UNIVERSITY of the
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FACULTY OF COMMUNITY AND HEALTH SCIENCES
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Title: The experiences of mothers living with HIV of the PMTCT programme in Khayelitsha, Cape Town.

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the degree of Master Curationis.

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DECLARATION

I, Linda Velapi, declare that the dissertation entitled *The experiences of mothers living with HIV of the PMTCT programme in Khayelitsha, Cape Town,* is my own work and all sources that have been used or quoted have been indicated and acknowledged by means of a complete reference list, and that it was not submitted for any other degree at any institution.

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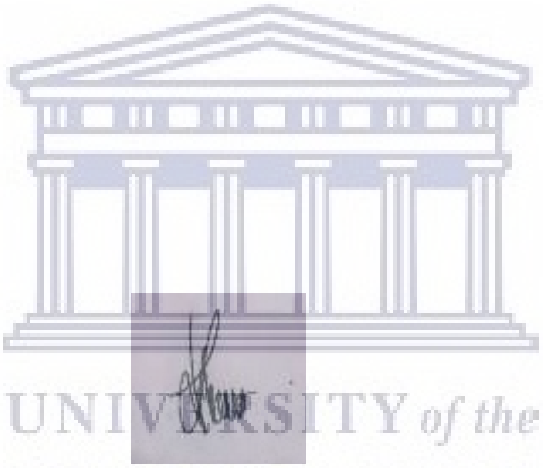
Date: March 2021



Student's signature: _____

DEDICATION

I dedicate this mini-thesis to my wonderful son, who's continuous love has contributed tremendously to the completion of this mini-thesis, and to my family for all their prayers and support during this trying time.

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I would first like to thank God for giving me the strength to push through and complete my studies.

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ABSTRACT

Background: The pandemic of HIV is the most severe health challenge affecting children across the world and it is estimated that more than 90% of all HIV infections in children result from Mother to Child Transmissions (MTCT). The global target of <2% MTCT risk of HIV has still not been achieved despite the duration of the implementation of the programme and its great progress. The prevention of mother to child transmission (PMTCT) programme is a programme developed to enable health care practitioners to provide essential care to mothers in order to prevent the transmission of the virus to their infants.

Aim: This study aimed to explore the experiences of mothers living with HIV on the PMTCT programme in Khayelitsha, Cape Town. The objectives were to determine and describe postpartum mothers' knowledge and understanding of HIV and the PMTCT programme, explore mothers' experiences of being in the PMTCT programme, and to explore their experiences of their infants' treatment process.

Research design: The study adopted a qualitative approach in order to allow for a richer and more in-depth understanding of the phenomenon and to give the researcher the opportunity to understand the participants' lived experiences.

Population and sampling: The target population was mothers who had been diagnosed as HIV-positive with exposed but HIV-negative infants who were being managed in the PMTCT programme in the health facility in Khayelitsha. Non-probability purposive and snowball sampling were sampling methods used to collect data.

Data collection and analysis: Data was collected by means of face to face interviews. Data was organized and analysed using the ATLAS ti software. Data analysis was done using Clarke and Braun's six-step thematic analysis approach.

Ethical consideration: Formal approval to conduct the study was obtained from the Biomedical Research Ethics Committee of the University of the Western Cape. The Western Cape Department of Health gave permission to conduct the study in one of their health facilities. All the participants were given an information sheet and a consent form. The ethical principles were adhered to for the duration of the study.

Findings: The study revealed that mothers that were informed about their illness were

aware of the importance of adherence in their infants' treatment process. Mothers had difficulty in understanding the rationale of the programme and this influenced their adherence, which for some was erratic. Family support, partner involvement, and health system related factors played a role in participants' response to the programme and in their treatment experience.

Recommendations: Recommendations from the study include: education regarding PMTCT practices be improved during initiation of the programme to facilitate prevention of the transmission of HIV, remove barriers such as the specific demarcation of HIV services in the facility as this contributes to patient identification and stigma and facilities should offer flexible opening times for mothers who find it difficult to attend as they are employed.

KEY WORDS

Adherence

Experience

Mothers living with HIV

Mother to child transmission (MTCT)

Prevention of Mother to Child Transmission (PMTCT)

Treatment

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Anti-retroviral therapy
EID	Early Infant Diagnosis
EPI	Extended Programme for Immunization
HIV	Human Immunodeficiency Virus
IMCI	Integrated Management of Childhood Illnesses
LTFU	Loss-to-follow-up
MTCT	Mother to Child Transmission
NIMART	Nurse Initiated Management of ART
PCR	Polymerase Chain Reaction
PHC	Primary Health Care
PMTCT	Prevention of Mother to Child Transmission
UNICEF	United Nations International Children's Emergency Fund
USAID	United States Agency for International Development
UWC	University of the Western Cape
WHO	World Health Organization

DEFINITION OF TERMS

Antenatal: The period before birth whereby care is provided for the pregnant woman to prevent complications (Medical Dictionary Online, 2018).

Adherence: The degree to which a person's behaviour corresponds with the agreed recommendations from a health care worker (Chakrabarti, 2014).

Exclusive breastfeeding: Exclusive breastfeeding is a type of infant feeding where the infant only consumes breast milk. The infant is not given any other products such as water, solids, or other milk. (WHO, 2019).

Healthcare workers: Healthcare workers are individuals whose primary role is to protect and improve the health of people in the community (Joseph & Joseph, 2016).

HIV exposed infant: An infant that is born to an HIV positive mother but is HIV-negative and is at risk of acquiring the HI-Virus (i.e. through breastfeeding) (WHO, 2006).

HIV infected woman: A woman who has tested positive for the Human Immunodeficiency Virus.

Interview: An interview is a conversation between the researcher and the interviewee that occurs for the purpose of gathering information (Easwaramoorthy & Zarinpoush, 2006).

Intrapartum: The period during the act of birth, which is from the onset of labour till the delivery of the placenta (Solnes Miltenburg, Kiritta, Meguid & Sundby, 2018).

Loss-to-follow-up: Refers to a patient who fails to attend the clinic within a specific period after their previous visit (also known as defaulting) (Chi et al., 2011).

Mother to child transmission: The transmission of HIV from a HIV-positive mother to her HIV-negative infant through pregnancy, labour, delivery, or breastfeeding (Ramoshaba & Sithole, 2017).

Option A: WHO implementation plan for HIV treatment in which individuals are started on HIV treatment if their CD4 is below 350 (Coutsoudis et al., 2013).

Option B: HIV treatment option where HIV pregnant women start treatment from 14 weeks of pregnancy until birth or cessation of breastfeeding. The infant uses NVP

syrup up to 4-6 weeks of age (Coutsoudis et al., 2013).

Option B+: Treatment option that advocates for lifelong ART as soon as a pregnant woman is diagnosed as HIV positive and infant receives NVP for 4-6 weeks (Karnon & Orji, 2016).

Opt-out testing: Opt-out testing is HIV testing offered where consent of the offered test is assumed unless the patient specifically refuses it (Leidel, McConigley, Boldy, Girdler & Wilson, 2015).

Postpartum: The period after childbirth (MedicineNet, 2018a).

Prophylaxis: Treatment given in order to prevent infection from a disease (MedicineNet, 2018b).

Qualitative research: Qualitative research is research that is associated with a subjective quality of a phenomenon, it is not quantified, instead it is expressed in words. Qualitative aspects are abstract and do not require measurement (Taylor, Bogdan & DeVault, 2016).

Retention in care: Refers to patients connected to medical care after initiation, patients that are known to be alive and receiving routine treatment at the end of a follow-up period (Geng et al., 2010).

CHAPTER 1: INTRODUCTION AND BACKGROUND

1.1 Introduction and background

The Human Immunodeficiency Virus (HIV) pandemic is the most severe health challenge affecting children across the world and it is estimated that more than 90% of all HIV infections in children result from Mother to Child Transmissions (Ramoshaba & Sithole, 2017). Banja and Gebrehanna (2020) state that more than 50% of postnatal transmission in the first 6 months of life is due to breastfeeding. In an HIV-infected woman, the virus can be transmitted during pregnancy, during delivery, and through breastfeeding (Thomas, Bassi, Continoho, & Goyal, 2017). South Africa is one of the countries worst affected by the HIV epidemic (Khamisa & Mokgobi, 2018). The effect of HIV and AIDS on childhood mortality rates has been marked but the destructive effect was significantly reduced due to the provision of ARVs and the implementation of the Prevention of Mother to Child Transmission of HIV (PMTCT) (Nannan et al., 2019).

The PMTCT programme was implemented as an intervention by reducing the accumulative numbers of paediatric HIV infections (Ramoshaba & Sithole, 2017). The PMTCT programme allows health care practitioners to provide Anti-Retroviral Treatment (ART) to mothers in order to prevent the transmission of the virus to their infants (AVERT, 2018). Without treatment, chances of the virus being transmitted from mother to child is 15% to 45%; however, effective PMTCT programmes have reduced this likelihood to below 5% (Banja & Gebrehanna, 2020). According to UNAIDS (2018), in 2016, South Africa had 4 100 000 women (15 years and older) and 320 000 children aged 0 to 14 years living with HIV. In the same year, 160 000 were new infant infections by means of vertical transmission as a result of 24% of pregnant women not having access to ARV's (AVERT, 2020). Goldberg and Short (2016) state that HIV-exposed children are at increased risk of mortality which is further increased when the mothers are not virologically suppressed. Such children are also exposed to the risk of contracting other opportunistic infections that contribute to the under-five morbidity. Access to life-saving ARV drugs during and after pregnancy have been proven to effectively reduce the risk of MTCT of HIV and to preserve maternal health (Mitiku, Arefayne, Mesfin & Gizaw, 2016). Banja and Gebrehanna (2020) have emphasized that the PMTCT programme is hindered by failure to initiate ART early enough for the

HIV-infected mothers, poor adherence to ante-retroviral treatment, and poor application of the national Option B+ policy.

In South Africa the PMTCT programme was first initiated in 2002 in Khayelitsha, Cape Town's largest township (Nicol, Dudley & Bradshaw, 2016), which had the highest HIV prevalence in the Western Cape - 34.3% of pregnant HIV positive women in 2012 (Stinson et al., 2016). According to the most recent census of 2011, Khayelitsha has a population of 391 749 (Frith, 2019). The national PMTCT programme began with maternal and infant single dose Nevirapine (NVP) and later transitioned to triple ARV therapy in February 2008. The programme has been amended and updated over the years and currently is Option B+, which is the provision of ARV's to all women living with HIV irrespective of CD4 or WHO clinical staging (Goga et al., 2016a). The PMTCT programme is implemented through a comprehensive approach whereby women are given comprehensive antenatal services including HIV testing, implementation of safe childbirth services including counselling on infant feeding, and follow-up of mother and infant in the postnatal period (AVERT, 2018).

The Western Cape PMTCT programme offers HIV testing for all pregnant women and those who test positive are immediately started on lifelong HIV treatment (Western Cape Government, 2018). The risk of transmission is prevented during labour, after delivery and right through the postpartum phase, including monitoring the mothers' viral load every three months for the duration of breastfeeding (Western Cape Government, 2018). The new WHO global health strategy on HIV was endorsed by the World Health Assembly in 2016 and called for all states and the WHO to aim towards the target of zero new HIV infections in infants by 2020 (Banja & Gebrehanna, 2020).

