 and more pregnancies	3	23
CURRENT SEXUAL PARTNERS	0	03	23
	1	10	77
	2	0	0
	3 and more	0	0
YEARS OF HIV-POSITIVE STATUS	<1	3	23
	1–2	6	46
	2–3	2	15
	3–4	0	0
	>4	2	15

Table 4.1 shows that the age distribution of the participants ranged from 18 to 35 years. In practice, only black African women participated because of the location of the study and based on the actual PCR test results that were found to be positive. Most of the participants were single or cohabitating with a partner, and many of the participants had reached some form of higher basic education level.

In this study, the age distribution of the study participants showed that four were aged 18–24, five were aged 25–30, and four were aged 31–35. Most of the participants (84%) were single at the time of the interview. A total of 10 participants had reached high school, with two (15%) having reached tertiary level education. Nine of the thirteen participants were unemployed, while four were employed. Seven participants had been pregnant twice, while three had been pregnant once, and three had been pregnant three or more times. While ten participants claimed to have only one sexual partner, further probing revealed that some had changed sexual partners more than once. Some had babies from different partners.

Regarding the point at which the participants had been diagnosed HIV positive, the study found that nine of them had been diagnosed for the first time during their last pregnancy when they presented for ANC, while a few had been diagnosed HIV positive already when they fell pregnant. One participant was born HIV positive. Four of the nine participants presented for ANC after four months of pregnancy.

4.4 STUDY FINDINGS

The thematic analysis of the study findings revealed five themes, namely: (i) access to PMTCT services, (ii) disclosure and support, (iii) sexual and reproductive health, (iv) participants' knowledge on risks to MTCT, and (v) proposed improvements to the EMTCT programme. These themes are summarised in Table 4.2 below.

Table 4.2: Themes and subthemes

Themes	**Categories**	**Subcategories**
Theme 1: Access to PMTCT services	1. Challenges experienced during PMTCT utilisation	1.1. Access to PMTCT information 1.2. Information on the prevention of transmissible diseases 1.3 Acceptable access to facilities
	2. Provision of appropriate HIV treatment, care, and support	2.1 Early initiation of HIV-positive mothers on ART 2.2. Availability of drugs and lab services
Theme 2: Disclosure and support	1. Acceptance and disclosure of HIV status to significant others	1.1 Partner attitude and support 1.2 Family attitude and support 1.3 Community attitude and support
	2. Psychosocial support	
	3. Socio-economic Status	
Theme 3: Sexual and reproductive health	1. Knowledge and attitudes towards sexual and reproductive health	1.1 Prevention of unwanted pregnancies amongst HIV-positive women 1.2 Prevention of STIs and condom use 1.3 The right to know sexual partner's HIV status
Theme 4: Knowledge of the risks of MTCT	1. Infection of infants 2. Breastfeeding	

	3. Adherence to antiretroviral treatment	
Theme 5: Proposed improvements to the EMTCT programme	1.Quality of eMTCT programme	1.1the health care system, 1.2. the health care staff, 1.3.the health care users.

4.4.1 Theme 1: Access to PMTCT services

This theme emerged as participants explained their experiences with using the PMTCT services. Their experiences were compared with the ideal approach outlined in the SANDoH's *Guidelines for the prevention of mother to child transmission of communicable infections* (SANDoH 2019:16), which outlines the standards and procedures for managing women booking ANC and accessing maternal health services.

All 13 of the participants attested to having had access to ANC and PMTCT services, although only three participants were aware of the PMTCT programme and its benefits. This theme in the data analysis was related to the service delivery of PMTCT, which is guided by the four pillars of PMTCT, namely, primary 1) prevention of HIV infection, 2) prevention of unintended pregnancies among women living with HIV, 3) prevention of HIV transmission from infected women to their infants, and 4) treatment, care and support of HIV-infected women, their infants, and their families (SANDoH 2019).

The researcher further identified several categories and subcategories from the theme, which are described below. The participants' responses provide insight into possible missing links in the PMTCT cascade of services aimed at ensuring the continuum of care and the EMTCT of HIV.

4.4.1.1 Category 1: Challenges experienced during PMTCT utilisation

The participants reported experiencing challenges with accessing PMTCT services and with accessing information related to the four pillars of PMTCT. The researcher identified three subcategories from the participants' responses: 1) access to quality PMTCT information, 2) information on prevention of transmittable diseases, and 3) acceptable access to facilities. These categories related to the participants' ability to access services and to access the required health care education. These are both crucial elements in ensuring that empowered HIV-positive mothers are ready to take measures to ensure EMTCT, a gap yet to be filled in our health care facilities.

4.4.1.1.1 Subcategory 1.1: Access to PMTCT information

The participants reported that they were not fully empowered with information relating to the four pillars of PMTCT. Access can be interpreted in many ways. The researcher understood access to be the ability to gain entry, information, services, and benefits from health care services. For this study, access refers to the availability and acceptability of a total health care package in maternal health, including a comprehensive PMTCT package, as indicated in the four pillars of PMTCT (SANDoH 2019).

All 13 participants in this study attended ANC and were offered PMTCT services, but the researcher observed that the participants were not offered the expected quality of services, indicating a gap in access. There seemed to be poor education of the mothers on the topics of labour and delivery during their visits to the ANC clinics, which compromised their ability to take full responsibility for their infants' care throughout the PMTCT cascade. As many as ten of the participants explained that they had not been aware of and had not heard of the term "PMTCT", despite interacting several times with the clinic personnel. This could be seen in statements from three of the participants:

> ***Participant KNZ01:*** *"I have never heard of the word PMTCT."*
> ***Participant NEL01:*** *"I am hearing for the first time about PMTCT."*
> ***Participant MSG01:*** "*I do not know about PMTCT but have often heard nurses talking about it."*

These responses indicated that the participants had poor access to the comprehensive PMTCT package, which involves the education and empowerment of women during

interaction with health care workers. It was evident that these mothers did not have access to comprehensive information that was crucial to the outcomes of their pregnancies and to the EMTCT, as HIV-positive mothers are expected to ensure that they adhere to and comply with specific health care advice on feeding and medication until their infant is tested for HIV after the cessation of breastfeeding.

Another participant stated:

> ***Participant KAB003:*** *"I do not know what PMTCT is about. I was never told about it. I have been testing negative all along during my pregnancy, but when I was eight months pregnant, I tested positive. I was initiated on ART immediately, which I continued taking until I delivered. My baby was also found to be positive for HIV both at birth and at 10 weeks. He was also started on treatment.*"

This participant's statement clearly shows that whilst mothers attended the ANC clinic and obtained health care services, it did not mean that they were empowered or educated about PMTCT and the risks thereof. The researcher believes that had these mothers been properly made to understand their HIV status and the risk to their infants from ANC all through breastfeeding, they would have taken precautions to ensure that their infants did not seroconvert. The four pillars for PMTCT, as stated by the WHO (SANDoH 2019), were not enforced to ensure EMTCT.

Poor access to information was also a feature of the second sub-category in this category: information on the prevention of transmittable diseases.

4.2.1.1.2 Subcategory 1.2: Information on the prevention of transmissible diseases

The participants reported varying levels of information on the prevention of transmissible diseases, with most showing a poor level of understanding. One key type of information mothers should receive when receiving maternal and PMTCT services is about the prevention of transmissible diseases. The researcher established that the participants had not been provided with adequate information that enabled them to understand transmissible infections and how to prevent them, as emphasised in the third pillar of PMTCT and the application of the U=U principle.

From the participants' responses, it was observed that many of them were aware that STIs must be prevented to avoid infection and harm to their babies during pregnancy, but that their understanding was not good enough for them to apply the expected prevention measures. During their ANC visits, most participants admitted that they had heard about the transmission of HIV to the infant, and that its prevention included taking ART regularly (both mother and infant), avoiding breastfeeding (which may be misinformation), and using a condom when having sex, but the messages seem to have not been understood in the PMTCT context, where the mothers were key role players in ensuring EMTCT.

It also appeared as if the participants' knowledge of STIs had not only been obtained from the ANC/PMTCT health education sessions, but from other media as well. Not all pregnant women are thoroughly taught about the sexual transmission of STIs and their effects on their unborn baby, including syphilis. The participants were also not given proper health education on prevention of these transmissible diseases and the risks in pregnancy and breastfeeding. One participant highlighted:

> ***Participant KNZ2:*** *"Although the clinic staff did not teach me about primary prevention of transmittable diseases when I tested positive, that I must use condoms to protect myself from sexually transmitted infections. Both my partner and I should use condoms."*

Another two participants mentioned:

> ***Participant MSG02:*** *"As far as transmissible diseases are concerned, I know about HIV, TB, chickenpox, and corona."*

> ***Participant KAB01:*** *"I am aware of STIs and HIV. I was taught about these at the primary school level when we were also advised on safe sex."*

The first pillar for the prevention of transmissible diseases from mother to child (SANDoH 2019:2) requires that health care providers empower women of childbearing age at each engagement to protect and prevent them from getting infections, especially sexually transmitted infections. This can only be achieved through quality health education and patient engagement by the health care providers. 11 of the participants were either HIV negative or had an unknown HIV status during their first ANC appointment, which should have prompted

an emphasis on prevention interventions and the risks of new HIV diagnosis to their unborn baby or infants, due to the high viral load.

4.2.1.1.3 Subcategory 1.3: Acceptable access to facilities

Five of the 13 participants indicated that they experienced poor access to the PMTCT services due to the health care workers' attitude. This is a major challenge to quality maternal care and PMTCT, as it hampers acceptable, available, and user-friendly services, creating a barrier for mothers who should have full access to comprehensive and quality health care.

Furthermore, the researcher noted that of the remaining eight participants, three had booked ANC appointments after seven months of pregnancy, while the remaining five had booked within the expected BANC period. Late ANC appointments affect early testing, early viral load testing, and the initiation of the mothers onto ART to ensure viral suppression and reduce the risk of HIV transmission. The South African PMTCT guidelines require that mothers return to the health care facility for follow-up visits and to monitor their infants' health, including PCR testing. However, poor access due to the non-caring attitudes of health care professionals is a barrier to free and acceptable access to health care services. In an article titled "Accelerating progress towards the elimination of mother-to-child transmission of HIV: a narrative review", Chi, Mbori-Ngacha, Essajee, Mofenson, Tsiouris, Mahy and Luo (2020) recommended timely engagement with ANC, access to HIV testing and ART, retention of care, and adherence support as interventions for accelerating progress towards EMTCT.