Despite great progress in the implementation of this programme, there is still room for improvement due to the lack of adequate follow up treatment of mothers living with HIV, thus increasing the risk of mother-to-child transmission (Mutabazi, Zarowsky & Trottier, 2017). Goga et al. (2016a) reported that, in 2016, the national target for South Africa of <2% transmission risk at six weeks had not yet been achieved. UNAIDS (2010) and the WHO (2011) shared that the cumulative loss-to-follow-up (LTFU) in sub-Saharan Africa PMTCT programme is estimated between 20-28% during antenatal care, up to 70% after four months after delivery, and close to 81% at six

months after delivery. Retention in care is essential as it provides opportunities to monitor response to treatment, prevent HIV associated complications and reduce the risk of transmission (Yehia et al., 2015). ART and retention of mothers in care are also vital in achieving the goal of eliminating new infections among children at a global level. Mothers who are retained in care are less likely to transmit the virus to their infants and both have improved health outcomes.

There are many strategic interventions that have been put in place to improve the effectiveness of the programme (Mutabazi et al., 2017). Literature highlights the favourable outcomes during the antenatal and intrapartum phases, which is then followed by a reduction in adherence during the postnatal phase (Psaros, Remmert, Bangsberg, Safren & Smit, 2015; Banja & Gebrehanna, 2020). Despite this, there is still a concern that many mother-infant dyads are not retained in care, thus increasing the risk of morbidity and mortality. This prompted the researcher to explore the experiences of mothers in the postnatal phase of the PMTCT programme.

From this background, the study aimed to explore the experiences of mothers living with HIV on the PMTCT programme including challenges experienced by mothers in being adherent in the treatment process of their infants.

1.2 Significance of the study

Vertical transmission of HIV from mother to infant continues to be one of the biggest challenges in the world and the biggest contributor to infant mortality (Wubneh, Endalamaw & Tebeje, 2019). Since the initiation of the PMTCT programme, there has been a substantial decline in vertical transmissions (Burton, Giddy & Stinson, 2015). However, even with improved access to ARVs, utilization of PMTCT services remains suboptimal (Rawizza et al., 2015). The literature review of this study reflects that studies conducted regarding PMTCT services primarily discuss how optimal results have not been achieved and possible flaws in the implementation of the PMTCT programme. However, there is limited information regarding the receivers of the care. Consequently, this study contributes towards understanding the experiences of mothers in the PMTCT programme in a South African context. The understanding on how the mothers experience the treatment process and their perceptions regarding the service offered may offer information which can be utilized toward enhancing the current knowledge, as this information is vital in evaluating the effectiveness of the

programme. The study highlights a holistic approach that will facilitate improved quality of the services rendered. This information could assist in improving the programme outcomes and contribute positively towards the success of the program.

This research provides information that may be used to improve PMTCT services and nurses' knowledge on managing the programme. The information may also prove useful for nursing education institutions. More so in planning the training of primary care nurse practitioners and undergraduate nurses who interact with such mothers and infants during their training, through the understanding of mothers' experiences of being in the programme.

1.3 Problem statement

MTCT remains the most common cause of paediatric HIV infection in sub-Saharan Africa. In the absence of interventions, the risk of MTCT increases (Obai et al., 2017). Globally there has been significant progress in the prevention of mother to child transmission towards the goal of eliminating paediatric HIV infection. Retention of mothers and infants in the PMTCT programme is vital in achieving this goal. Women and children who are retained in care are likely to have better health outcomes and are also more likely to adhere to prescribed treatment (Woelk et al., 2016). Retention in care in the PMTCT programme remains a challenging problem, even though access to ARV treatment and the PMTCT programme has improved (Fayorsey et al., 2016). In the Western Cape, the MTCT rates vary between 3.6% and 7.5% which is still above the global stipulated target of reduction of transmission (Akinsanya, Wiseberg-Fitell, Akpomiemie, Adeniyi & Kaswa, 2017). According to Bhardwaj et al. (2014), the South African government aims to achieve less than 2% transmission rate at six weeks of age, however, current strategies are still not yielding the required outcomes. There are a number of possible reasons for the continued transmission rate; however, there is limited information about patient related experiences with regards to being in the PMTCT programme. An understanding of mothers' experiences of the PMTCT treatment programme is important to be able to obtain information which could facilitate the retention of mothers and infants in the programme and optimize their treatment experience.

1.4 Research aim

The study aimed to explore the experiences of postpartum mothers, living with HIV,

on the PMTCT programme in Khayelitsha, Cape Town.

1.5 Objectives:

- To explore and describe postpartum mothers' knowledge and understanding of HIV and the PMTCT programme.
- To explore mothers' experiences of being in the PMTCT programme.
- To explore mothers' experiences of their infants' treatment process.

1.6 Overview of thesis

Chapter one introduces the study and provides a background to the research. The research aims and its objectives are identified.

Chapter two presents a review of the literature relevant to the topic. The literature is focused on both a national and an international perspective.

Chapter three presents the research design, the setting, population and sampling methods, recruitment of participants, data collection and analysis. In this chapter, strategies to ensure trustworthiness of the study are discussed together with consideration of the ethical principles.

In chapter four the study findings are presented. The themes that emerged through thematic analysis are also presented. Each of the themes and sub-themes are identified and discussed.

Chapter five discusses the findings in relation to the literature that has been published. The researcher lists each theme that was identified and discusses it in depth and the relation to past literature is analysed and discussed in a critical sense. The researcher also shares the limitations that were encountered during the research journey and emanating from the study.

1.7 Summary

This chapter introduced the study and provided the background, problem statement and significance of the study. The aim and objectives were identified.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Reviewing literature is important because it helps the researcher familiarize herself with the topic in depth, provides insight on what has already been studied, and gives a sense of the most important issues that need addressing (Hart, 2018). Hart (2018) further describes it as the critical evaluation and analysis of constructed knowledge relevant to the research problem. The literature review enables the researcher to conceptually understand the topic and to justify the need for the study (Marin, Pathak & Singh, 2017).

This review discusses HIV in breastfeeding mothers in the context of PMTCT and the various aspects related to PMTCT. This literature review is categorized into two themes: PMTCT as a programme, and LTFU. This literature review will be specific to the period 2012 to date as the management of PMTCT has been consistent over this period. The search was conducted using the following key words: PMTCT, Mother to child transmission, experience, treatment, HIV-infected mothers, adherence. Databases searched were Science Direct, Ebsco host, Sabinet, Google scholar and Health source databases.

2.2 Prevention of Mother to Child Transmission (PMTCT)

HIV is transmitted through unsafe sexual practices, contaminated sharp objects, exposure to bodily fluids and vertical transmission from an infected mother to her infant, whether in utero, at birth or during the postnatal period (Kate, Chikee, Ikechukwu & Chuka, 2019). MTCT is the major means of HIV transmission in children under 15 years of age, particularly in resource-poor countries where there is a high HIV prevalence. A global estimate of 2.6 million children below 15 years of age are living with HIV, 88% originating in sub-Saharan Africa (B-Lajoie et al., 2016).

The PMTCT is a global intervention programme that was initiated by the United Nations (UN) to protect children around the world from HIV infection (Nyamhanga, Frumence & Simba, 2017). PMTCT aims to ensure that no child is born with HIV by providing medication and psychological support to assist mothers to protect their infants against the virus, thus ensuring an AIDS free generation (UNICEF, 2017). The PMTCT programme is recognized internationally as being essential in reducing the

incidence of HIV infections in children (Nyamhanga, Frumence & Simba, 2017). The Global Plan was implemented based on the four prongs of Prevention of Mother to Child Transmission (PMTCT). The emphasis was on expanding comprehensive care, eliminating new infections, and to achieve set targets of eradicating any new vertical transmissions by 2015 (Hamilton et al., 2017).

The PMTCT programme has undergone extensive transformation since its initiation and current global guidelines recommend lifelong antiretroviral treatment for all HIV-infected pregnant women (Chersich, Newbatt, Ng'oma & de Zoysa, 2018). In order to ensure comprehensiveness of the PMTCT programme, the WHO and UNICEF have endorsed the following four components:

- To prevent HIV infection in women of reproductive age: This includes offering counselling services and testing, educating on condom use and safe sex health education.
- To reduce the number of unplanned pregnancies in women living with HIV: This includes strengthening family planning programmes for all women and most importantly, giving the opportunity for HIV infected couples to avoid having undesired pregnancies.
- To exercise all efforts in preventing the transmission of HIV from the woman to her infant by guiding the mother, ensuring that ARV care is provided during pregnancy, breastfeeding, and delivery, and to support safe infant practices.
- To provide care and support that is appropriate for women living with HIV and their families (Anigilaje, Ageda & Nweke, 2016).

The WHO (2011) recommended that all HIV-infected women be initiated on a life-long ART regimen as per Option B+ protocol and most countries proceeded to implement this protocol as a means of improving the outcome of the programme (Haas et al., 2017). Many infants become HIV infected as a result of being born to that selected number of mothers who were not initially diagnosed as HIV infected, did not initiate ART, or just had poor adherence to their HIV treatment. The infants that become infected are at a higher risk of mortality as untreated HIV-infected infants do not usually survive beyond the age of two (Ahoua et al., 2011). This is in part due to a compromised immune system which predisposes them to other recurrent opportunistic

infections such as pneumonia, diarrhoea and malnutrition (Yassin & Gebretekle, 2017). The WHO recommends that all HIV-exposed infants are followed up in a structured manner to facilitate prompt HIV diagnosis and initiation of ART. The PMTCT programme is important because these infants are monitored closely and should they seroconvert, they can be diagnosed and treated as soon as possible. The importance of the implementation of the PMTCT is well recognized internationally, however, each country adopts a unique strategy in their attempt to adhere to the global plan of eliminating paediatric infections of HIV.

2.2.1 Implementation of PMTCT: an international overview

There have been a number of approaches to the implementation of PMTCT worldwide. In the United States (US) elective caesarean sections are performed for women with poorly suppressed viral loads and replacement feeding is the norm for infants of HIV-infected mothers (Richardson et al., 2015; Kennedy, Yeh, Pandey, Betran & Narasimhan, 2017). Despite the WHO recommendations of exclusive breastfeeding by all HIV-infected mothers, the US still discourages breastfeeding in all HIV-infected mothers as neither maternal well-being nor ARV prophylaxis completely eliminates the risk of HIV transmission (Levison, Weber & Cohan, 2014; Tuthill, Tomori, Van Natta & Coleman, 2019), and maintains the reduction of perinatal transmission through good access to comprehensive HIV and pregnancy services in conjunction with the avoidance of breastfeeding (Flynn, Abrams & Fowler, 2017).

Mothers who decided to breastfeed their infants in southern Thailand were identified as being immoral and irresponsible for going against the advice of healthcare professionals in avoiding breastfeeding to eliminate the risk of transmission of the virus (Suwankhong & Liamputhona, 2017). As in the United States, Thailand also discourages breastfeeding for HIV-exposed infants even if the mother is on HAART and free formula is provided for infants at risk for up to 18 months of age (Suwankhong & Liamputhona, 2017). Even though these two countries have good intentions in continuing to maintain the old WHO guidelines of discouraging breastfeeding in HIV exposed babies, they have failed to state how such mothers will overcome the issue of social stigma. Breastfeeding is a cultural norm in most parts of the world, mothers who are denied the opportunity to breastfeed their infants stand a chance of having their HIV-status questioned by society at a vulnerable moment. The authors who

conducted the studies in the respective countries also failed to mention what intervention these countries have in place should the infants not tolerate replacement feeding or whether the amount issued will be sufficient till the next date of issue. It is imperative that strategies to overcome these factors are discussed because if they are not prioritized, they can lead to the downfall of the PMTCT programme.

The success of the implementation of the PMTCT programme in Ethiopia lies in the effective execution of Option B+ in treating mothers living with HIV. This protocol was adopted by the Ethiopian government as a national policy to prevent MTCT of HIV and it has been effective since 2013 (Chaka, Abebe & Kassa, 2019). Mothers not taking ARV prophylaxis, absence of PMTCT intervention, urban resistance, and mixed infant feeding practices are significant predictors of MTCT in Ethiopia (Endalamaw, Demsie, Eshetie & Habtewold, 2018). Obsa, Dabsu and Ejeta (2018) investigated the rate of MTCT and factors associated among exposed infants, documenting higher risk of infection in infants who were not given Nevirapine prophylaxis at birth, did not receive cotrimoxazole prophylaxis, infants on a mix-fed diet and those born to mothers with shorter duration of ART treatment, confirming the findings of Endalamaw et al. (2018). However, with this specific intervention that was carried out in 2013, there is prolonged exposure to ART, which may lead to difficulties in adhering to treatment for HIV-infected pregnant women (Adeniyi et al., 2018).

Difficulties with patient adherence is minimized in Ghana through the integration of PMTCT interventions with standard primary care for maternal, neonatal and child health programmes (MNCH), as recommended by the WHO. The integration of MNCH-PMTCT is executed either at a single point of access or at referral institutions at national, regional and district health centre level, that include the private and public sectors (Dako-Gyeke et al., 2016). Other African countries like Malawi are also effectively implementing the Option B+ policy for pregnant and breastfeeding women. All HIV-exposed infants are initiated in the PMTCT programme as soon as they are born with routine follow up visits commencing at 6 weeks. Similarly, in South Africa, infants are pharmacologically initiated on Nevirapine prophylaxis at birth until six weeks and thereafter commence on cotrimoxazole prophylaxis for the duration of breastfeeding or until they are confirmed as HIV-negative.

South Africa has the highest number of people living with HIV in the world, with an

estimated prevalence of up to 40% among public antenatal clinic attendees (Balogun & Owoaje, 2015). New paediatric HIV incidents continue to be reported regardless of the global scale up of PMTCT interventions. In South Africa, the Option B+ protocol is provided to mothers and the implemented PMTCT guidelines recommend exclusive breastfeeding of infants for the first six months of life, while the infant and mother continue antiretroviral therapy, thus increasing the infant's chance of survival through good nutrition from protective factors in breast milk (Balogun & Owoaje, 2015). The variable coverage in PMTCT services has led to missed opportunities for reduction of transmission. In a national evaluation of the PMTCT programme, Goga et al. (2016b) revealed MTCT rates rose from 2.6% at six weeks to 4.3% at 18 months, which highlighted gaps in the programme. Pellowski et al. (2019), in response to these gaps, recommends rigorous application of HIV retesting of HIV-negative mothers during later pregnancies, during labour, and during breastfeeding periods. South Africa continues to test HIV exposed infants using the PCR test during the intervals stipulated in the national guidelines (Mnyani et al., 2020).

In the past, prevention of transmission of HIV meant the provision of ARVs to the mother only during her pregnancy; the mother was not offered any further HIV services postpartum (Stinson et al., 2016). However, in 2000, MSF offered the first services for pregnant women living with HIV and requiring ARVs in Khayelitsha Site B, Cape Town, where there was a high prevalence of persons living with HIV (Stinson et al., 2016). Due to a number of political challenges, Khayelitsha PMTCT sites were only effectively established by 2002/2003. Since its implementation, the PMTCT programme has continued to evolve in Khayelitsha and the treatment policy of Option B+ along with a whole comprehensive treatment strategy was implemented in July 2013. According to Stinson et al. (2016), the implementation of this policy has been remarkably smooth as women are initiated same day with a fixed-dose combination. The current challenge is achieving sustained virological suppression and retaining mothers and their infants in the postpartum phase. Currently, the strategy of Post Natal Clubs (PNC) has recently been initiated in Khayelitsha in an attempt to incorporate mother and child health (MCH). The core benefit of this strategy is the combination of care for mother-infant pairs, timesaving and peer dynamic (Duvivier et al., 2020). The PNC model facilitates the mothers' understanding of HIV transmission, importance of adherence of ART, infant feeding and health, and the importance of follow-up tests. Duvivier et

al. (2020) reports that there is a positive health behaviour in response to peer support amongst mothers and a great influence in the reduction of transmissions.

According to the current UNAIDS estimates, improvement in services to prevent mother-to-child HIV transmission since 2010 has reduced the annual number of new infections among children around the globe. However, the limited available programmatic data on long term residual HIV transmission rates suggest that this is mainly accounted for by reduced in utero and intrapartum HIV transmission rather than in postnatal transmission through breastfeeding. Van de Perre et al. (2017) argued that other individuals who are at high risk of contracting the virus have been more prioritized in receiving beneficial preventive health measures compared to HIV-exposed infants. These individuals include pregnant/breastfeeding women, discordant couples, and sex workers. Van de Perre et al. (2017) argued that infants should also receive Pre-Exposure Prophylaxis (PreP) and that it is immoral and unethical that this has been withheld from such patients considering the evidence behind its effectiveness. The Western Cape Government's (2018) consolidated guidelines for HIV treatment stipulate, under the post exposure section, that NVP prophylaxis be given immediately after birth for a duration of six weeks followed by cotrimoxazole for the duration of breastfeeding should the mother be virologically suppressed.

2.2.2 PMTCT: High-income vs. low-income countries

Low- to middle-income countries bear the overwhelming burden of HIV epidemic with respect to the number of persons living with HIV and AIDS, high grades of viral diversity, and social and economic factors that compromise current control measures (Shao & Williamson, 2012). A country that has had relatively good results with regards to HIV is China. There are, however, remote and poor areas such as Liangshan, in the Sichuan Province that are faced with challenges. Not only does Liangshan have a high incidence of drug trafficking close to the area, but, according to Shao and Williamson (2012), it also has the highest HIV prevalence which contributed to concerning MTCT numbers. The PMTCT programme has been operational since 2009 with a prevalence of 3.83% in women of reproductive age. Even with this implementation, its administration has not been optimal (Ma et al., 2018). On account of the poor socio-economic status, women residing in Liangshan are illiterate and only understand their native tongue which ultimately becomes a challenge when health

messages need to be conveyed, including messages regarding reproductive health. This is further complicated as reproductive and maternal health content is offered in Mandarin text instead of illustrations. These poor socio-economic conditions, inability to access good health care services, economic and political displacement of communities and, to a certain degree, cultural practices and gender inequalities create fertile settings for virus replication (Shao & Williamson, 2012).

Yah and Tambo (2019) investigated reasons why HIV remains a threat to new-borns in sub-Saharan Africa despite the numerous services available to achieve the goal of a HIV free generation. They identified contributing factors such as women of reproductive age not being aware of their HIV status and those who are aware not being on treatment during pregnancy. Routine "opt-out" testing for all pregnant women has long been implemented, predominantly in high-income countries, as it maximizes case discovery and reduces the risk of transmission when ART treatment is commenced (Kate et al., 2019). What is not clear is whether routine "opt-out" testing is really being done and if so, what interventions are available for pregnant women and mothers who tested positive but refused treatment.

Dlamini and Mokoboto-Zwane (2019) stated that the attendance at PMTCT services is directly affected by mothers' knowledge of PMTCT, their psychosocial well-being, the use of ART, and their physical health. Dlamini and Mokoboto-Zwane (2019) further reported that women who have background knowledge about PMTCT are more motivated to be involved in the services. If women understand the importance of the programme, they are more likely to adhere to it. Limited knowledge regarding PMTCT could be influenced by lack of education which is, in turn, related to poverty (Ma et al., 2018). According to Yourkavitch et al. (2018), a woman's psychosocial health is vital in adapting to and adopting any new information including that of the PMTCT services. Her psychosocial health is influenced by the knowledge she possesses regarding PMTCT. If she is in a healthy psychosocial state, which is also influenced by the family support she receives, then she is more likely to engage in her health journey and her psychosocial well-being continues to improve as her condition improves (Yourkavitch et al., 2018). In addition, when a mother discontinues her treatment journey for a long period, it is usually attributed to psychosocial barriers rather than structural barriers that lead to an undocumented transfer of the patients (Igumbor et al., 2019).

Recommended practices in high-income countries include initiation of ART in the antenatal period, proper management during delivery, post-exposure prophylaxis for the infant, and avoidance of breastfeeding (Johnson, Levison & Malek, 2016). Ensuring adherence to prescribed ART remains an area of concern in both high- and low-income countries. It is essential that adherence is monitored and improved upon as it is critical for both maternal health and PMTCT in the postnatal period.

2.3 Loss-to-follow-up (LTFU) contributors

2.3.1 Mothers' knowledge on PMTCT of HIV

Poor awareness and knowledge regarding PMTCT remains one of the major problems in the successful implementation of the programme. In South Africa, the majority of mothers are aware of breastfeeding as a mode of transmission of HIV but have limited knowledge about the other modes of transmission (Oloruntemi & Dudley, 2018). The role of mothers in the treatment process of infants contributes significantly to the utilization of the services. Alemu, Habtewold and Alemu (2018) stated that women who are knowledgeable about HIV prevention are more likely to protect themselves and their families, including their infants, from HIV infection. Those who lack awareness do not understand the importance of PMTCT follow-up services and consequently miss important treatment (Ramoshaba & Sithole, 2017). Ramoshaba and Sithole (2017) hold that, in most cases, women lack knowledge on how they can transmit the virus to their infants and how they can use the available services to prevent such transmission. The mothers' knowledge is proportionate to the prevalence of HIV infections in infants through the usage of PMTCT services (Ramoshaba & Sithole, 2017). Kassa (2018) recommends that PMTCT educational programmes be strengthened to prevent any unnecessary health issues and further challenges mothers' adherence.

2.3.2 Challenges of the PMTCT programme

Low enrolment in the PMTCT programme in sub-Saharan Africa has remained a challenge since its initiation. HIV testing is offered routinely for all women during antenatal care (Yah & Tambo, 2019). However, some women decline the test, which means more missed opportunities. Untested mothers represent the highest risk of delivering HIV-infected infants due to the uncertainty of their HIV-status (Yah &

Tambo, 2019), yet there are still women of child-bearing age living in various parts of the world that are unaware of their HIV status. This could be facilitated by the fact that there is a lack of awareness of susceptibility and testing of HIV (Peng, Wang & Wang, 2017). HIV-exposed infants who are not identified early experience delayed diagnosis and are unfortunately identified when they have severe morbidity (Sowale et al., 2018). There is also a low coverage of mother-child pairs in the programme, this could be attributed to poor insight of the mother regarding HIV and ART importance.