However, the participants in this study were not afforded these interventions. Three participants experienced negative staff attitudes as a result of being foreign nationals, booking ANC late, or not being consistent with PMTCT services utilization.

Participant KNZ03 sadly said:

> *''I arrived in South Africa from Mozambique in 2009. Ever since I started HIV treatment, all has been well except for negative attitudes by the clinic nurses to us foreigners. We are called all sorts of names and scolded, even suggestions that we have brought HIV*

to this country. This has resulted in most of us fearing to go to the clinic because of these attitudes. We have come to accept this state of affairs, none the less."

Participant MSG01 also stated:

"*When I tested positive, I was advised to start ART. But because they were about to close, I was asked if I was breastfeeding my baby and I said yes. They told me to stop breastfeeding and to bring the baby for testing the following day. The child tested positive and was put on treatment immediately. We are both taking treatment even now."*

Participant KNZ04 explained receiving harsh treatment:

"Well, according to myself, I have received seriously harsh treatment from the clinic that I can criticize, as such, but in general, I think counselling could be improved where this is offered to the person who has just received the test results. Sympathy and kindness are also necessary from the health care worker (HCW) …. [silence]. Although the clinic staff tried to assist me by contacting my husband to agree to test and know his status; he refused, more effort is needed in this regard."

4.4.1.2 Category 2: Provision of appropriate HIV treatment, care, and support

The participants reported that they had received appropriate HIV treatment in that they were initiated on ART as soon as they tested positive. However, they were very vocal about the lack of care and support they had received in relation to other aspects of HIV care, which the researcher also noted from their narratives.

HIV care and treatment is the cornerstone of controlling the HIV epidemic. The PMTCT programme evolved from a single dose NVP intervention in its early implementation phases to the current efficacious regimens. Initiating and keeping HIV-positive mothers on HIV treatment, from ANC until after the cessation of breastfeeding, are key interventions in achieving EMTCT. As seen in the countries where MTCT of HIV has been declared eliminated (such as Cuba, Belarus and Thailand), identifying HIV-positive mothers early, putting them on treatment early, and supporting them to remain on treatment for viral suppression was pivotal in achieving EMTCT.

The findings of this study in this regard were, firstly, that the participants were initiated on treatment, with only two of the 13 having had a delayed start on treatment due to problems in the health system where clinics ran out of drugs and patients had to return for their medication. One participant expressed this as follows:

> ***Participant KNZ03:*** *"... Although we get our treatment regularly from the clinic, it does happen now and then that treatment is out of stock, and we have to return after some time to get it. This is quite common where I have to fetch treatment in the middle of the month."*

Secondly, participants who had no access to refrigerators struggled to store their medication (especially paediatric preparations) at the right temperature. One single and unemployed mother said:

> ***Participant MSG02:*** *"In terms of support from the clinic during my visits, I think all was well and I was treated well. The only challenge that I had regarding the baby's medication was that I was to keep it in the fridge, which I did, but the nurses blamed me for not doing so when the condition of the baby changed resulting in his death at home. I informed the clinic about the death of my baby."*

Another key barrier to EMTCT identified in all the interviews was that no evidence of viral load monitoring and support could be obtained from any participant, despite their initiation on ART and the repeated provision of treatment during their visits. Some of the health care providers would provide support beyond testing and handing out ART, while most had no time to treat the patients holistically. When asked about the support she received during the time she was accessing PMTCT services, one of the participants said:

> ***Participant KNZ02:*** *"When I was found to be HIV positive, I was just put on treatment. I was not informed of a programme."*

The researcher is of the opinion that ideal PMTCT services should entail proper education of a client on ART, the benefits, why they need to adhere to it, and the use of combination prevention. The participants' responses clearly illustrated that this is not happening in our PMTCT services. In general terms, most of the participants expressed some form of support by the clinic antenatally, during delivery and one after delivery. The researcher noticed, however, that the positive responses were from participants at one health care facility, whilst

the negative responses were from participants from the other facilities. At the one positive facility, several participants shared the following sentiment:

> ***Participant NEL01:*** *"Our relationship with the clinic and clinic staff is acceptable. When I started attending ANC and throughout that period, I received good support from the clinic."*

EMTCT is anchored in the fourth pillar of PMTCT (SANDoH 2019), which requires that any woman testing positive for HIV should be initiated on treatment and remain on treatment for viral suppression for life. Chi et al (2020) recommended timely engagement with ANC services, access to HIV testing and ART, retention to care, and adherence support as interventions.

4.4.1.2.1 Subcategory 2.1: Early initiation of HIV-positive mothers on ART

The researcher noted from the participants' responses that eleven out of the thirteen participants had received treatment immediately after testing HIV positive. It is common knowledge that when taking ART, the ARVs pass from mother to infant across the placenta during delivery, thus preventing perinatal transmission of HIV. To reduce MTCT of HIV, therefore, women who are already on ARVs before labour should continue taking their medication regularly, including during childbirth itself and the postnatal breastfeeding period (National Institutes of Health: Office of AIDS Research 2021). Another complementary practice to initiating pregnant HIV-positive mothers on ART is constant and regular monitoring of their viral load and adherence to treatment through ANC.

The researcher found that ART initiation had been implemented as per the South African PMTCT guidelines for those participants who had sought ANC, with only two out of the 13 indicating that their treatment had not been initiated immediately:

> ***Participant KNZ03:*** *"Yes. My children and I were put on treatment, and we continue to get our treatment from the clinic. Apart from the insults about me being a foreigner, there is nothing negative to report."*

Participants at all five of the sites had positive responses concerning the initiation of their HIV treatment, indicating that there is better enforcement of policy and guidelines at the initial point of treatment where the patient is started on ART, but this does not answer the question of why

their infants had still seroconverted along the treatment cascade. This is emphasised by the responses below from two of the participants:

> ***Participant KNZ02:*** *"When I was initially diagnosed as HIV positive and was put on treatment, I felt awfully bad from knowing that I had HIV. However, ever since I started treatment, all has been well. When I started ANC for my second pregnancy, I was again tested for HIV and advised on how to take care of myself during the pregnancy. They emphasized that I take my treatment regularly to protect my baby. They further advised that once the baby is born, I should breastfeed for six weeks only."*
>
> ***Participant KAB03:*** *"When I presented to the clinic four months pregnant, I was tested and found to be HIV positive. I was put on treatment again. I took my treatment regularly during pregnancy until I delivered my baby at nine months on 03/03/2021. After delivering the child at the hospital, my child was not given Nevirapine. I was discharged and I started breastfeeding my baby. The baby was given Nevirapine during my second visit when my baby was six weeks old. I stopped breastfeeding and Nevirapine at four months because I had to return to work. My baby tested negative at two months and again at six months. Also, when the child was admitted to the hospital, he was tested for HIV and found to be HIV-negative. However, when the child was again tested this year (2022) in March when he was one year old, he tested positive".*

The researcher gathered from the participants' statements above that health care professionals do not always implement the prescribed guidelines after initiation of treatment, shown by them testing a woman who was already HIV positive and had been in the PMTCT programme since her initial pregnancy. No viral load or other required tests were administered, and the participant was put on basic treatment. In both cases the health care providers did not assess the patients' responses to the treatment, including viral suppression, which is an omission that can lead to treatment failure. While the researcher understands and appreciates that the health care providers adhered to the policy on initiating HIV-positive pregnant mothers on ART, follow-up treatment after initiation, as well as education of the mothers, fell short. Nine of the 13 mothers displayed a consistent lack of knowledge and understanding of why they were supposed to take the treatment as prescribed. Most of them did not know the treatment by name, and did not seem to understand that they were expected to take the ART daily with no interruption so that they could be virally suppressed.

4.4.1.2.2 Subcategory 2.2: Availability of drugs and laboratory services

The consistent availability of ARVs and laboratory services is very important for EMTCT, because of the need for viral suppression for better maternal and child health outcomes. The researcher, however, noticed from the participants that due to the health care staff being overburdened, there was a lack of oversight on policy and guidelines, and poor accountability and adherence to operability standards, which resulted in some patients often not even being informed that they should adhere to ART.

Regarding the availability of drugs and laboratory services, positive responses from the participants indicated that they were available. **Participant KNZ03** said, "*Yes. Both of us were put on treatment immediately after we tested positive*" while **Participant TEK01** said, "*My baby and I are still in treatment*". **Participant NEL01** said, "*While we waited for the HIV test results shortly after delivery, the baby was issued two bottles of HIV medication"*.

Only three out of the 13 participants experienced situations where the drugs were out of stock and they were required to come back for their supplies, as indicated by one of the participants:

> **Participant KNZ03:** *"All of us who have tested positive are taking ART. Although we get our treatment regularly from the clinic, it does happen now and then that treatment is out of stock, and we have to return after some time to get it. This is quite common where I have to fetch treatment in the middle of the month."*

The findings in this regard were that the participants reported that drugs and laboratory testing were generally available, with only two out of the 13 participants having had a delayed start on treatment due to health system issues, one having to come back for supplies in the middle of the month due to no drugs at the facility.

However, participants who had no access to refrigerators struggled to store their medication (especially paediatric preparations) at the right temperature. One single, unemployed mother said:

> ***Participant MSG02:*** *"In terms of support from the clinic during my visits, I think all was well and I was treated well. The only challenge that I had regarding the baby's medication was that I was to keep it in the fridge … but the nurses blamed me when the condition of my baby changed …"*

4.4.2 Theme 2: Experience with disclosure and support

4.4.2.1 Category 1: Acceptance and disclosure of HIV status to significant others

Disclosing their HIV status to their significant others is crucial for ensuring HIV positive people's adherence to treatment and for eliciting support. Several studies have shown that viral suppression and better health outcomes are reliant on adherence, which is in turn reliant on psychosocial support and patient acceptance of their HIV status. Three different types of disclosure could be discerned in the participants' responses, namely disclosure to a partner, disclosure to family members, and lastly disclosure to the community. These three categories of people offer different forms of psychosocial support. This observation was supported by Adeniyi, Nwogwugwu, Ajayi and Lambert (2021), who concluded that complicated relationship dynamics and fear of social exclusion still create barriers to HIV status disclosure, in spite of patient counselling.