The barriers that limit optimal effects of the PMTCT programme can be categorized as external, internal, or internal-external. External barriers, such as poverty and unemployment, influence adherence. Internal barriers include failure to take action and lack of knowledge. Knowledge is not only low in patients but also in health care workers, which contributes negatively to the effectiveness of the PMTCT programme (Mnyani & McIntyre, 2013). Internal-external barriers include HIV-related stigma, marital disharmony, cultural characteristics, and religious beliefs. Rasmussen et al. (2018) suggests that barriers that limit the optimal uptake of the PMTCT programme reside primarily within the health care system. These can range from the presence of skilled staff at the facility, availability of treatment and counselling rooms, inadequacy of time to deliver PMTCT services, unavailability of resources, and distance to health facilities. Women who are referred to other facilities that offer ART and PMTCT programmes due to the lack of these services at their initial site are inconvenienced and are at higher risk for LTFU (Dlamini & Mokoboto-Zwane, 2019). Due to these challenges, the retention of the mother-infant pair is affected.

2.3.3 Retention of mothers in PMTCT programmes

Retention in the PMTCT programme is complex and should not only focus on continuity of care from the antenatal period to the postnatal period, but also include the variety of factors that impact mother and infant treatment outcomes (Fayorsey et al., 2016). A study in the Eastern Cape, South Africa, focusing on retention of mother-infant pairs reported that only 69% of mothers self-reported complete adherence (Adeniyi et al., 2018).

Approximately 5 % of infants in Malawi were estimated to have become HIV infected at 30 months of age (Haas et al., 2017). Only half of these HIV-infected infants were diagnosed in the PMTCT programme, primarily due to LTFU. Eighty percent of the

infants received Nevirapine prophylaxis upon initiation in the programme, but retention was very poor. Vrazo et al. (2017) suggest that the highest risk of poor retention are mother-infant pairs that are enrolled in the programme at a later stage and those whose mothers were not on ART during pregnancy. As a consequence of poor retention in the PMTCT programme, it is estimated that approximately every second child in the PMTCT programme is undiagnosed. Attempts to improve retention in the programme could contribute significantly towards early infant diagnosis and early initiation of treatment (Vrazo et al., 2017). This could also improve the health outcomes of HIV-negative infants who continue to be HIV-exposed. These efforts to improve should focus on all the aspects that pose threats to retention in care and reduce the possibilities of loss-to-follow-up (Haas et al., 2017).

2.3.4 Consequences of loss-to-follow-up (LTFU)

Follow up visits play a crucial role in providing comprehensive care. These visits allow the health care practitioner to evaluate the effectiveness of the treatment, identify changes, and possible serious problems. Lack of consistent follow-up increases the risk of serious complications that could have been avoided during a routine visit (Global Health Network, 2016). Many infants do not access the full package of PMTCT services due to LTFU which denies EID to HIV exposed infants, immediate initiation of ART for infants testing positive and routine counselling on safe feeding practices (Wohlleben et al., 2017). Infants and children who are not followed up miss out on life-saving services (Kalembo & Zgambo, 2012). A large number of PMTCT LTFU cases occur in the initial stages of the programme (Woelk et al., 2016). Approximately 33% of mother-infant pairs are lost by day 30 after registration into the programme. Haas et al. (2017) recommends an increase with regards to the tracing of children lost in care as well as routine testing at outpatient sites, ensuring all HIV infected children receive timely ART.

2.4 Understanding mother's experiences of being in the PMTCT programme

The mothers' role as an active participant in the PMTCT programme is a crucial aspect towards the production of satisfactory results. Nyati-Jokomo, Chitsike, Mbizvo and January (2019) note the paucity of data with regards to the experiences of mothers in being active participants in the programme. Understanding the mothers' experiences highlights the various decisions they have to make in reducing the risk of HIV

transmission. Therefore, this section explored mothers' experiences of being in the PMTCT programme.

2.4.1 Lack of family support: Role of male partners in PMTCT

Family support, in particular that of the male partner/father was a factor that has been identified as limiting effective participation in the PMTCT programme (Matseke et al., 2017). The women avoided disclosing their status to their partners as they feared rejection and violence, instead the women preferred to disclose to their own mothers and sisters (Nyati-Jokomo et al., 2019).

Nyondo, Chimwaza and Muula (2018) asserted that many sub-Saharan countries implemented male partner involvement in the PMTCT programme with the intention to enhance the uptake of PMTCT services. The participation of the partner to offer care during the pregnancy is also encouraged as well as HIV testing for this partner (Sherr & Croome, 2012). However, PMTCT programs in Africa still find it problematic to reach male partners of women in antenatal care (ANC), as reported in the study done in Burkina Faso (Nyondo, et al., 2018).

Partners with comprehensive knowledge on HIV/AIDS were more likely to be involved in the PMTCT programme than those who do not have that comprehensive knowledge. Sarker, Sanou, Snow, Ganame and Gondos (2017) also attributed low uptake of PMTCT and failure of women to return for their HIV results to poor partners' support. Furthermore, Sarker et al. (2017) suggested that women should engage in discussions about testing with their partners as dropout among those who have discussed HIV testing with their partners was found to be low.

In Malawi, a study by Obermeyer, Sankara, Bastien and Parsons (2019) revealed that male partner involvement increases the uptake of some PMTCT interventions by HIV-positive women. The study notes that male partners need to be considered and treated as a constitutive part of reproductive health and can no longer be excluded from any debate surrounding issues like pregnancy or HIV/AIDS.

2.4.2 Mothers' knowledge regarding the implementation of PMTCT principles

It is essential that mothers are fully aware of how PMTCT is implemented. Nyati-Jokomo et al. (2019) reported how women feared breastfeeding due to a belief of increased risk of HIV transmission to their infants. The women experienced stress

when having to decide on the infant feeding method as there was a possibility of them experiencing judgment associated with HIV. Rowan et al. (2018) stated that it is the responsibility of the health care professionals to improve the patients' knowledge and enhance factors that encourage effective participation of mothers in the PMTCT programme.

2.4.3 Experience of stigma and fear of disclosure of HIV status

Research conducted in Kenya revealed that stigma (28.9%) was identified as one of the factors affecting adherence to treatment with ARVs. This stigma is not restricted to the individual's immediate family as some of the mothers believe that it will not only disrupt their family but that they will also be socially stigmatized in the health setting and outside the clinic (Katushabe, 2007).

Adamu (2009) in a study on KAP (Knowledge, Attitude and Practice) of HIV services in Gombe State of Nigeria, noted that even well-educated people are as likely to have a negative attitude towards people living with HIV as are those with secondary, primary and Islamic education.

The experiences of mothers living with HIV in Zimbabwe revealed that women developed internalised stigma which was a result of the community and health related stigma that was projected to them. The various forms of stigma they were subjected to resulted in them developing low self-esteem and a fragile sense of self-worth. This is similar to the findings of Yator et al. (2016), where women presented with signs of depression due to discrimination after acquiring their HIV diagnosis. Apart from the depressive state contributed by stigma, women living with HIV experience a disproportionate burden of mental health issues (Ashaba et al., 2017). According to Mills et al. (2012), the adherence to ART of women in a depressive state is negatively influenced.

2.5 Summary

Globally there is a common goal in reducing and ultimately eliminating the risk of HIV transmission, however, the strategies implemented are different in each country. It is evident from literature that there are challenges in the PMTCT programme in various countries and that there is a need to support and improve the programme. Reduced retention in the programme negatively affects health outcomes for both the mother

and her infant. Limited local information is available on mothers' understanding and engagement in the PMTCT programme. This study aimed to explore mothers' experiences in being in the programme and what they perceive as factors affecting the treatment process. This chapter reviewed the literature available on the following topics; Prevention of Mother to Child Transmission (PMTCT), Challenges of the PMTCT programme, Implementation of PMTCT: An international overview, PMTCT: High income vs low-income countries, Retention in PMTCT and consequences of LTFU.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

Taylor, Bogdan and DeVault (2016) refer to research methodology as a systematic approach in identifying and solving a noted problem. The research methodology guides the researcher to adhere to a blueprint of steps in carrying out the research process (Grove, Burns & Gray, 2012). This chapter provides a description of the research process, research design, the setting, population, sampling, how access to the participants was gained, data collection and data analysis. Ethical considerations and trustworthiness are also discussed.

3.2 Qualitative research design

This study utilized a qualitative approach. Strauss and Corbin (2015) state that: "by the term 'qualitative research' we mean any type of research that produces findings not arrived at by statistical procedures or other means of quantification" (pp. 10–11). Qualitative research is considered to be an interpretative and descriptive form of research, hence the researcher engaged with the experiences of the participants. According to Leavy (2017), qualitative research is essential in building knowledge and constructing meaning through inductive approaches. This type of research design allowed for a richer and more in-depth understanding of the phenomenon, which enabled the researcher to access the thoughts and feelings of participants, thus contributing to the understanding of participants' lived experiences (Taylor et al., 2016). According to Holloway and Galvin (2016), qualitative research requires the researcher to be sensitive to the perceptions and experiences of the participants, engage with the natural setting and recognize that the 'emic' perspective is the researcher's main focus with regards to the research subjects. The 'emic' perspective is referred to as the insider's perspective which is influenced by the individual's culture (Xue & Kerstetter, 2018). According to Squires and Dorsen (2018), qualitative research is critical for studies across the health discipline and in this study, the mothers' experiences were explored in depth.

The type of approach adopted involved understanding the world as another person experiences it. This helped the researcher gain insight into what it feels like to be the person that is sharing their experience (Austin & Sutton, 2014). The qualitative process

involves explaining human behaviour within the social structure framework that the behaviour has occurred. So, in the current context of health, the researcher explored how the patient feels about “being a patient” (Austin & Sutton, 2014). Qualitative approaches have been used in various studies to disclose potential problems by enabling its participants to thoroughly explain their experiences. (Hammarberg, Kirkman & de Lacey, 2016).

3.3 Justification for adopting a qualitative design

A qualitative approach enables human beings to be understood from “inside” their subjective experiences (Mayoh & Onwuegbzuie, 2013). The researcher wanted to explore how mothers living with HIV experience and engage with the PMTCT programme and the treatment given to them and their infants. The researcher has worked as a nurse in a primary health care setting and has been aware that many health programmes are not always sufficiently understood or taken up by patients who attend the health facilities. The researcher deemed it vital that the experiences of mothers with HIV in the PMTCT programme be explored in order to understand their experiences and challenges.

3.4 Reflexivity

Reflexivity reflects what has been done in the research study by the researcher. In qualitative research, the researcher is required to engage in a self-aware analysis of her role as a researcher in the study (Holloway & Galvin, 2016). Dowling (2006) explains it as the analytical attention to the role of the researcher in a qualitative study. It is also considered to be the manner in which the researcher engages in continuous self-critique and the explanation of how his/her experience influences the stages of the research process. The researcher plays a crucial role as an instrument in the research process. Parker (1994) states that when a researcher acknowledges subjectivity during the research process, he or she is able to account for the reasons for investigating the phenomenon.

The researcher in this research project is a professional nurse and mother to a young child. As much as the researcher could relate to being a mother with a busy lifestyle and having to comply with regular clinic appointments, the researcher did not impose her values and beliefs on the research participants during the interviews. The researcher maintained reflexivity in this research study by keeping a diary in which

she recorded how she felt each day of the research journey. The researcher also used the diary to reflect on current emotional states experienced during the study; this was done in order to refer back to it when writing memos and field notes. This enabled the researcher to adjust her interpretation of what was heard in each interview as needed. The researcher reflected continuously on her role in the research process and focused on the content of the interviews.