All of the participants in this study had disclosed their HIV status to someone, but had reasons for keeping their status a secret from certain people. For example, the researcher found that six of the 13 participants could not disclose their HIV status to new partners for fear of rejection and loss of financial support. A 27-year-old, unemployed participant with two children related the following:

> ***Participant KNZ02:*** *"After being diagnosed as HIV positive, I informed my partner, but he did not take me seriously up to now. I also informed other members of the family about my status, and they accepted the situation. However, my partner's family blamed me saying I am the one who has come with the disease, they were pushing him to chase me away!"*

The researcher noted that participants still felt depressed about having tested positive, as noted below:

> **Participant KNZ02*:*** *"It was heart breaking to learn that I was HIV positive.*
> *"I informed my partner about my status; however, he refused to go and test and is not on any treatment currently. We have since stopped our affair with the baby's father. He is only paying for support at the moment."*

Seven of the participants reported that their partners had not been supportive or cooperative when the participants disclosed their HIV status. Some relationships were destroyed by the disclosure, which led the researcher to conclude that acceptance or lack of acceptance has implications for whether mothers disclose their status, which has an additional influence on their adherence to treatment and their compliance with the PMTCT cascade.

One participant attested:

> ***Participant KNZ03: "…*** *my current partner is well. We went to test, and he tested negative. We had to stop our relationship because of disagreements about safe sex."*

The issues of disclosure and adherence to treatment were reflected in the fact that most of the participants indicated that they were single, unemployed and had a new partner. One participant sadly stated:

> ***Participant MSG 01: "****When I tested positive, I informed my first boyfriend, but he continued to have many girlfriends, which resulted in us stopping our relationship when our child was four months. He took no responsibility for the infection. He refused to go and test for HIV****."***

Another participant said:

> ***Participant KNZ02: "****He initially did not believe the story first but later accepted the situation. He was found to be positive for HIV and was put on treatment. We are continuing with treatment as we speak."*

The researcher noted that most of the participants had accepted their HIV status and were keen to disclose their status to their partners. However, this openness was often not reciprocated by their partners, leading some participants to withhold their status due to fact that their partners did not want to discuss testing and knowing their HIV status. This finding aligned with Thomson et al's (2018) recommendation that in order to overcome gaps in PMTCT, to improve uptake of care and retention in care, and to optimise the HIV-prevention benefit, the involvement of male partners should be part of the PMTCT interventions.

4.4.2.1.1 Subcategory 1.1: Partner attitude and support

Ten of the 13 participants had informed their partners of their HIV status. The reactions of those partners included initial denial, agreement to HIV testing and treatment, refusal to take treatment, and the breaking down of the relationship. Three of the 13 participants admitted that they were scared to disclose their HIV-positive status to their partners for fear of rejection, and seven of the 13 participants reported that their partners had been uncooperative when told about their HIV status.

Partner involvement and support for HIV-positive and breastfeeding mothers plays a pivotal role in maternal and child health outcomes, and especially in PMTCT. A report by The New Humanitarian (2012) found that male partner involvement in PMTCT may reduce the risk of MTCT by more than 40%. In this study, partner support was found to be lacking, despite the participants having disclosed their status, and participants often reported a negative attitude on the part of their male partners, as shown by the following participant:

> ***Participant MSG02:*** *"I never informed my boyfriend of my status. This is because we are not living a normal life in the house. He wakes up early in the morning, goes to work and comes back extremely late in the evening. We do not have time to discuss issues that relate to our family. He spends most of his time with friends and spends his money with them. He is drunk most of the time and sleeps out during weekends. I have therefore not found time to sit him down and tell him about my situation. A possible contributing factor to this is the fact that the first four children are not my current boyfriends' but are from my former boyfriend. Secondly, when we met with my current boyfriend, I invited him to come over and stay with us. Despite all this, he appears to be comfortable with having my other children around. However, he does not share his income with me and the children. We survive on the grant for the children. As far as my relationship with the community I live in I have no problems. The only person I informed about my status is one elderly lady whom I confide in."*

A participant who explained why mothers still do not feel comfortable with disclosure to certain family members or relatives alluded to the following:

> ***Participant KNZ02:*** *"While I do not fear any stigma about my condition, I normally do not tell other people about my life. Life between myself and my partner continues normally, and we use condoms for safe sex. My in-laws do not know about our situation*

yet. My partner is reluctant to tell them for fear of stigmatisation. Once a person knows about your status, he is likely to divulge this when you clash over something."

The fear of being stigmatised and labelled is a barrier to HIV-mothers' efforts to live a positive, health-seeking life and ensure that their infants are not infected. This can be achieved through viral suppression, as supported by UNAIDS U=U, which lessens the risk of infections.

4.4.2.1.2 Subcategory 1.2: Family attitude and support

Eight of the 13 participants had informed some of their family members about their status, and the reactions they had received were mostly supportive. The researcher noted that family attitude could have a negative impact on treatment adherence, as some of the participants clearly did not want certain family members to know their HIV-positive status. Four of the participants could not inform their family members for various reasons, including stigma.

Family, whether the relationship is close or distant, is a known system of support and socialisation. The researcher found that a supportive family served as a pillar of strength and confidence for the HIV-positive mothers, who in most cases required financial, social, and psychological family support. In this study, the researcher found that ten of the 13 participants had disclosed their status to either a close or distant family member and had received varying levels of support. Some of the participants said*:*

> ***Participant KAB02:*** *"After finding out that I was HIV positive, I returned home and told my mother about it. The response from my mother was that I continue with treatment as advised. On the side of my family, it is only my mother who knows my status and not my brothers because they have their own families now. I could not tell them about my condition."*

A 30-year-old participant whose partner later died, said:

> ***Participant KNZ04:*** *"Within my family, I never disclosed my status to my family up to now. However, I did tell my sister-in-law who assisted me and advised me on how to deal with the situation, she is the one who advised me to continue talking to my boyfriend to force him to go and test. No members of my immediate community are aware of my status."*

The researcher noted that the negative reactions and statements of some family members affected the participants' adherence to treatment. A depressed 22-year-old mother, who had been born HIV positive in the year 2000, had been orphaned by HIV, and did not look healthy said:

> ***Participant KAB03:*** ***"****I defaulted treatment because my grandmother was going around telling people that I am HIV positive and taking ARVs. When I fell pregnant, I was started on treatment again at four months of gestation.****"***

4.4.2.1.3 Subcategory 2.3: Community attitude and support

Some of the participants reported that disclosure to their community was less problematic than disclosure to their partners or families because the community as a whole was equally affected by HIV, while others felt that avoiding social stigma by keeping their status to themselves was best for them. Almost half of the participants seven of the 13, did not divulge their status for fear of stigma, and only six of the 13 participants divulged their status to the community. Disclosure to the community did not therefore happen very often, as shown in the following excerpts:

> ***Participant MSG03:*** *"The community we live in, is not aware of our HIV status. HIV is common in the community with community members talking loosely about it. Stigma is not a problem."*

A single mother from Maputo said:

> ***Participant NEL01:*** "*I have no challenges with the community I live in because they do not know about my situation.*"

The participants' responses in relation to disclosure of their status to their partners, family and community, and the resulting acceptance or lack of acceptance, revealed that they disclosed their HIV-positive status to these groups of people only when it was necessary to do so, and emphasised the importance of confidentiality. It was clear that some family members who they should have been able to consider part of their support system, were not supportive, and the participants were not comfortable with disclosing their HIV status to them. This situation sometimes led to the participants' defaulting on their treatment, and implementing incorrect and harmful practices with their infants, such as breastfeeding. Although there is a perception that there is no longer stigmatisation around HIV in the community, it was clear from the

participants' responses that they did not possess enough confidence to disclose their HIV status to their communities.

4.4.2.2 Category 2: Psychosocial support

The participants reported that they did not receive psychosocial support. They were placed on ART with no support, even during follow-up visits. Physical, psychological, economic, and social support are required for better health care outcomes, especially for PLHIV as they may require psychosocial support to live positively. Nine of the 13 participants indicated that they had received health care support, even though it was not optimal, but no psychological counselling or support during follow-up visits during the treatment period was provided. Poor support of HIV-positive mothers can lead to them experiencing a psychological burden, and to them not being keen to openly discuss their status. A clearly shy mother responded:

> **Participant KNZ04:** *"Whenever I visit the clinic, the attitude is strictly professional where I am here to pick up my treatment and the nurse gives me what I have come for. There is no support talk from the nurses. The only kind nurse is the one who gave me my results."*

A lack of psychosocial support has implications for the PMTCT programme, as it can become a major barrier to implementation. This was clearly shown in the following statement from a mother who believed that her infant may not be positive, as she did everything according to the guidance provided. This mother was not provided with psychological support and was still in pain from learning about her child's HIV seroconversion. She explained:

> ***Participant KAB04****: "I am 28 years old, single, educated up to tertiary level (Auxiliary Nurse) and employed. I have had one pregnancy. I have one sexual partner. I was diagnosed HIV positive when my daughter was 1 year 6 months on the 2nd of June 2021. The whole thing is still confusing to me: I started ANC early (3 months), I was checked as usual and everything was fine, I tested negative. After the delivery of my baby, I tested negative. My baby was tested and found to be positive at birth. I continued testing after three months and still negative. My infant tested negative at 12 months. At one year six months, my baby tested positive again. I was taught about the PMTCT programme during my first ANC visit."*

The researcher reported earlier that three of the participants were from Mozambique, and that language differences created a barrier between them and the clinic personnel. This negatively affected their understanding of what PMTCT is, as the nurses were unable to teach them effectively about the programme and provide psychosocial support. The clinics did not have interpreters on site.

4.4.2.3 Category 3: Socio-economic status

As reported in the biographical and demographic data in section 4.3, the majority of the participants, nine of the 13, reported that they were unemployed and struggled to make a living. Only two of the participants had ever been married, and one of these participants was divorced. 11 of the 13 participants were therefore single and had changed partners more than once. In addition, only two of the participants had received a tertiary education. The participants' unemployment status, marital status, and level of education therefore indicated their poor socio-economic status.

Three of the participants were foreign (Mozambican) nationals who had come to SA with their partners, who were either farm workers or did odd jobs. Some of the participants also had unemployed partners. One of the participants was aged 31, unemployed, had six children alive after seven pregnancies, and cohabitated with an unemployed, heavy drinking partner. She shared that she had not divulged her status to her partner, and did not take treatment openly, as she did not have a good relationship with this partner. They survived on the social grants they received for their children, and she suggested that that was why she had had more than two children despite her being HIV positive. This example showed clearly how socio-economic status had an impact on sexual reproductive health and MTCT, as discussed under the next theme.

4.4.3 Theme 3: Sexual and reproductive health

4.4.3.1 Knowledge and attitudes towards sexual and reproductive health

4.4.3.1.1 Category 1: Prevention of unwanted pregnancies amongst HIV-positive women

The second pillar of PMTCT requires that unplanned and unwanted pregnancies be prevented in HIV-positive women of child-bearing age. This is in line with the support for integration of HIV into sexual and reproductive health rights (SRHR). The study found that the participants

had knowledge and insight into family planning methods but were not able to integrate this knowledge with their HIV status, namely, knowing their status, knowing their viral load, and knowing that this load should be suppressed before falling pregnant, through using condoms and adhering to ART. Most of the participants indicated that they knew about family planning before falling pregnant, with some admitting that they had not used the family planning services. Some of the responses from the participants indicated that they had gained information from non-health facilities and the media, which may have been distorted. One of the participants stated:

> ***Participant KNZ04:*** *"While I was not taught about prevention of unwanted pregnancies and that lessons on family planning are provided at the clinic, I know that one can prevent pregnancies by using a condom, prevention pills or injection or implant."*

Another participant said*:*

> ***Participant KAB03:*** *"I did not know about this because I was no longer coming to the clinic to collect my treatment. Even after delivering my baby, no one talked to me about the prevention of unwanted pregnancies."*

The statements above support the conclusion that the participants were not empowered with knowledge on the importance of preventing unintended pregnancies in HIV-positive women. The researcher also noted that none of the participants had planned for their pregnancies, including those who were already HIV positive, as supported by the statement below:

> ***Participant MSG01:*** *"We were also taught about family planning including the injection and pills. I was also told about the loop and the implant. I never used any of these prevention methods. I never planned for my pregnancies."*

4.4.3.1.2 Category 2: Prevention of STIs and condom use

The participants reported that they had never been properly educated and empowered on the prevention of STIs and the use of condoms. About 10 of the participants had accessed ANC/PMTCT services, but in the process had not received the quality of health education required for the prevention of transmissible infections, including STIs. Condom use was understood differently by the participants. One mother who fell pregnant 13 months after giving birth said:

Participant KNZ01: *"I never used any prevention method during this period. I was not aware that I should take any prevention method on both occasions. I was aware though of condoms as a method of prevention for both sexually transmitted infections and HIV but not when I am pregnant. The problem with condoms is that they get torn during sexual intercourse which has resulted in us not using them."*

In confirmation of the suboptimal empowerment of recipients of PMTCT services, another young mother said:

Participant KAB01: *I am aware of STIs and HIV. I was taught about these at the primary school level when we were also advised on safe sex. Yes. I was informed of the prevention of transmittable diseases, but no one told me to use condoms. I was only advised that I should take my prevention pills regularly so that my baby can be delivered well."*

The lack of education and empowerment of HIV-positive mothers was supported by another young mother in the response below:

Participant MSG02: *"I was not taught about sexually transmitted infections when I attended antenatal care. I know about STIs from school when we were taught about them. These diseases include STIs and HIV."*

The study findings on gaps in the second pillar of PMTCT suggest the need to examine why health care providers are not able to implement the available policies and guidelines.

4.4.3.1.3 Category 3: The right to know sexual partner's HIV status

The participants reported that they did not trust their male partners, who were generally unwilling to be tested for HIV and adhere to prevention interventions such as condom use during pregnancy and breastfeeding, even though they were known to have more than one sexual partner.

Their male sexual partner's HIV status was not known by the majority of the participants, even though they had disclosed their own HIV status. One participant said:

Participant MSG01: *"I think men are not trustworthy and need to be counselled some more."*

Most of the participants indicated that their partners had refused to be tested for HIV or to practise safe sex. One participant attested to this as follows*:*

> ***Participant KNZ03:*** *"Although my first partner claimed to be HIV negative when we were still together, I was puzzled to get calls from the clinic enquiring about his treatment. However, I do not know what his status is as we separated about three years ago."*

Roughly half of the participants, (seven of the 13) indicated that they had attempted to find out their partners' status, with no success. One of the biggest barriers noted by the participants was the threat of rejection from their partners. A significant number of the participants stated that they would not disclose their status or ask a new partner about his status for fear of losing the relationship*.*

4.4.4 Theme 4: Knowledge of the risks of MTCT

The PMTCT programme was initiated to prevent the vertical transmission of HIV from infected mothers to their infants. In SA, a pilot PMTCT programme was introduced in 2001, which has since evolved into a comprehensive programme that is fully integrated into MCWH and primary health care services. The interventions prescribed by the PMTCT programme require dedicated implementation, as they seek to prevent new HIV infections in infants whose mothers are already HIV infected. This is achieved by ensuring that HIV-positive mothers are placed on ART and have their viral load monitored to ensure they are virally suppressed before childbirth (and ideally before falling pregnant). Their infants are also tested for HIV at prescribed points of their lives. The PMTCT also seeks to prevent unintended pregnancies in HIV-positive women.

Mothers play a pivotal role in ensuring that these processes are followed for PMTCT to be achieved as outlined in the four PMTCT pillars (described in section 1.2) (SANDoH 2019). The full knowledge and capacity of mothers is therefore important to ensure that EMTCT is achieved. The theme *Knowledge of the risks of MTCT* emerged from the insights participants shared of their experiences with PMTCT and their knowledge of the risk factors that may cause their infants' seroconversion. Despite the progress made in reducing MTCT rates in many countries, including SA, data shows that most seroconversion occurs postnatally through breastfeeding (Joseph Davey, Davies, Raphael & Pillay 2021).

However, the researcher noted from the responses that the participants had no clear information on the risk factors that contribute to MTCT. They were not aware of how their infants became HIV positive, or of the importance of condom use in pregnancy and safe breastfeeding. The mothers who had initially tested negative at their first appointment also lacked information on the importance of retesting and knowing whether their status had changed.

4.4.4.1 Category 1: Infection of infant

Most of the participants stated repeatedly that they did not know why their infants had seroconverted, and some questioned whether their infants had indeed tested positive. It emerged that when the infants tested negative and the mothers continued with breastfeeding, they were not reminded of the need for prevention measures in relation to the breastfeeding. They were therefore surprised and confused when subsequent testing showed that their infants had become HIV positive.

The following response was echoed by several participants:

> ***Participant KAB05:*** *"I do not know because I was taking my treatment regularly and had stopped breastfeeding the baby at 3 months."*

The researcher noted that although the mothers were placed on ART, they did not understand how these drugs prevented HIV infection of their infant. It emerged from the responses that the mothers thought that a negative PCR test at birth was a safety net for the infant, even during the postnatal period. At least four of the 13 participants indicated that they had been taking their treatment diligently until the cessation of breastfeeding, but no clear explanations had been provided to them on condom use, viral load monitoring, and adherence to infant prophylaxis during the same period. The researcher also noted that two of the 13 participants alluded to having received a positive PCR test at birth but had then resorted to going to more than two other facilities to conduct another test. This indicated a denial of their infants' status, and a possible duplication of a positive test due to the lack of a unique identifier.

The researcher has already reported on the gap in the prevention of STIs through condom use in pregnant and breastfeeding mothers in section 4.4.3.1.2 above. This was not directly identified as a barrier to EMTCT by the participants themselves, but the data shows that

postnatal seroconversion can happen when initially HIV-negative mothers test positive at a later stage and continue to breastfeed, as was noted in this study.

4.4.4.2 Category 2: Breastfeeding

The participants reported that their infants had seroconverted due to breastfeeding. The researcher noted that the participants perceived breastfeeding in HIV-positive mothers to be a bad practice, as four of the 13 participants stated that they were told by their health care providers to stop breastfeeding as soon as the infant tested positive. However, the researcher noted inconsistencies in the participants' understanding of the breastfeeding period. Only three of the 13 participants understood that they were required to be virally suppressed during breastfeeding.

A 30-year-old participant who said she had no partner stated:

> ***Participant KNZ04:*** *"I think the child was infected by breastfeeding. As I said earlier, I am aware that as an HIV-positive mother, I can transmit the virus to my baby. I know that the virus can be transmitted to the baby during pregnancy but am not sure how this happens."*

Another participant, who was a mother of two children, also stated*:*

> ***Participant KNZ01:*** *"Yes, I breastfed the baby for two years. During this time, I was taking my treatment."*

She continued explaining:

> ***Participant KNZ01:*** *"I am aware that HIV can be transmitted from the mother to her baby. To prevent this, I think the baby must not be breastfed and I, as the mother should take my ARVs regularly. I have been on ART since my first pregnancy in 2017 and I am still taking my treatment. I have had no problems with my treatment so far, I breastfed my baby for one and a half years before knowing about her status. I was also subsequently tested and found HIV positive."*

Of the 13 participants, eight were sure that they had given birth to HIV-negative infants. Of these infants, three seroconverted within 24 months of birth. All of these infants were breastfed. Six of the participants ascribed the HIV-positive status of their infants to

breastfeeding, while four ascribed it to delays and non-adherence to treatment. Ten of the 13 participants breastfed their infants for six months or more. Four of the 13 participants seemed to be unsure of the birth HIV status of their infants, while one mentioned that she had changed health care facilities after her infant had tested positive at birth, and had had her infant retested, as she was not convinced that the child was HIV positive.

The responses revealed that the participants were aware that breastfeeding, non-adherence to treatment, and non-safe sex are the three major routes through which HIV can be transmitted by mothers to their babies. The responses also revealed that ANC does not ensure that pregnant women are taught and warned of the risks of MTCT of HIV.

The study findings regarding infant feeding revealed that almost all the participants had some knowledge about breastfeeding. The majority breastfed their babies for at least six months from birth, with a few not being clear about the recommended duration of breastfeeding. About two of the participants mentioned having not breastfed their babies. This suggests that the health education on breastfeeding received by the participants was inadequate.