3.5 Research setting

The research setting can be viewed as the physical site where the researcher conducts the study (Given, 2012). This study was conducted in the Khayelitsha township of Cape Town, in one of the largest community health care centres. Khayelitsha has one of the highest HIV burdens globally (Berkowitz et al., 2018). In the Western Cape, Khayelitsha has the highest HIV prevalence (Stinson et al., 2016). Patients in Khayelitsha that are on ART account for 17.5% of the total number of people on ART in the Western Cape. In this province, treatment is provided in over 250 clinics, which is approximately 1% of the total number of patients nationally across 3 800 clinics (Kaplan et al., 2017). There has been an increase in the percentage of HIV-infected pregnant women from 19.3% in 2000 to 34.3% in 2012, compared with 29.5 % on a national scale (Stinson et al., 2016).

Khayelitsha is the largest peri-urban township in the Cape Town metropole, located approximately 35km from the city centre and is an area of 43.51 square kilometres. The population is estimated to be 391 749 with an unemployment rate of 38%. Similar to other areas, migration from South Africa's bordering provinces and countries is the main contributor to the high population density in Khayelitsha (Stinson et al., 2016).

Figure 1: Demographic Profile – 2011 Census

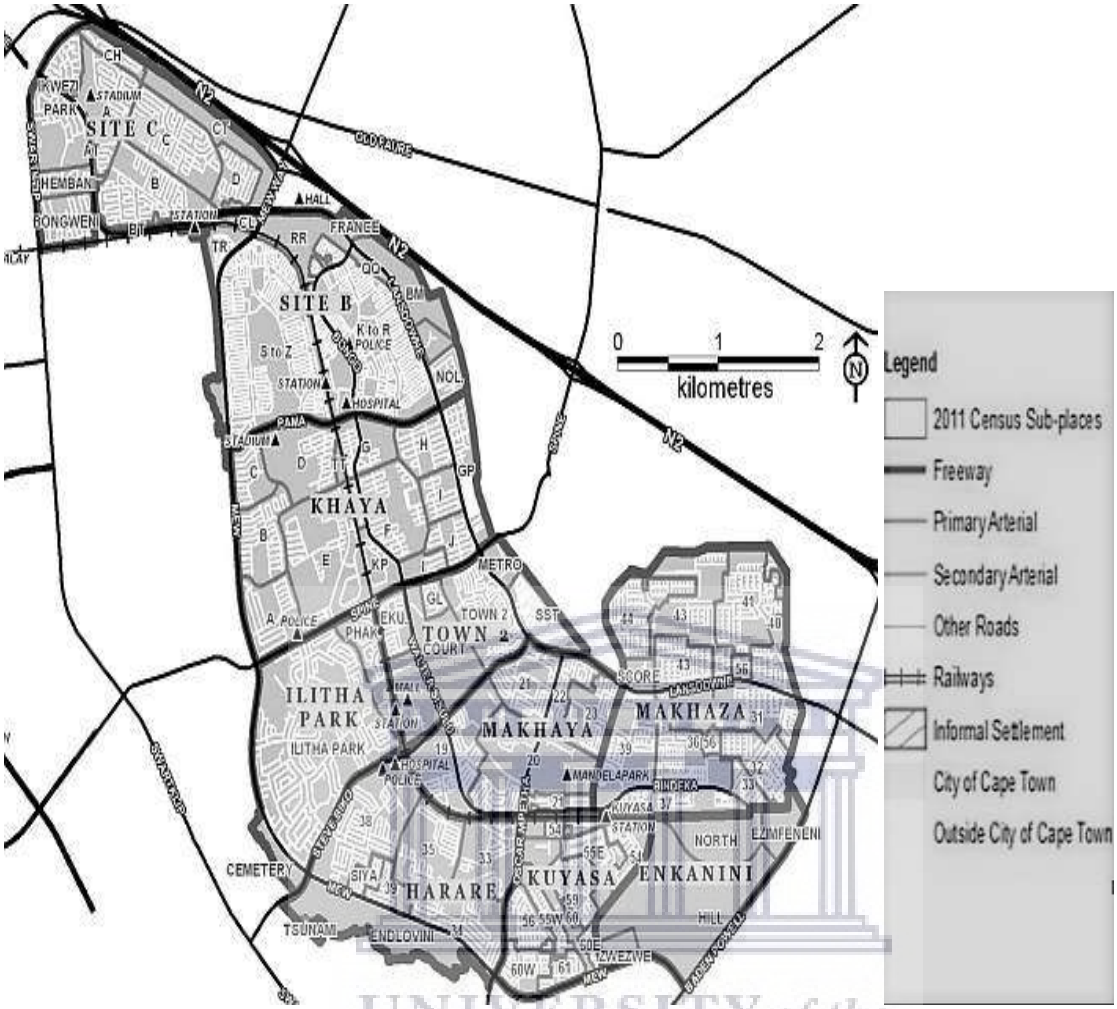
Demographic Profile – 2011 Census

Khayelitsha Population	Male		Female		Total	
	Num	%	Num	%	Num	%
Black African	188 336	48.1%	198 022	50.5%	386 358	98.6%
Coloured	1 024	0.3%	1 291	0.3%	2 315	0.6%
Asian	164	0.0%	107	0.0%	271	0.1%
White	168	0.0%	159	0.0%	327	0.1%
Other	1 869	0.5%	608	0.2%	2 477	0.6%
Total	191 561	48.9%	200 187	51.1%	391 748	100.0%

Adopted: SSA (2019)

Khayelitsha comprises old and new formal areas, as well as new informal areas (figure 2). The environment of Khayelitsha has negative effects on the health of the residents, contributing to a high prevalence of chronic conditions (Smit et al., 2016).

Figure 2: Map of Khayelitsha, Cape Town



Adopted: SSA (2019).

The high prevalence of unemployment and poverty were contributing factors for the choice of this setting as these two factors are known to be contributors of non-adherence as discussed in the literature review. Approximately 63% of households in the Khayelitsha district fall within the low-income bracket, of which 16.5% have no income (Western Cape Government, 2016).

The setting in which data were collected was natural and uncontrolled. Data were collected in an environment in which the participants felt comfortable enough to express themselves.

3.6 Population and sampling methods

A population is a broad group of individuals who possess common characteristics, this group of individuals is the focus of the researcher's intended enquiry. Kenton and Scott

(2020) consider it as the group for which the actual benefit of the research is intended. A sample is a subset that is used to represent the entire population (Cherry, 2018). Sampling refers to the process whereby the researcher selects the sample from the population, where the sample is a representation of the population of interest.

3.6.1 Population

Approximately one fifth of women of childbearing age (15–49 years) in South Africa are HIV-infected (Statistics SA, 2018). According to Stinson et al. (2016), in 2012, 34% of pregnant women in Khayelitsha were HIV-infected. For this research, the target population was mothers who had been diagnosed as HIV-positive with exposed but HIV-negative infants who were being managed in the PMTCT programme in the health facility in Khayelitsha. The participants that were included were mothers who have been in the programme since initiation, mothers who seldom participated in the programme, and mothers who were recently initiated into the programme. The researcher's experience of working in this particular field as a professional nurse in a different clinic, under a different district, directed the selection of this sample due to the different experiences that were anticipated from participants who had attended the programme in each of the above categories.

3.6.2 Sampling

Non-probability purposive and snowball sampling were sampling methods used to collect data in this study at the Khayelitsha community health centre. The inclusion and exclusion criteria are described in Table 1. The researcher initially purposively selected participants who met the criteria. Snowball sampling was then used as the researcher requested the participants to refer the researcher to other possible participants who might be willing to share information about their experiences. The final number of research participants was influenced by data saturation. In this study 11 mothers were interviewed.

Table 1: Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
• Women 18 years of age and older diagnosed HIV-positive (on ART) who had given birth to HIV- exposed infants • Mother-Infant pair recorded on the PMTCT register • Able to communicate in English and Xhosa	• Mothers who could be included but were unable to due to limits such as illness, time constraints • Mothers who were unwilling to participate. • Mothers who were attending routine wellness visits and were newly diagnosed as HIV-positive with young infants

3.7 Gaining access to participants

Participants were recruited by means of mediated access. Mediated access is accessing participants through the assistance of gatekeepers. Gatekeepers are healthcare professionals with access to potential participants for research studies who recommend which potential participants to approach and also request consent from the participants to be approached by the researcher about the study (Preston et al., 2016). Healthcare professionals were requested to give potential participants a verbal explanation of the study. Those who were interested to be involved in the study were recruited during routine follow up visits and they were only considered as a confirmed participant after retrieval of a completed informed consent form. This mediated access technique is important as it ensures that the health status and HIV-status of the participant is shared with the researcher by the healthcare professional with the consent of the participant when they agree to be approached by the researcher.

3.8 Recruitment process

After the researcher received permission to conduct the study from the Department of Health (Appendix H), the researcher approached the facility manager to obtain consent to conduct the study in the facility. In order to access potential participants, the health care professionals were approached to request their assistance in identifying appropriate persons. This was done so that there was no undue influence or pressure on potential participants to protect their privacy.

Mothers who expressed interest in participating were then contacted by the

researcher, either at the clinic or at a subsequent time and place suitable for the participant. The researcher explained the rationale of the study and their role as the research participants. The study was verbally explained to the potential participants along with what was required of them, the advantages and disadvantages of their participation, and the aim and the purpose of the study. Those who were willing to be involved were given information sheets (Appendix A and B) that provided further explanation and a consent form (Appendix C and D) to complete. The participants were informed of their right to voluntarily participate and the right to discontinue at any point. They were informed about the use of audio-recordings, which was stated on the consent form.

3.9 Pilot interview

A pilot study is considered a crucial part of the research process and it is advisable that the researcher conducts one for the ultimate benefit of the research (Malmqvist, Hellberg, Möllås, Rose, & Shevlin, 2019). A pilot study is conducted in order to test the feasibility of the main study by testing and validating all the procedures of the main study, including assessing the inclusion and exclusion criteria of the study (In, 2017). According to Malmqvist et al. (2019), pilot studies are most essential with regards to health inquiries in the nursing and medical profession.

In qualitative studies, a pilot exercise "relates to identifying specific methodological and epistemological issues so that researchers can affirm, sharpen, or revise how to pursue and achieve their goals in their proposed studies" (Kim, 2010).

A pilot interview was conducted prior to the main study in order to explore the practical aspects proposed in the main study. The pilot interview also enabled the researcher to gain experience with the phenomenon of study, the methodology and the setting. The pilot interview was conducted with one participant who met the study inclusion criteria. This interview was conducted to ensure that the questions in the interview were clearly formulated and understood by the participant, to assess the time required for the interviews and to refine the interview skills of the researcher. The most important aim of the pilot interview was to increase the quality of the research (Malmqvist et al., 2019). Data collected from the pilot interview were included in the main study, as valuable information was produced and no changes were applied to the interview guide.

3.10 Data collection

Data refers to information collected during the course of an investigation for reference and analysis (Surkis & Read, 2015). Data collection is the process of abstracting relevant information from the subjects under investigation (Geurink, 2014). In this study, data were collected in the form of interviews. The researcher began by recognizing that one's world view exerts significant influence on the research, especially considering her current role as a professional nurse in a setting similar to that of the proposed study. Understood or not, this world view has an impact in the way research questions are raised, and how the research is conducted (Hammarberg, Kirkman & de Lacey, 2016).