4.4.4.3 Category 3: Adherence to ART

The participants reported that they had been taking the ART provided to them, but only three of the 13 were adhering to the treatment correctly. The researcher noted that while the participants were aware that they should take the ART, they seemed to have no idea that it was crucial for them to remain on ART consistently. Most of the participants reported interruptions to their treatment, and their viral load was not measured to ensure suppression. While consistent and regular collection of ART was reported by most of the participants , a few reported occasions when the facilities had been out of stock, or when they had travelled elsewhere and were not able to refill their ART medication. ***Participant KNZ03*** said*:*

> *"This may have been because I never took treatment correctly from the beginning. The clinic teaches us to take treatment correctly, but I did not do this. The clinic tested me again and checked my viral load which was found to be extremely high. They referred me to Rob Ferreira Hospital, but I could not go at that time because I delivered my baby the same day."*

4.4.5 Theme 5: Proposed improvements to the EMTCT programme

The third research question of the study (as reflected in the fourth section of the interview schedule) required the participants as the recipients of care who had experienced barriers to the implementation of EMTCT, to share their views on how the EMTCT programme could be improved to achieve the goal of EMTCT. The participants' responses are presented below:

The participants' recommendations to improve the EMTCT programme were categorised into three domains: the health care system, the health care staff, and the health care users. These recommendations are discussed below.

4.4.5.1 Health care system

Some participants felt strongly that regular testing for HIV should be conducted to assist mothers in knowing their own and their baby's HIV status. They also stated that the counselling of mothers about HIV should be improved, as summed up by one of the participants:

> ***Participant KAB04:*** *"My advice to nurses is for them to test pregnant women from the time they present for ANC and after they deliver. I think counselling must be improved … Newborn babies must be tested regularly so that their status is known, and treatment given as early as possible … When babies are born to these mothers, they must be put on Nevirapine so that they do not become infected."*

The participants also stated that staff shortages at clinics should receive urgent attention, as they attributed the poor quality of care and of nurse-patient engagements to such shortages. In this way, as explained by one of the participants, the education of mothers on HIV, breastfeeding and the PMTCT programme could be strengthened:

> ***Participant TEK01:*** *"I think that clinics do not conduct adequate counselling for mothers. When they tell you about your status, the nurses do not seem to take that seriously and see the need for you to be counselled. Often, we do not get medication when we return for a check-up. This must be corrected. When nurses are relocated there must be communicated to the mothers. Often a nurse will just disappear without us being told. There must be an adequate explanation of when medication is changed and the reasons thereof. It will help if the school health programme could be strengthened so that we are taught about these issues at an early stage. I think that clinics do not conduct adequate counselling for mothers. When they tell you about your*

status, the nurses do not seem to take that seriously and see the need for you to be counselled."

An important observation from the participants was that the availability of medicines at the clinics needed to be improved, to reduce unnecessary repeat visits to the clinics when medicines are out of stock:

Participant KAB01: *"Stock shortages in clinics should be attended to."*

Lastly, the participants suggested that outreach visits by clinics to patients' homes, especially those with disclosure challenges, should be improved:

Participant KAB02: *"Home visits should be made to educate families about HIV to improve their understanding of the disease. These days you find that most people living with HIV are rejected by families and communities."*

4.4.5.2 Health care workers

The participants did not experience many challenges with the health care workers, but the primary challenge they mentioned was a very important one, and related to the poor attitude of many of the health care workers towards foreign nationals. The participants expressed a desire for these attitudes to change. They also suggested that the health care workers ensure that the necessary tests (PCR, viral load, and CD4 count) are conducted in accordance with the relevant protocols, so that the health status of both the mothers and their infants is known. It was also suggested that health care workers improve pregnant mothers' knowledge of the PMTCT programme. One participant stated:

Participant KAB04: *"My advice to nurses is for them to test pregnant women from the time they present for ANC and after they deliver. I think counselling must be improved."*

4.4.5.3 Health care users

The participants directed some of their recommendations towards the health care users of the PMTCT services themselves. These included always knowing one's HIV status; presenting early for ANC after falling pregnant; adherence to treatment before and after delivery; safe sexual practices, especially when changing partners; and persuading partners to present

themselves for testing and treatment. Two of the participants summed up these potential improvements as follows.

> ***Participant KAB03:*** *"When HIV-positive mothers fall pregnant, they must continue taking their treatment and follow the instructions of doctors and nurses about breastfeeding."*

> ***Participant KAB02:*** *"I can advise pregnant mothers to attend ANC early. I started late which is why I think I experienced the challenges that I did. I think it is important that pregnant mothers know what is happening in their lives, especially concerning HIV and STIs. Support is particularly important."*

Finally, three of the participants recommended that women should be supported socio-economically so that they can stand on their own and not be dependent on partners.

4.5 SUMMARY

In this chapter the researcher presented the findings of the study. The data was presented according to the themes, categories and subcategories that emerged from the thematic analysis. The meaning of these themes, categories and subcategories were supported with verbatim quotations from the participants.

In Chapter 5, the researcher discusses and interprets the findings of the study to form conclusions, while acknowledging its limitations and possible weaknesses. Recommendations for improving EMTCT are also presented.

CHAPTER 5
DISCUSSION OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the researcher discusses and interprets the findings of the study on mothers' experiences of barriers to EMTCT of HIV in SA, in relation to the literature review. The limitations and possible weaknesses of this study are acknowledged, and the overall recommendations that emerged from this study for improving EMTCT are also presented. These recommendations are based on the participants' experiences and are aimed at moving SA closer to achieving EMTCT. After recommending possible future studies on this research topic, and describing the overall contribution of this study, a final conclusion is presented.

5.2 DISCUSSION AND INTERPRETATION OF STUDY RESULTS

Presenting the biographical and demographic characteristics of participants in a qualitative study strengthens the transferability of the study's findings by allowing for the findings to be considered in comparable research settings (Bryman, Bell, Hirschsohn, Dos Santos, Du Toit, Masenge, Van Aardt & Wagner 2014:45). Most of the participants in this study were of African ethnicity, unemployed and single, with some having changed partners more than once. The participants had varying levels of education, but almost 10 of them had no knowledge of the PMTCT services they were receiving from the health care facilities.

These demographics were broadly similar to those in Ramoshaba and Sithole's (2017) study on the knowledge and awareness of HIV-infected mothers about MTCT and PMTCT in postnatal follow-up services in the Mankweng region of SA. The demographic variables of the HIV-infected mothers who were interviewed in Ramoshaba and Sithole's (2017) study showed that majority of the participants were between the ages of 26 and 35, with a significant number (40%) being single. Of these respondents, a little over half (54%) had achieved secondary/high-school education, while 13% had tertiary education. Three quarters (73%) of their participants were unemployed.

In another study on the experiences of HIV-positive women who utilised the PMTCT programme in one of the central hospitals in Bulawayo, Zimbabwe (Moyo 2016), the ages of the participants ranged from 18 to 39 years. All these participants were married, and the

majority had a secondary education. All the participants were unemployed. This aligns with the findings of this study, where all the participants were below the age of 40 with majority of them being unemployed. Moyo's (2016) study found that the majority (77%) of the participants were not aware of the PMTCT programme and had not even heard of the term "PMTCT".

A qualitative study by Vieira, Rasmussen, Oliveira, Gomes, Aaby, Wejse, Sodemann, Reynolds and Unger (2017) explored the awareness, attitudes, and perceptions regarding HIV and PMTCT amongst pregnant women in Guinea-Bissau. Vieira et al's (2017) findings that very few pregnant women who had been tested for HIV, and that they were unaware of and had limited knowledge of HIV and PMTCT, aligned with this study's findings. However, Ramoshaba and Sithole's (2017) finding that most of their participants were aware of MTCT contrasts with both this study and Vieira et al (2017). Ramoshaba and Sithole's (2017) finding is supported by Nyarko, Pencille, Akoku and Tarkang's (2019) descriptive, cross-sectional study on the knowledge, attitudes, and practices regarding the PMTCT of HIV among pregnant women in the Bosome Freho District in the Ashanti region of Ghana. Nyarko et al (2019) found that 77% their participants had a level of knowledge, 71.1% had a good attitude towards PMTCT, and the uptake of PMTCT was very high (95.9%).

The researcher observed that most of the participants in this study were aware of STIs, and that they must be prevented to avoid harm to their infants during pregnancy, but that this awareness was inadequate, as it did not operate at an impactful level. Some alluded to having received this information from the media. During their ANC visits, most of the participants (11) admitted that they had been somewhat taught about the transmission of HIV to infants, and that preventing this transmission required taking ART regularly (both mother and infant), avoiding breastfeeding, and using a condom when having sex. However, not all of the participants had adequate knowledge about STIs and their effects on unborn infants. The information on avoiding breastfeeding is inaccurate in that safe breastfeeding is advocated in the National Department of Health 2023 ART Guidelines (Health 2023).

Teshale, Tessema, Alem, Yeshaw, Liyew, Alamneh, Tesema and Worku's (2021) sub-Saharan study on the knowledge of mothers of child-bearing age on transmissible diseases, similarly found that only 56.21% of the participants had adequate knowledge about MTCT of HIV and its prevention. However, Liyeh, Cherkose, Limenih, Yimer and Tebeje's (2020) in a similar study that sought to establish the knowledge of the prevention of MTCT of HIV among women of reproductive age in Northwest Ethiopia, found that only about 22.4% of the

participants were knowledgeable about the transmission of HIV. With regard to the right to knowledge, UNAIDS (2014) emphasises the need for women living with HIV to enjoy all human rights, including the right to information.

Almost all the participants in this study experienced no serious challenges with receiving both their own medication and that of their infants from clinics. They also expressed satisfaction with the support that they received from the clinics when it comes to collecting medication. Their knowledge of the importance of preventing unintended pregnancies seemed to be adequate, however, although some admitted to knowing about it, they admitted to not utilising the available prevention measures. Preventing unintended pregnancies in women living with HIV has been observed to (i) improve MCWH, (ii) prevent MTCT of HIV, and (iii) reduce the numbers of infants orphaned because of HIV (Leach-Lemens 2010). More than a decade ago, Sweat, O'Reilly, Schmid, Denison and De Zoysa (2004) showed that reducing unintended pregnancies by 16% among women with HIV would have a similar effect on infant HIV infections, reducing HIV prevalence by 1.25%. From these observations, therefore, it may be deduced that acceptable baseline work has been done by the Mpumalanga DoH in respect of family planning among women living with HIV.