The research study was conducted with HIV-infected mothers with their infants who were registered in the PMTCT programme. Data were collected from the participants by means of face to face interviews and field notes were taken (Creswell, 2014). An interview guide was designed with questions which aimed to explore the mothers' experience of the treatment process of their infants, including possible challenges and possible factors that enhance adherence, and to elicit the mothers' perspectives on their infants' treatment process during the PMTCT programme (Appendix D). A topic guide containing broad questions was used to ensure flexibility of individual questioning (Lingen-Stallard, Furber & Lavender, 2016). The rationale for collecting data by these means was to provide a deeper understanding of the mothers' experiences.

The interviews took place at the health facility in a quiet consultation room. The interviews were conducted in Aug 2019 and over a period of three weeks. No more than two interviews were conducted each day. During the interviews, probe follow-ups were used in order to enhance detailed exploration. Brink et al. (2012) define probes as prompting questions that encourage the participant to elaborate on what was asked. Using probes also assisted the researcher to clarify and expand responses, thus enhancing rapport. The interviews were conducted in the participant's preferred language. The duration of the interviews was approximately 45-60 minutes. The interviews were audio-recorded for the participants and field notes were taken for any non-verbal aspects (e.g. gestures) that could contribute to collection of rich data. Field notes documented were observational, reflective and descriptive and they were used

to inform analysis of the data.

A total of 11 interviews were conducted, at which point data saturation was achieved, as no new information was forthcoming. Data saturation is a criterion used in qualitative research to discontinue data collection (Saunders et al., 2018). It is said that data saturation is reached in the research process when the collection of data yields no new content, this redundancy informs the researcher that the data collection process may be terminated and enough data were collected to achieve the research purpose (Faulkner & Trotter, 2017). Due to the constraints of making further contact with the participants, member checking was not done.

3.11 Data analysis

Data analysis is the process of bringing structure and meaning to the mass of collected data (Vosloo, 2014). Analysing qualitative data entails a subjective approach of exploring in depth the information presented in words; this process also involves forming themes and categories by tracing similarities and differences from an immense amount of data (Friese, 2019).

Interviews were transcribed verbatim by the researcher and were listened to while reading the transcriptions. The interviews which were conducted in IsiXhosa were translated into English and back translated to ensure accuracy. The researcher translated the interviews as isiXhosa is her home language and she is fluent in English. Data was organized and analysed using the ATLAS ti 8.0 which is a software used to analyse, interpret and contextualize the data by generating codes (Strubing, 2005).

The researcher read and re-read all the transcripts to get a sense of the entire data and doing initial coding as she read. The researcher also made notes and wrote down her opinions after the analysis of each transcript. This helped the researcher form the codes, redefine the codes and later form the categories. The codes were based on similar phrases that emerged from the transcribed interviews. Thematic analysis was used which is associated with inductive approaches and identifying themes that emerge. It was used for the purpose of producing trustworthy and insightful findings and was also beneficial in finding patterns in the data that relate to the aim. The interpretive approach of thematic analysis focused on the individual and aimed to discover how their life experience, background, and psychological make-up influenced

the way they experienced the phenomena (Parahoo, 2014). Clarke and Braun's (2017) six steps of thematic analysis were used in analysing the data. The six steps comprise:

- Familiarization with the data: The interviews were listened to and notes made.
- Generating initial codes: Certain segments in the raw data were marked and given a code.
- Searching for themes: Separate spreadsheets were compiled in which all codes were entered, similar codes were identified and put into similar themes.
- Reviewing the themes: In order to ensure validity, the themes were reviewed. The researcher re-read the themes and made revisions where necessary.
- Defining and naming the themes: The researcher went through the data and the themes to ensure that the themes correlate with the captured data.
- Finally producing the report.

3.12 Trustworthiness

Trustworthiness is defined as the believability of the researcher's findings, all that the researcher has done in planning, implementing and reporting the research to make the results credible (Moyo, 2007; Korstjens, Moser, 2017), and is the demonstration of the true value of the research findings. It is suggested that establishing the trustworthiness of the study increases the readers' confidence that the findings are worthy of attention (Connelly, 2016). For this research study, credibility, transferability, confirmability and dependability were used as trustworthiness criteria to ensure rigour of qualitative findings (Vicent, 2014).

3.12.1 Credibility

Credibility is the assurance that can be placed in the truth of the research findings. Credibility establishes whether or not the findings of the research are a true interpretation of the participants' experiences and that the information corresponds with the original data collected from the participants (Vicent, 2014). The researcher interacted and spent adequate time with the participants to allow for the collection of rich data, for the in-depth understanding of the participants' experiences, and for the development of a trusting relationship between researcher and participant. The researcher made use of reflexivity to enhance the credibility of research findings.

3.12.2 Transferability

Transferability is a type of validity that focuses on the applicability of the findings in one study for use in practice or further pursued research (Moon, Brewer, Januchowski-Hartley, Adams & Blackman, 2016). The data collected in the current study should be applicable in a different context with other participants (Brink, Van der Walt & Van Rensburg, 2012). In this study, transferability is facilitated by the provision of a detailed description of the study, the collection of data, and its analysis.

3.12.3 Confirmability

Confirmability implies the degree to which the findings of a research study could be confirmed or corroborated by other researchers and the collected data is a true reflection of the information provided by the research participants and is not changed by the researcher (Fords, 2016). The researcher kept detailed notes to provide a clear audit trail of how themes and sub-themes were decided upon.

3.12.4 Dependability

Dependability includes the aspect of consistency, it refers to the stability of findings over time (Korstjens & Moser, 2017; Brink et al., 2012). The researcher promoted dependability through the use of the same interview guide with all the research participants. Participants' characteristics are described. The researcher also made reflective notes of interviews and meetings with the participants.

3.13 Ethical considerations

Ethics refers to the manner that the research participants are treated by the researcher during the research process, the researcher ensuring the rights of the research participants remain protected (Brink et al., 2012). Formal approval to conduct the study was obtained from the Bio Medical Research Ethics Committee of the University of the Western Cape (Appendix G). The Western Cape Department of Health gave permission to conduct the study in one of their health facilities (Appendix H); thereafter the sub-district manager and the health facility manager granted the researcher permission to access the selected facility to collect data (Appendix H). Participants were informed of the aim and objectives prior to being part of the proposed study. All participants were given an information sheet and an informed consent form that they were required to complete after information about the prospective study had been

discussed (Appendices C and D). It was made clear to all the participants that participation was voluntary and completion of the consent form confirmed their willingness to participate in the research study. Vulnerable populations such as those who are exposed to poverty, limited health care facilities, illiteracy, limited understanding of scientific research are risk factors exploitation (Emanuel, Wendler, Killen & Grady, 2004). Although Khayelitsha had characteristics synonymous to these, the researcher was guided by ethical guidelines that minimized this risk of this exploitation. These included adherence to the principles of dignity, respect for persons beneficence, non-maleficence and justice.

The principles of the Declaration of Helsinki were adhered to (World Medical Association, 2013). This declaration is a set of ethical principles developed by the World Medical Association (WMA) regarding experimentation on human subjects and protecting patients involved in medical research (Skierka & Michels, 2018). This study incorporated the following ethical considerations:

- The health, well-being, and the rights of the participants were safe guarded at all times by assessment of the risks and benefits for the participant.
- The researcher informed all the research participants about the risks (risks including possible loss of confidentiality and psychological risks such as; anxiety, depression, guilt, shock, loss of self-esteem or any altered behaviour), burdens, and benefits of participation. In a case where a participant required further support, provisions were clearly stipulated in the information sheet (Appendices A and B).
- As part of informed consent, all information was disclosed to the participants including what was expected of them, level of confidentiality offered, the right to decline participation, and their right to withdraw consent at any time without reprisal.
- The researcher ensured respect for all the research participants by accepting the truth value of the information the participant was willing to share, putting the participants' preferences first.
- The dignity and the right to self-determination of the research participants was protected by respecting the participants' privacy, autonomy, and providing for

emotional support where necessary.

- The researcher ensured confidentiality with regards to personal information of the research participants by not sharing information with anyone and also replacing participant names with codes.
- The research was conducted in such a way that no harm was inflicted on the research participants (Non-maleficence) (Appendices A & B) This was ensured by handling the participants' information with care and minimizing the risk for loss of confidentiality by only collecting personal information that was absolutely essential to the research.
- The researcher exercised equitable selection process for the research participants (Justice); no individual received certain preferences over another due to race, fluency in a particular language, or any other factor.

3.14 Summary

This chapter discussed the methodology and research process. The study design, setting, population and sampling methods, recruitment process, data collection and analysis were described. Trustworthiness of the study (transferability, confirmability, dependability) and ethical considerations were discussed.

CHAPTER 4: FINDINGS

4.1 Introduction

In this chapter, the findings of the study are presented. The purpose of the study was to explore mothers' experiences of being in the PMTCT programme. Clarke and Braun's (2017) six step thematic analysis approach was used to analyse the data. Six themes emerged during data analysis: *Knowledge of HIV/AIDS and PMTCT programme, Experience of living with HIV and being in the PMTCT programme, Support system, Health care system experience, Raising the HIV-exposed infant and Novel and unanticipated challenges*. Each theme will be presented and supported by verbatim quotes from the participant transcripts.

4.2 Demographic Profile of Participants.

Interviews were conducted with 11 women living with HIV who were in the PMTCT programme. The participants' ages ranged from 22-39 years. All participants had infants that were being cared for in the PMTCT programme (Table 2).

Table 2: Participant profiles

Interviewees	Age	Marital status	Infant's age	No. of children	Feeding
Participant 1	27	Dating boyfriend	4 months	1	Breastfeeding
Participant 2	30	Married	6 weeks	4	Breastfeeding
Participant 3	27	Dating boyfriend	6 weeks	1	Breastfeeding
Participant 4	25	Dating boyfriend	14 weeks	1	Breastfeeding
Participant 5	29	Single	6 weeks	2	Breastfeeding
Participant 6	23	Dating boyfriend	9 months	1	Breastfeeding
Participant 7	39	Dating boyfriend	6 weeks	3	Mixed feeding
Participant 8	35	Married	9 months	3	Breastfeeding
Participant 9	29	Married	5 months	4	Breastfeeding
Participant 10	33	Married	10 weeks	3	Breastfeeding
Participant 11	22	Single	14 weeks	1	Breastfeeding

4.3 Themes and sub-themes

Each theme is presented with its subthemes as indicated in Table 3.

Table 3: Themes and sub-themes

THEMES	SUB-THEMES
Knowledge of HIV/AIDS and PMTCT programme	Mothers' understanding of HIV Mothers' knowledge regarding PMTCT programme Mothers' knowledge regarding reducing ways of transmission
Experience of living with HIV and being in the PMTCT programme	Immediate thoughts after testing HIV positive Testing HIV positive Perception about being pregnant and HIV infected Experience of taking ARV's Mothers' observation of routine consultation
Support system	Marriage partner support Family support Community support
Health care system experience	Health system factors Concerns regarding health care workers' attitudes
Raising the HIV-exposed infant	Breastfeeding experience The infants' test results Motivators of bringing the baby to the clinic
Novel and unanticipated challenges	Limitations to the infant's clinic visit Disclosing mothers' HIV status to the child Missing the child's appointment

4.3.1 Theme 1: Knowledge of HIV/AIDS and PMTCT programme

This theme discusses the mothers' knowledge about HIV, AIDS and the PMTCT programme. The participants were aware of their HIV status but did not fully understand what it meant to be living with HIV. It was difficult for them to explain what it meant. The participants also struggled to define it in their own words.

4.3.1.1 Mothers' understanding of HIV

Participants were knowledgeable about their HIV status but could not explain what HIV is and how to continue living a healthy life with HIV. Participant 2 expressed her understanding of HIV:

"I don't really know sis, I don't want to lie. But I just heard HIV and that it can kill you- That's why I am also scared" [P: 2]

Participant 6 also found it difficult to explain what HIV is:

"It would be very difficult for me to explain what it is because I can't explain what it is. I can't say it is this and that" [P: 6]

For some participants there was a strong belief that the transmission of the HI-Virus was from a genetic origin, as expressed by this participant:

"Bubele, my big brother is HIV-positive. It was first my sister, they found out she is positive…I asked him why are all of us going to be HIV positive? That is what I also keep asking myself, what is making us all positive?"

The participant and her mother had the same beliefs:

"And even when I disclosed to my mother, she was shocked and said maybe this is a family disease" [P: 2]

They referred to families where one person was diagnosed with HIV and other family members also ended up being diagnosed with HIV. Participant 5 stated:

"No, I have seen it before. For instance, next to my home. There was an aunt, she was positive and all the children after that" [P: 5]

For Participant 2 it was difficult to deal with:

"Even when my younger sister, in the rural areas, they said she is also positive. So, they said Bosh is positive, but I was like "no ways" and they are lying" [P: 2]

Participants were concerned about the lack of support they received from the clinic staff. They felt that their level of knowledge was influenced by the information that was passed on to them by the health care professionals they encountered on their treatment journey. Participant 7 stated:

"To be honest, I don't want to bad mouth other people neh, but I think some other nurses or whoever is in the profession, in this government thingy, they are doing jobs that they don't like because she never explained it to me, she just told me I am HIV positive, and no counselling no nothing" [P: 7]

One participant, prior to being diagnosed with HIV, had been working for a Health

Technology Assessment organization after completing her high school education. During her employment she had completed a short course about HIV prior to her work of door to door supportive visits to assist people in adhering to ART. She reported that she was already knowledgeable about the disease when she contracted it, thus she had coped with her HIV diagnosis. She described how she would share regarding her knowledge about HIV:

> *"I would explain it to them that HIV is a virus. With it being a virus, it's a type of virus that lives in your blood, it is controllable. Controlling it involves you taking treatment, you need to take your treatment properly. If you are supposed to take Bactrim, then you take your Bactrim, that time we were taking Bactrim, and we did, you also need to eat healthy. When you have the virus and you are HIV positive, it doesn't mean your time is over, it's not a death sentence, you don't die. The only thing you have to do is live with it, and you are able to control it. But controlling it depends on your lifestyle. For instance, if you were diagnosed as HIV positive and drink alcohol, you need to stop drinking because when you drink, you will end up forgetting to take your tablets. So, there are certain things you will have to give up on for your health"* [P: 8]

4.3.1.2 Mothers' knowledge regarding the PMTCT programme

Participants had very limited knowledge about the PMTCT programme or why they were part of it. PMTCT was a term they heard for the first time from the researcher. Some participants were unclear about the purpose of the programme and the importance of exclusive breastfeeding. Participants were also unaware of their role in preventing the risk of transmission to their infants:

> *"What's that?"* [P: 1],

was the response from one participant, and another stated:

> *"I don't have any knowledge about that"* [P: 4]

Despite the length of time they had spent in the programme, participants expressed concern about the process:

> *"Ja...would like to ask neh, uhh…now my infant is four months, now he is negative neh and I am breastfeeding, uh is there any chances that he will be negative forever or maybe someday he will be positive just because I am breastfeeding?"* [P: 1]

This participant had a concern about feeding:

"Wait, I just want to ask, now that I might go back to work. They say we shouldn't feed them now. So, is there really a problem when you feed the infant?" [P: 3]

Participants were also unclear about the effectiveness of the treatment:

"What I would like to know is, seeing that my child is negative now, will she always remain negative? If I continue to take my treatment and all that. I want to know if there is really nothing that will make her positive now?" [P: 6]

4.3.1.3 Mothers' knowledge regarding reducing ways of transmission

The main objective of the PMTCT programme is to eliminate transmission of the virus to the infant. Participants were asked to reflect on how they think the risk of transmission could be reduced. It was easier for participants to respond when the question related to reducing risk of transmission of HIV to their infants. When phrased in relation to mother-infant transmission, a participant responded:

"I have to take my tablets and I mustn't give him like pap, water. I have to breastfeed him only until he is 6 months" [P: 1]

For this participant, her understanding was related to the medication*:*

"Don't you protect them by taking your medication" [P: 2]

One participant found it difficult to understand. When asked how she would advise a newly diagnosed mother on how to reduce ways of transmission to her infant, she said:

"She must drink her medication that she gets from the clinic all the time and at the time she is supposed to drink it. They also told us not to mix-feed, to breastfeed until 6 months, because if you mix-feed and give food, then the medication they drink gets washed away when you are giving other things. If you don't give other things, then the infant will be alright. Even now ... she tested and was negative but we going to test again next month" [P: 5]

Another mother corroborated that mechanism of prevention, as shown in the quote below:

"What I do is that I make sure my virus is suppressed, so I take my treatment the way I always take it … he also gets medicine that he is given to drink, I have to make sure he drinks his medication. Another thing I do is breastfeed exclusively. We are told at

the clinic not to feed the infants until they are 6 months old, not to give water or formula. If they are on the breast then they should be on the breast only, so I follow that advice. I don't want to have that thing of "Ok, I must feed this child food" then if the child gets positive, I will know I am to blame" [P: 8]

4.3.2 Theme 2: Experience of living with HIV and being in the PMTCT programme

This theme describes how mothers experienced living with HIV and being treated in the PMTCT programme. For some participants, it was difficult reliving their experiences and they became emotional while sharing them. Participants shared how they struggled with social acceptance and stigma during their time in the programme.

4.3.2.1 Immediate thoughts after testing HIV positive

Participants expressed how hurt and disappointed they were about their acquired HIV status. It was described as a rollercoaster experience by participants and difficult to accept. As with any diagnosis, there was a fear of the prognosis and overall health. The manner in which they contracted the virus and the implications of this caused much emotional distress. One participant was so overwhelmed that she wanted to process the news of her new HIV status alone:

"I was so emotional, I was crying the whole day, just because I didn't tell anyone" [P:1]

Participant 5 found comfort in reflecting and remembering that her relatives have the same diagnosis but are living healthy lives:

"When I first found out, I thought I was going to die. It's a disease that has killed people. But then I told myself no! most people, like my mom and dad are fine, they still living. If I drink my treatment well, I will be like other people." [P: 5]

Participant 10 was not only fearful of her new diagnosis but was also fearful of the risk of transmission to her infant:

"I was very scared. The first thing that came to my mind was that I am going to die. Then I was informed about the baby, that I am going to give birth to a HIV positive baby." [P: 10]

One participant had not completely accepted her HIV status. Although she was following health advice and living a healthy life, she felt overwhelmed by the betrayal and emotion associated with being infected with HIV:

"Even now I haven't accepted it completely, but I have accepted it in a way because it won't go away…he wasn't honest that he is HIV positive but then we broke up and I found out I was positive. So that is the most hurtful part for me, is that I was sitting with one person but I am still going to get this" [P: 6]

Participant 9 tried to hold her tears back as she spoke:

"I have accepted it but when I go back and think about how I contracted this disease, it's not easy, it's very hurtful to talk about it."

4.3.2.2 Testing HIV positive

Participants had not anticipated the HIV diagnosis. As they suspected that they may be pregnant, they had attended a routine clinic visit. HIV testing is a standard component of routine antenatal care. Participant 4 had gone for her routine family planning visit but was advised to have a pregnancy test:

"I was going for family planning when I found out, and they told me to buy a pregnancy test … I tested positive for pregnancy then they referred me to the Maternity Obstetrics Unit." [P: 4]

One participant had tested negative during pregnancy then tested positive during labour. Because of the uncertainty of the period during which her status changed; her infant also tested HIV-positive. Due to complications during the delivery period, her infant also became deaf:

"I went into labour … at the hospital they told me since I don't have my maternity book with me, they are going to test me again … I delivered on the 7th and they tested me on the 8th or 9th… So that's when I found out I am HIV positive, 2013." [P: 5]

Participant 7 was initially tested after she became unwell. She had been incorrectly diagnosed with TB, but as she was on ART, was HIV negative during her pregnancy. She was excited when she was told she could breastfeed but was not informed of being positive and breastfeeding. She was concerned that she might transmit the virus to her infant as she had not been consistently adherent. She had not disclosed her HIV status to her boyfriend who is the father of her child:

"Uhm ...It was a roller coaster. You know why I am saying that? Because I knew all these years that I am positive neh, so now I got pregnant. So obviously I needed to go test again, to do an HIV test and all that. And then it came out negative, twice!" [P: 7]

The participant was upset during the interview. She expressed how she felt violated and how confused she was:

> *"I think our lives depend on doctors and then things like these happen, you expect them to explain how it happens. From this to this, and this is how it happens. I am taking treatment every day. So apparently it happens that it...what? Suppresses? My thing. So, there they couldn't explain, you understand? So now my question is…What if I was wrongly diagnosed? You know why I am saying what if I was wrongly diagnosed? Because they were using the same tests in 2012 till now, and then they come back to me to say uhm…they are going to draw bloods, and this blood that they are drawing is 100%.... So, if it says negative, so I find it strange that I can be positive all these years, and end up negative. So now I am waiting for those results. Because they are telling me they will know everything from that, from the tests they took, the blood they took."* [P: 7]

4.3.2.3 Perceptions about being pregnant and HIV infected

The participants' greatest concern after testing was not the HIV diagnosis itself nor the treatment, but the fear of transmitting the virus to the infant. It was such an overwhelming fear that some considered terminating the pregnancy:

> *"In terms of the infant? Well it was like must I do abortion? But I was like joh I want this infant, but what if it's positive, what am I going to do. So, it was too much for me at that time."* [P: 1]

Participant 4 had also considered the option of termination, but her partner reassured her of his support, and she reconsidered:

> *"I couldn't handle it at first, I wanted to abort the infant but then again that wouldn't get rid of the HIV… but then again I told myself if I take my treatment well then I will be fine and the transmission to the infant will be prevented. I told my boyfriend… he told me not to terminate the infant, he will support me throughout"*

One participant had witnessed a relative going through the challenges of raising an HIV infected infant. She had seriously considered terminating the pregnancy because of this:

> *"I told myself that I am going to give birth to a HIV positive infant. And in my head, I was thinking I wanted an abortion. Like, I have an aunt that is HIV positive … I saw how she struggled with her child. I had that thing too, that I didn't want to go through*

that stage … I told myself I don't want to go through that. It's just best I abort and just know that I deal with it alone and not involve the child in all that." [P: 6]

Concern about the risk of transmission to the infant was for some a greater concern than being HIV positive oneself. For this participant, whose children were born prior to the current lifelong ART protocol, it has been very stressful:

"I wasn't really stressed about me being positive, but my infant was stressing me out. That time we didn't have anti-retrovirals, you only had to drink one tablet when you were in labour… They only gave us that one pill, Bactrim to take when you went to deliver the baby. So, I had that concern of whether or not I will transmit the virus to my infant. My fear was that the virus is not transmitted because he is innocent. But God intervened because all four of my children are HIV negative." [P: 8]

4.3.2.4 Experience of taking ARVs

The consumption of ARVs is related to the risk of transmission. Participants revealed how their consumption of ARVs was related to their treatment adherence which ultimately affects the risk of transmission. They shared what it was like to consume the medication on a daily basis and the experiences of them not taking it at certain times. They also expressed the terrible side effects experienced with the medication:

"Yho. You don't want to know, I was going crazy. The first day I took it, I was alone and my boyfriend wasn't there. Because he didn't know what was going to happen, neither did I. But they did tell us that I would have bad dreams, you might hallucinate and all that they said, but I didn't know what to actually expect so I drank them. Yho, I was seeing weird things, crying at night. I was all by myself because I lived alone." [P: 6]

"Yes, the child too. The medication has that bitter taste. It was difficult at first to administer the medication. Because he can taste the bitterness then he doesn't want it" [P: 5],

was the experience of one participant whose child is on ARVs due to MTCT.