The participants' responses regarding the experiences of the attitudes of their partners, family members, and community members who had come to know about their HIV-positive status revealed that:

(i) Some partners were not informed of the participant's HIV status, and the attitude of those partners who had been informed had ranged between initial denial to agreement to HIV testing and treatment, refusal to take treatment, or the breakdown of the relationship.

(ii) Some family members were not informed of the participant's HIV status, but the attitude of those who were informed was mostly supportive.

(iii) For fear of stigmatisation, most of the participants did not inform community members of their HIV status.

An analysis of the overall experiences from the participants in this study, revealed that three factors played a role in the successful implementation of the PMTCT programme, namely, the health care system, the health care workers, and the health care users. This aligns with the

findings of Peng et al's (2017) similar study. Ntsime, Makhado and Sehularo (2022) similarly group these factors into management-related, staff-related, and patient-related factors. In this study the researcher discussed the findings in line with Peng et al (2017). The study found, firstly, that there are instances where clinics did run out of drugs, resulting in patients having to return for their medication. Secondly, participants who had no access to refrigerators struggled to store their medication (especially paediatric preparations) at the right temperature.

The participant responses revealed that the most mothers (eight) attributed the seroconversion of their infants to breastfeeding. Others (three) believed that poor adherence to treatment had resulted in their infants becoming infected with HIV. One mother did not know why her infant had become infected. In a similar study by Kahungu, Kiwanuka, Kaharuza and Wanyenze (2018:2), which investigated the factors associated with an HIV-positive sero-status among infants attending care at health facilities in rural Uganda, the authors found that long waiting time, program understaffing, a weak community follow-up system, stock shortages of Nevirapine syrup, and lack of HIV testing kits were health system factors that negatively affected EMTCT. However, other than mentioning occasions where the prescribed ART was unavailable due to a lack of stock, these factors were not stated by the participants of this study but remain relevant for enhancing the uptake of PMTCT as they all revolve around the mother as the key role player.

Mbena, Seni, Kajura, Matovelo and Kihunrwa (2014) conducted a study to explore the HIV seroconversion and associated risk factors among pregnant women who delivered at Bugando Medical Centre in Mwanza, Tanzania. They found HIV seroconversion in 5.3% of the participants, with polygamous marriage and a history of syphilis during an ANC visit being independent predictors of HIV seroconversion. One of the 21 infants (4.8%) born to the HIV seroconverted women was confirmed to be HIV infected. The study concluded that the high rate of HIV seroconversion implies that HIV re-testing should be emphasised to allow for the timely provision of ART prophylaxis. This Tanzanian study therefore highlighted the contribution of the mother's HIV status to the seroconversion of the infant.

Another study conducted by Cunga, Souza, Rosa, Iser and Schuelter-Trevisol (2022) assessing the risk factors for seroconversion of HIV among children exposed in the Brazilian state of Santa Catarina between 2007 and 2017, found that of a total of 4,559 records of HIV-exposed infants that were screened, 130 (2.9%) of the infants had seroconverted. Cunga et

al (2022) identified the independent risk factors for this as the failure to use ARV drugs during pregnancy and breastfeeding.

In this study, findings regarding infant feeding revealed that almost all the participants had some knowledge about breastfeeding, with only a few not being clear on the recommended duration for breastfeeding. Most of the participants breastfed their infants for at least six months from birth, only two alluded to having not breastfed their infants. This suggests that HIV-positive mothers receive inadequate health education on breastfeeding, with most giving the impression that breastfeeding causes seroconversion. There was poor understanding of the fact that viral suppression plays a role in safe breastfeeding.

Despite registered critical worldwide progress in the reduction of MTCT of HIV, transmission through breastfeeding still contributes to almost 50% of the infant HIV infections recorded every year (Nlend 2022). To curb this situation, Nlend (2022) suggested tracking all women of child-bearing age through HIV testing, improving testing, and retesting women during pregnancy and breastfeeding. Additionally, adherence to ART among pregnant and lactating women should be strengthened, ensuring a continuum and retention in care of mother-infant pairs for up to 24 months. Due to the burden of seroconversion during pregnancy or thereafter through breastfeeding, Nlend (2022) suggested that PrEP be urgently implemented for women most at risk.

The participants 'shared lived experiences revealed that most of the them experienced no challenges with receiving both their own medication and that of their infants from clinics. They also expressed satisfaction with the support that they received from the clinics based on what they understood to be acceptable standard. The non-availability of medication did not present as a barrier to the uptake of PMTCT. However, Hall, Sou, Beanland, Lacky, Tso, Ma, Doherty and Tucker's (2017) meta-synthesis study emphasised the importance of retention in HIV care to the HIV care continuum for every patient. The study sought to identify facilitators and barriers to HIV retention in care interventions. A total of eight themes were identified as facilitators or barriers for retention in HIV care intervention: (1) stigma and discrimination, (2) fear of HIV status disclosure, (3) task shifting to lay health workers, (4) human resource and institutional challenges, (5) mobile health (mHealth), (6) family and friend support, (7) intensive case management, and (8) relationships with caregivers. As expressed in other sections of the findings of this study, there is agreement with most of these barriers identified by Hall et al (2017).

The participants` lived experiences in this study revealed that the HIV-positive mothers experienced acceptable support at the clinic, both during antenatal care and after delivery. No specific barriers were mentioned by most of the participants in this regard despite some mentioning being a foreigner disadvantaging them to quality care. However, Slomian, Emonts, Vigneron, Acconcia, Glowacz, Reginster, Oumourgh and Bruyère (2017) categorised the needs of mothers after childbirth into four categories: (i) the need for information, (ii) the need for psychological support, (iii) the need to share experiences, and (iv) the need for practical and material support. Sloman et al (2017) asserted that women do not feel sufficiently informed about this difficult period of life, and that they do not feel sufficiently supported, not only from a psychological point of view but also from a more practical point of view, for example with household chores. Sloman et al (2017) found that women need to share their experiences of life, need to be reassured, and need to feel understood. The researcher noted that these support services were not available to the participants of this study and they did not mention them because of lack of knowledge and awareness.

The participants' responses regarding whether or not their partners, family members, or community members were informed about their HIV status revealed the following:

1. Almost three-quarters of the participants informed their partners about their HIV-positive status. The attitude of those partners, however, ranged between initial denial, agreement to HIV testing and treatment, refusal to take treatment, and the breakdown of the relationship. Four of the participants admitted that they were scared to inform their partners for fear of rejection.
2. Almost two-thirds of the study participants had informed their family members about their HIV-positive status. The attitude of those who were informed was mostly supportive. A few of the participants could not inform their family members for various reasons, including stigma.
3. Regarding their communities, almost half of the participants did not divulge their status for fear of stigma. Only four of the participants had divulged their HIV status to their community.

In summary, the participants lacked knowledge on the PMTCT programme, lacked knowledge on their role in achieving EMTCT, and lacked the capacity to deal with their partners and significant others in relation to disclosure of their HIV-positive status and adherence to ART.

Figure 5.1 below illustrates the four key areas in which support can be offered to HIV-positive pregnant mothers in relation to EMTCT: partner support, family support, community support, and psychosocial support. It also highlights potential recommendations for targeted interventions to overcome barriers to deliver comprehensive MTCT Services that will result in the elimination of MTCT, with the key focus on partner, family and community playing a participative role in improving MTCT outcomes. It also emphasizes the importance of key role players in EMTCT

:


Psychosocial Support
Implementation of the psychosocial support package strengthened by better dissemination of MTCT guidelines, CPD points Enforced PMTCT guidelines through measurement of the five pillars. Informed patients through support groups and social media such as WhatsApp, Telegram and Facebook
Community
Patients do not trust that their status will be kept confidential resulting in lack of support from the community. Support groups are essential
Family
Confidentiality of HIV status emphasized. Patients have limited confidence in family support hence they do not disclose making support groups essential
Partner Support
To know and accept your own and your partners' status can reduce the MTCT rate by 40%
Partner support is crucial for adherence, viral load suppression and achieving better outcomes

5.3 LIMITATIONS OF THE STUDY

The researcher identified some limitations of this research study. Polit and Beck (2012:65) stated that reporting the limitations of a study is important, as it indicates that the researcher was able to identify them and take them into account. These limitations were as follows:

- Section 35, 1(a) of the Health Act 61 (Republic of South Africa, 2003) requires that a parent or guardian must formally consent to information being collected from a child, where the latter is defined as a person under the age of 18 years. Women under the age of 18 are therefore legally defined as minors in SA and cannot consent to participate in a study without parental support. A significant younger section of the childbearing population was therefore excluded from this study. However, this criterion is true of most studies.
- Mothers with children older than 24 months were excluded from this study, as they fell outside of the PMTCT period.
- The researcher experienced a language barrier with some of the foreign participants from neighbouring countries. This potentially limited the range of views obtained in this study as two participants were released due to foreign language barrier. The researcher can speak “spoken”’ iSiswati but resorted to a translator to avoid misunderstanding and wrong translation of sentences.
- Some potential participants in the research population refused to take part in this study. One potential participant stated that she was not comfortable with being interviewed. Another arrived for the interview, but when told that the interview would take 45 minutes to an hour, she stood up and said that her partner may find out that she was not at home as he would be waking up for his night shift.
- One mother could not be interviewed as she had a HIV positive infant at birth but denied the status. All participants were HIV-positive mothers of infants who had tested HIV-negative at birth, as the study examined why the infants had seroconverted.
- All participants were of African ethnicity due to the geographic area and the PCR results used to select them.

5.4 STUDY WEAKNESSES

5.4.1 Trustworthiness

While all the participants were asked the same questions in the same order, and all the data was coded at once at the end of the data collection period, the interviews were conducted by the researcher, who could not speak fluent siSwati, which the participants spoke. The researcher therefore required a translator who had a better understanding of siSwati. It was also not easy to interview the participants from Mozambique, who were not fluent in either English or siSwati. These language barriers may have weakened the trustworthiness of the study.

5.4.2 Credibility

The interview schedule was written in English, and no translated versions of this questionnaire were available. As a result, questions were often asked in English where the participant had a high level of education and could respond in English. The credibility of the data, therefore, could not be absolutely assured in all instances. However, the researcher's use of interview notes in addition to the interview recordings may have assisted in mitigating this.

5.4.3 Limitations of descriptive studies

Descriptive qualitative studies are able to describe the answers to the research questions. However, the results cannot be generalised to represent the views of the population outside of the facilities where the interviews were conducted. All the participants were young, black African women due to the location of the study sites.

5.5 RECOMMENDATIONS

5.5.1 Health care system

Based on the findings of this study, the following recommendations were made in relation to the health care system:

i) Regular HIV testing of mothers should be conducted at clinics, so that mothers know their own HIV status and that of their infants. Testing policies should also emphasise partner testing at all contact periods of ANC and postnatal care. These tests should be reflected in the SANDoH patient monitoring systems. The current system monitors

the status of the infant only. The existing information systems, such as Tier.net, should incorporate the reporting of mother-infant pairs.

iii) A EMTCT focal point should be appointed and made available at each health care facility. This focal point should be responsible and accountable for checking on and ensuring regular HIV testing and viral load testing of HIV-positive mothers, as well as their adherence to ART. The latter should be linked to the relevant staff members' performance agreements.

(iii) Counselling of mothers about HIV must be improved. This should include regular education on the four pillars of PMTCT, and the relevant implications for mother-infant pairs.

(iv) Staff shortages in clinics should receive urgent attention. A lack of staff can have negative implications for maternal and child health outcomes, and staffing therefore needs to be given urgent attention. This can be achieved through revised collaboration with donors and implementing partners.

(v) The education of mothers on HIV, breastfeeding and the PMTCT programme must be strengthened. The data from this study showed that eleven of the infants may have seroconverted during breastfeeding, and educating mothers is therefore crucial. Every health care facility should be provided with pictorial brochures that teach mothers about the PMTCT pillars. Where possible, information and reminders should be sent to the cell phones of registered mothers. The role of media comes in strong here with mothers educated frequently in all media platforms.

(vi) Knowledge about HIV prevention, sexual and reproductive health rights (SRHR), and PMTCT should be strengthened. Health talks at facilities should incorporate SRHR and PMTCT. The use of mHealth should be reinvigorated (SMS, TikTok, FB and other platforms)

(vii) Innovations should include planning for interoperability between the National Laboratory, the HIV monitoring systems (Tier.net) and the Stock Visibility System (SVS), so that stock levels of essential ARTs can be planned and projected more efficiently and effectively.

(ix) Further innovations such as the use of lockers at strategic points of medication collection would also strengthen integrated disease management. The SANDoH should consider the urgent use of UNIQUE identifiers for ease of follow up and adherence.

(x) Outreach visits by health care workers to patients' homes, especially for those patients experiencing challenges related to disclosure, should be improved.

5.5.2 Health care workers

Based on the findings of this study, the following recommendations were made in relation to the health care workers:

(i) Health care workers should be trained and incentivized to change their attitudes towards foreign nationals, by providing them with packages to attend conferences, by paying for them to attend courses with CPD point and by issuing special awards in this regard.

(ii) Health care workers must ensure that the necessary tests (PCR, viral load, and CD4 count) are conducted and recorded in accordance with the relevant protocols, so that the HIV status of both the mothers and their infants is accurately known. Patients could be requested to share their experience via centralised systems, such as Facebook, where they can either complain about or compliment the clinic staff. This type of activity-related output monitoring system could be organised by the SANDoH and should be linked to an electronic system that shows the guidelines implemented by a health care worker when in contact with patients.

(vi) Health care workers must improve pregnant mothers' knowledge of the PMTCT programme, by providing information specific to their context.

(vii) The SANDoH, with support from implementing partners, should ensure continuous HIV education, screening, and support for all women of childbearing age.

(viii) Health talks at health facilities should include information about PMTCT.

5.5.3 Health care users

Based on the findings of this study, the following recommendations were made in relation to the health care users:

(i) Pregnant women should be encouraged to attend ANC early. This messaging should be communicated through all media platforms used by community members.

(ii) Women should be encouraged to take responsibility for their own health and wellbeing, and need to be encouraged to avoid compromising their health status

because they fear rejection. Programmes such as the Mothers2Mothers programme could be instrumental in communicating this message.

(ii) Women must always strive to know their HIV status at all times, especially when in new and risky relationships.

(iii) HIV-positive women must adhere to their treatment before and after delivery.

(iv) Women must always practice safe sex, especially after changing partners.

(v) Women who live with HIV must encourage their partners to present themselves for testing and treatment.

(vi) Knowledge of sexual and reproductive health (SRH) should be conveyed to women and, if possible, their partners, in order to prevent unplanned pregnancies, MTCT of diseases, and unintended pregnancies. Knowledge about viral load and ART needs to be communicated before pregnancy, during pregnancy, at the time of delivery, after delivery, and during the breastfeeding period.

vii) The study responses made it clear that HIV-positive women do not get a lot of support from their partners, their family or their community. There is therefore a need to strengthen psychosocial support systems in an already burdened health system. Psychosocial support should include counselling for women and their partners and should be incorporated into popular platforms that link community members to specific health care facilities, and to specific linkage officers, community partners and other available staff. The SANDoH could address this need by using existing systems such as MomConnect and social media platforms such as WhatsApp, Telegram, SMS and Facebook, to include messages that will support EMTCT. It would also be necessary to include empowerment programmes where the issue of unemployment could be addressed efficiently. Existing programmes should incorporate information on managing finances, entrepreneurship, sexual and reproductive health, and negotiation skills.

5.6 RECOMMENDED FUTURE RESEARCH

The following future studies are recommended on EMTCT in South Africa:

1. Evaluations of the implementation of the EMTCT programme in South Africa, broken down by province.
2. Studies on enablers that will provide solutions to the barriers to EMTCT in South Africa.
3. Studies on barriers to effective family planning and SRH in South Africa.
4. Studies on the role played by socio-economic factors in the positive disclosure of HIV status.
5. A strong quantitative study in e-MTCT in SA using recent data from National department of health

5.7 CONTRIBUTIONS OF THE STUDY

The findings and recommendations of the study may be able to assist facilities and policy makers to review their implementation of the PMTCT guidelines in line with EMTCT criteria in SA.

Programme planning should be aligned with activities that aim to:

1. Build capacity among health care providers, community members and recipients of care.
2. Mobilise resources and channel activities towards supporting EMTCT.
3. Improving the implementation of sexual reproductive health programmes.
4. Encourage women to make better decisions in relation to measures to prevent vertical transmission.
5. Reinvigorate the PMTCT programme.

5.8 CONCLUSION

Most HIV-positive mothers who present at health clinics for ANC are not made adequately aware of the EMTCT programme but do have information about certain aspects of the programme, such as the prevention of transmissible diseases; the prevention of unintended pregnancies; the support required during pregnancy, delivery and after delivery; and the necessary support of the HIV-positive mother by her partner, family, and community. The challenges that HIV-infected mothers experienced in Ehlanzeni included poor access to PMTCT services due to the attitudes of health care providers, inadequate knowledge of why infants seroconvert after

delivery, inadequate knowledge of the importance of adherence to ART, inadequate knowledge and understanding of the role a mother can play in the PMTCT cascade, an inability to disclose and act on their HIV status without the fear of rejection by their partner, and inadequate support from their partners, families, and communities. This study found that fear of stigmatisation is still a great concern for HIV-positive women.

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LIST OF ANNEXURES

ANNEXURE 1: APPROVAL FROM THE UNIVERSITY OF SOUTH AFRICA

UNISA university of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

21 May 2021

Dear Precious Audia Robinson

Decision:
Ethics Approval from 21 May 2021 to 21 May 2024

NHREC Registration # :
Rec-240816-052
CREC Reference # :
40760561_CREC_CHS_2021

Researcher(s): **Name: Precious Audia Robinson**
Contact details: 40760561@mylife.unisa.ac.za
Supervisor(s): **Name: Dr C Prinsloo**
Contact details: Eprinsc2@unisa.ac.za

Title: *Mother's experiences on barriers to elimination of mother to child transmission of HIV in South Africa.*

Degree Purpose: Masters

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for three year.

The *medium risk application was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the

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ANNEXURE 2: LETTER OF APPROVAL: MPUMALANGA DEPARTMENT OF HEALTH

health
MPUMALANGA PROVINCE
REPUBLIC OF SOUTH AFRICA

Indwe Building, Government Boulevard, Riverside Park, Ext. 2, Mbombela, 1200, Mpumalanga Province
Private Bag X11285, Mbombela, 1200, Mpumalanga Province
Tel I: +27 (13) 766 3429, Fax: +27 (13) 766 3458

Litiko Letemphilo | Departement van Gesondheid | UmNyango WezeMaphilo

Enq: 013 766 3766
Ref: MP_202107_001

Research Permission Letter

Ms Precious Robinson
NO 17A LERORO TOWNSHIP
207 Brown Pelican Avenue
Pretoria, 0081

STUDY TITLE: MOTHERS EXPERIENCES ON BARRIERS TO ELIMINATION OF MOTHER TO CHILD TRANSMISSION OF HIV IN SA

Dear Ms Robinson

The Provincial Department of Health Research Committee has approved your research proposal in the latest format you sent, and hereby grant you permission to conduct your research as detailed below.

- Approval Reference Number: MP_202107_001
- Data Collection Period: 01/08/2021 to 01/02/2022
- Approved Data Collection Facilities:

* KABOKWENI CHC, KANYAMAZANE CHC, MATSULU CHC, MSOGWABA CLINIC, NELSPRUIT CIVIC CENTRE CLINIC & PHOLA-NZIKASI CHC.

Kindly ensure that conditions mentioned below are adhered to, and that the study is conducted with minimal disruption and impact on our staff, and also ensure that you provide us with a soft or hard copy of the report once your research project has been completed.

Conditions:
- *Researchers not allowed to make copies or take pictures of medical records.*
- *Kindly notify the facility manager a week BEFORE you start with data collection to ensure that conditions are conducive in the facility*

Kind regards

DR C NELSON
MPUMALANGA PHRC CHAIRPERSON
DATE: 19 / 07 / 2021

ANNEXURE 3: PARTICIPANT INFORMATION SHEET AND CONSENT

UNISA university of south africa

PARTICIPANT INFORMATION SHEET

03 August 2022

Study Title:

MOTHER'S EXPERIENCES ON BARRIERS TO ELIMINATION OF MOTHER TO CHILD TRANSMISSION OF HIV IN SOUTH AFRICA

Dear Prospective Participant

My name is **PRECIOUS AUDIA ROBINSON** and I am doing research with **DR C PRINSLOO**, a lecturer in the Department of Health Studies towards a master's degree at the University of South Africa. We are inviting you to participate in a study entitled Mother's experiences on barriers to elimination of mother to child transmission of HIV in South Africa.

WHAT IS THE PURPOSE OF THE STUDY?

I am conducting this research to investigate HIV-positive mothers' experiences on the barriers to the elimination of Mother to Child Transmission (MTCT) in Ehlanzeni.

WHY YOU ARE BEING INVITED TO PARTICIPATE?

You are being invited to participate in the study because you are registered on the Department of Health's programme of the prevention of mother-to-child transmission of HIV, who delivered a baby who tested HIV positive during the period 2018 to 2022 with your baby testing HIV positive within twenty-four months after birth.

I obtained your contact details from your local clinic where you are registered and receive the well-baby services for your baby. You were chosen because you are one of the mothers whose babies seroconverted within twenty-four months after birth. A total of ten mothers have been chosen to participate in the study, including yourself.

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ANNEXURE 4: NATURE OF THE PARTICIPATION IN THE STUDY

THE NATURE OF YOUR PARTICIPATION IN THIS STUDY.

As the purpose of the study indicates, your role in participating in the study is to, firstly, share and describe your experiences in prevention of mother to child transmission (PMTCT) programme from the time you joined it; secondly, to share your experiences regarding the barriers that you experienced in during your participation in the programme, and lastly to make recommendations for the improvement in the implementation of the PMTCT programme that will enhance the elimination of the mother-to-child transmission of HIV (e-MTCT).

The study involves audio taping, a questionnaire using semi-structured interview. The questions are open-ended and give you an opportunity to express yourself freely on the issue under consideration. I will come in here and there with clarity-seeking questions and confirmation of my understanding of points you have made. The interview will last for about 45 – 60 minutes.

WITHDRAWAL FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE

Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason.

THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY

Please note that there will not be any additional financial benefit to you for participating in the study except for a R100 which will cover your transport expenses.

ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT

You will not suffer any negative consequences by participating in this study.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

You have the right to insist that your name be not recorded anywhere and that no one, apart from the researcher and identified members of the research team, will know about your

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involvement in this research. Your answers will be given a code number, or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings. Please also note that your anonymous data may be used for other purposes, such as a research report, journal articles and/or conference proceedings and that in any report of the study that is submitted for publication, individual participants will not be identifiable.

HOW THE RESEARCHER WILL PROTECT THE SECURITY OF DATA

Hard copies of your answers will be stored by the researcher for a period of five years in a locked cupboard/filing cabinet at my private residence for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable.

PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY

R100 will be paid to you in cash after the interview to cover any travel costs that you might have incurred when presenting for the interview.

HAS THE STUDY RECEIVED ETHICS APPROVAL?

This study has received written approval from the Research Ethics Review Committee of the University of South Africa (UNISA). A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

Should you require any further information or want to contact the researcher about any aspect of this study, please contact:

Name: **Precious Robinson**
Mobile: **078 841 8876**
Email: **Precious.Robinson@rightbecare.org**

Thank you for taking time to read this information sheet and for participating in this study.

Precious Robinson

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ANNEXURE 5: CONSENT FORM- ENGLISH VERSION

CONSENT TO PARTICIPATE IN THIS STUDY

I, _____ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty.

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree to the audio-recording of the interview.

I have received a signed copy of the informed consent agreement.

Participant Name & Surname……. (Please print)

Participant Signature……Date……

Researcher's Name & Surname…… (Please print)

Researcher's signature…… Date……

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ANNEXURE 6: INTERVIEW SCHEDULE

Questionnaire: English Version

Questionnaire:

Study Title:

Mother's experiences on barriers to the elimination of mother-to-child transmission of HIV in South Africa.

Name of interviewer	
Date of interview	
Time of interview	
Location of interview	
Participant Code Name	

SECTION 1: BIOGRAPHICAL AND DEMOGRAPHIC DATA

1.1 Gender:

Female	
Male	

1.2 Race:

Black African	
Asian	
Colored	
White	

1.3 Date of Birth:

yyyy	mm	dd

1.4 Marital status:

Married	
Divorced	
Single	

1.5 **Highest level of education:**

Tertiary	
High School	
Primary School	
No formal school	

1.6 **Employment status:**

Employed	
Self-employed	
Unemployed	

1.7 **The number of pregnancies:**

One	
Two	
Three and more	

1.8 **The number of sexual partners:**

One	
Two	
Three and more	

1.9 **When first diagnosed as HIV positive:**

yyyy	mm	dd

SECTION 2: WHAT IS YOUR KNOWLEDGE, ATTITUDE AND EXPERIENCE OF THE PMTCT PROGRAMME?

2.1 What do you understand by primary prevention of transmittable diseases among women of childbearing age in the PMTCT programme?

2.2 The PMTCT programme requires that unintended pregnancies among women diagnosed with HIV be prevented. Please explain how this was done in your case.

2.3 The PMTCT programme requires that HIV transmission from a woman living with HIV to her infant be prevented. How should this be done and what is your experience as a person living with HIV?

2.4 Appropriate HIV treatment, care and support should be provided to women, their children, partners and families. Share your experience in this regard.

SECTION 3: WHAT BARRIERS DID YOU ENCOUNTER DURING THE IMPLEMENTATION OF THE PMTCT PROGRAMME?

3.1 What would you consider as barriers in preventing disease transmission from a woman living with HIV to her infant? Share your personal experience in this regard.

3.2 What barriers have you encountered with the provision of appropriate treatment to yourself, your infant, your partner and your family during pregnancy, delivery and after delivery in the light of your HIV status?

3.3 What barriers have you encountered with the provision of appropriate treatment to yourself, your infant, your partner and your family during pregnancy, delivery and after delivery in the light of your HIV status?

3.4 What barriers have you encountered with the provision of appropriate care to yourself, and your infant during pregnancy, delivery and after delivery in the light of your HIV status?

3.5 What barriers have you encountered with receiving appropriate support from yourself, by your health facility and staff during pregnancy, delivery and after delivery in the light of your HIV status?

SECTION 4: WHAT FIVE RECOMMENDATIONS DO YOU HAVE FOR THE ACHIEVEMENT OF EMTCT

4.1

4.2

4.3

4.4

4.5

ANNEXURE 7: TRANSCRIBER CONFIDENTIALITY AGREEMENT

MOTHERS' EXPERIENCES ON BARRIERS TO ELIMINATION OF MOTHER TO CHILD TRANSMISSION OF HIV IN SOUTH AFRICA

Transcriber Confidentiality Agreement

A. INSTRUCTIONS

Please read through the entirety of this form carefully before signing.

Electronic signatures are not valid for this form. After completing the required fields, please sign this form in black ink. After this form has been signed by the research assistant, it should be given to the principal investigator of the research study for submission. After receiving the *Transcriber Confidentiality Agreement*, the principal investigator should scan and upload the signed form to their project package.

The transcriber should keep a copy of the *Transcriber Confidentiality Agreement* for their records.

B. CONFIDENTIALITY OF A RESEARCH STUDY:

Confidentiality is the treatment and maintenance of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure (the consent form) without permission. Confidential information relating to human subjects in a research study may include, but is not limited to:

- Name, date of birth, age, sex, address, and contact information.
- Current contact details of family, guardian etc.
- Medical or educational history and/or records.
- Sexual lifestyle.
- Personal care issues.
- Service records and progress notes.
- Assessments or reports.
- Ethnic or racial origin.
- Political opinions, religious or philosophical beliefs.

As a transcriber, you will have access to confidential information pertaining to the research study. Many participants have only revealed information to investigators because principal investigators have assured participants that every effort will be made to maintain confidentiality. That is why it is of the upmost importance to maintain full confidentiality when conducting a research study.

Below is a list of expectations you will be required to adhere to as a transcriber. Please carefully review these expectations before signing this form.

Revised: 07/27/2022

C. EXPECTATIONS FOR A TRANSCRIBER OF RESEARCH DATAIn order to maintain confidentiality, I agree to:

1. Keep all research information that is shared with me (e.g., flash drives, notes, transcripts, data, etc.) confidential by not discussing or sharing this information verbally or in any format with anyone other than the principal investigator of this study.

2. Ensure the security of research information while it is in my possession. This may include:
   - Keeping all documents and/or data related to the research study on a password protected computer with password protected files.
   - Closing any programs, documents, or data files related to the research study when away from the computer.
   - Keeping any printed documents and/or data related to the research study in a secure location such as a locked filing cabinet.
   - Permanently deleting any digital communication containing documents and/or data related to the research study.

3. Not make copies of documents and/or data related to the research study unless specifically instructed to do so by the principal investigator.

4. Give all research information/data and research participant information/data back to the principal investigator upon completion of my duties as a transcriber.

5. After discussing it with the principal investigator, erase or destroy all research information that cannot be returned to the principal investigator upon completion of my duties as a transcriber.

Name of Transcriber:

Title of Research Study: Mothers' Experiences On Barriers To Elimination Of Mother To Child Transmission Of Hiv In South Africa

Name of Principal Investigator: Precious Robinson

By signing this form I acknowledge that I have reviewed, understand, and agree to adhere to the expectations for a transcriber described above. I agree to maintain confidentiality while performing my duties as a research data transcriber and recognize that failure to comply with these expectations may result in disciplinary action.

_____ ~~August 2022~~

Signature of Transcriber Date

_____

Print Name

Revised: 07/27/2022

ANNEXURE 8: EDITOR'S CERTIFICATE

38 Montgomery Drive
Athlone, Pietermaritzburg
3201
21 January 2023

To whom it may concern,

I have edited the following dissertation for language errors, and in the process have performed a detailed audit of all the referencing:

Title: *Mothers' experiences of barriers to the elimination of mother-to-child transmission of HIV in South Africa*

Author: Precious Audia Robinson

Institution: University of South Africa

Degree: Master of Arts in Health Studies

Supervisor: Dr C. Prinsloo

Please feel free to contact me should you have any queries.

Kind regards,

Debbie Turrell

debbie.turrell@gmail.com
063 891 3870