Participant 7 admitted to not being as adherent as she should be to her treatment, as she often misses the time that she is supposed to be taking it:

"Yes, because it keeps me awake, sometimes I don't sleep. If I do sleep, I sleep when the baby sleeps. If she wakes up at 00:00 then I only get up, past my time (tablet time), you understand?" [P: 7]

Some participants recognized their struggles in being adherent to their treatment and made an attempt to improve their treatment experience:

"That was actually the most challenging of it all, having to take treatment every single day. Shortly after I started, I used to forget to take it. I used to take my tablets from Langa clinic, but I spoke and I informed them. I used to even forget my appointment date. So I spoke up and I was sent for counselling before I started ARV's, but I couldn't accept this thing of taking tablets every day, but I didn't give up on myself. I understood that I had to drink them every day for my own well-being, so I was fine after that." [P: 8]

4.3.2.5 Mothers' observation of routine consultation

The women shared what they had observed during a consultation visit with the sister. They mentioned things they had noted during the routine of the consultation. They expressed minimal problems during their PMTCT consultation with their infants, in fact some of them seemed very observant and content with the service received. They described their follow-up consultation as follows:

"Well, when I go in to see the sister...for instance, before my infant turned 6 months, she advised and encouraged exclusive feeding. So, I asked the reason behind that, she explained to me how small the infant's intestines are. So, if I feed him, I could give something that could irritate his intestines, with the breastfeeding so the child can get the virus. So, she told me to not give food, and exclusively breastfeed until 6 months. So, with this current sister, I don't know if it's because she is young, but she is very approachable. Anything you want to ask her… I honestly don't have a problem with her." [P: 8]

Participant 10 confirmed that the sister did attempt to give them education during the consultation about caring for the infant:

"She enquires about your knowledge about HIV and informs you about the do's and dont's. Then she teaches you about things you should be doing for the infant." [P: 10]

4.3.3 Theme 3: Support system

This theme speaks about the various support mechanisms that the women had available to them from the time they tested positive. After testing HIV-positive, each one had to disclose their status to people they trusted. This theme also speaks about the lack of support that these women received from their loved ones. The women also reported how the support received influenced their treatment journey.

4.3.3.1 Partner support

Participants seldom received adequate support from their partners, even if present. One participant reported that during the treatment journey, she struggled because of the absence of her partner. At one point she had even considered aborting her pregnancy as she did not believe she could cope with raising what she believed was going to be an HIV-positive infant:

> *"So, it was hard just because I was alone, even the father wasn't there, so for me it was hard but for the sake of the infant I was so focused because I wanted to put my infant, life goes on after all. So, it was not ok but now it's fine"* [P: 1]

Partners of participants were often not supportive and in some cases, absent. Participants expressed how much the presence of their partners was important to them but they did not have that opportunity to experience that form of support. For some participants, the poor support influenced the efficacy of the treatment they received and increased the risk of HIV transmission to the infant. One woman's husband refused to use condoms, which affected the woman's viral load:

> *"I tell him we are told to use a condom; he tells me to bring him the nurse that told me that"* [P: 2]

This participant had been raising her children on her own for an extended period as her husband left her in the Eastern Cape while she was sickly and very poor. She reflected on the emotional abuse that she experienced:

> *"After I kept on telling him, we were talking but he was drunk, and he said to me I go around embarrassing him that he has HIV. And I asked him what he meant because he said he doesn't have HIV, but he just doesn't want to. I even asked his sister what can I do about my situation."* [P: 2]

Participant 7 was still reluctant to disclose to her fiancé details about her status and the transmission risk to her infant. When she was asked about her fiancé's support and involvement in her PMTCT journey, she answered:

> *"He doesn't know"* [P: 7]

4.3.3.2 Family support

Some participants feared the opinions of their families when they had to disclose their HIV status, even more so when they had to report that they are pregnant as well. They opted to have no support rather than to disclose to their relatives and risk being judged by them:

> *"I just started to think what are people going to say, especially at home and in the community. It was just not nice"* [P: 3]

Participant 11 admitted that her reason for not disclosing her HIV status is that her family would never accept or understand her:

> *"They don't know much, they do not know my status as I am scared of how they will react, especially my mother. I do want to tell them but I just know my mother will never accept my status"* [P: 11]

A young woman who had been diagnosed with HIV in the year prior to the study, had a supportive partner. None of her family, however, were aware of her HIV status and the risk of transmission to her infant. This interview was among the lengthiest ones, as the participant was emotional in between segments and when she had to share her experiences. She expressed herself as follows:

> *"My brothers drink a lot. I feared that when they are drunk, they might embarrass me with my status. I haven't had a chance to tell my parents yet because they are in the Eastern Cape. I don't want to tell them over the phone, I want to tell them in person."* [P: 4]

She continued to share that her current boyfriend is the only form of support she has. She has no family in Cape Town, she is not working and is entirely dependent on her boyfriend. With great difficulty, she reported:

> *"I don't have anyone else, I haven't told anyone else besides him. Sometimes I have the urge to actually speak to my cousins but I hear how they sometimes speak about*

that friend who is HIV positive. I hear how terrible they speak about her, I end up feeling I would never be able to tell them because they would laugh at me and make a constant mock of me in front of people" [P: 4]

Participant 8 faced serious stigma when it came to disclosing her HIV status to her family, especially with being pregnant and requiring their support during the process. She was rejected by the people she relied on, people that she assumed would be in the frontline to support her.

"The only problem I had was with my family when I had to disclose, and telling them that I am HIV positive. Some rejected me, that is the challenges I had. But for me, it (Her HIV status) wasn't a problem" [P: 8]

She went on to elaborate on the feelings she processed during the times her family rejected her:

"It was not nice, it was not nice at all. Because at the end of the day, I have accepted myself but now they can't do the same. Sometimes if we are chatting, it was like a no-go-area, I felt I couldn't raise anything related to my status." [P: 8]

4.3.3.3 Community support

There are various forms of community support structures that are available for individuals seeking them. Participant 8 was delighted to share her experience about her community health care worker. She made use of that service that is provided at the health facility. The support she received helped her get through what she said was the most challenging time in her life:

"I had a treatment buddy. I disclosed to them and told them everything that was going on. Even when I went for counselling before I started ARV's, she was with me. So, whenever I had a problem, I would tell her. Also, when I didn't go to the clinic, I would go to her and tell her "yey! It's been a long time since I have been at the clinic", she would tell me to go to the clinic, as me not going was not to my benefit. I would be scared to go and be at home without treatment, which was not good for me. She would tell me its best to go face the sisters then to stay at home without treatment. She would even come with me when I am really scared, so I had a person to talk to most of the time." [P: 8]

One participant enrolled herself in various counselling groups which were quite

beneficial according to her. Her son was born deaf due to labour complications. Apart from that disability, the child was also born HIV positive. She shared how supportive the women in the Tygerberg group were, which she attended for her son's ARVs and over-all follow-up:

> *"The people there used to converse and I was chatting to other mothers. We were all comfortable and just conversing about our situations, because we were all coming for the same thing. We used to chat about managing stress and that this is not the end of the world. We used to converse about how the child is going to grow and I should continue taking treatment. We were comfortable and we were supporting each other. Whoever hid their story was for them, or maybe them not being comfortable with sharing, it was for them. But we were chatting and conversing. So, I conversed with them until it wasn't a big deal that the child is positive and that I was also positive. Because its already done now and I can't take it back, we need to carry on with life"* [P: 5]

4.3.4 Theme 4: Health care system experience

Several women reported on their experiences at the health facility that they visited. These experiences were related to the frustration of being poorly treated and included sharing past and current experiences.

4.3.4.1 Health system factors

The participants were concerned regarding the separation that was done at the clinic. Specific patients with certain conditions went to different areas and that was a problem for them. This made participant 6 very emotional as she was sharing her experience. She said:

> *"What I have noticed here is that it appears as though the areas which HIV positive people must go to have been classed, they are separated. That is what is making me uncomfortable. Sometimes you can accept something but people's classifications take you back. It just reawakens everything. I just have that thing like, If I walk in here, what is the other person going to assume I'm coming for. It would be better if we all went in one area then it is only the sister who knows what you are coming for. I think that would be easier."* [P: 6]

She emotionally continued to share how she had noted the separation in the facility and how it did not exist during her antenatal visits:

"Firstly, what I would like to compliment on is. When I was pregnant, no one knew who was the HIV-positive pregnant woman and who was the HIV-negative pregnant woman, because we all went in the same place. You just deal with the sister and she sees when she sees your folder then she knows who is positive and who is negative. She knows if you are here for treatment or you here for an antenatal visit only." [P: 6]

Participant 11 corroborated these findings, as narrated below:

"There is something that makes me very unhappy with this facility. My neighbor asked me once which door do I take my infant when I come to the clinic. She asked me if I go in the first door, so I told her yes as I did not catch on as to why she was asking. She then told me that only mothers who go in that door are HIV positive. All I said was "Oh ohk" but did say anything. I assume she knows because she also went in there with her children as she is also HIV positive, and has disclosed her status to most people in the community. So, I'm stressed because if she knows that then maybe some of my neighbours might see me go in that door then make assumptions about my status." [P: 11]

Participant 5 had a different experience; she did not mention the institutional segregation but emphasized on how happy she was regarding the service that was rendered to her:

"What I can complement is that service is fast. There is nothing wrong that they are doing, they are fast, Even the sisters here told me… well they asked me for my CD4 and what my viral load was" [P: 5]

4.3.4.2 Concerns regarding health care workers' attitude

The participants shared that they had previously experienced difficulty with the attitude of the staff when they reported to the clinic. For instance, if they miss their appointments, or they need clarity regarding their treatment, they feel they are unable to ask because the staff is strict and sometimes shout at them. After participant 3 completed her consultation and went for the interview with the researcher, the first thing she asked was how the infant's syrup was administered. When asked about her reasons for not clarifying during her recent consultation, she reported:

"They don't explain anything properly and sometimes a person is scared to ask." [P: 3]

Participant 2 was just as frustrated to share an experience she had in the past at a

different facility. Her frustration was evident in the disclosure of her experience:

> *"They shout at you even if you don't know how to…if you are so slow to dress the child. Even if it was your first attempt to have a baby, they will shout at you "Wheeeee, fast! Whhheeee leave that! Your child pee!!" (Imitating the staff). It's like someone who is going to give you stress if you come here. You have stress, you have headache just because..."* [P: 2]

For some participants, the disappointment they experienced in the attitudes of the staff made them unwilling to continue talking about it. The level of disappointment that participant 7 experienced was beyond what she could describe. She described how the service she received felt incomplete because she didn't get proper information at the end of her consultations:

> *"To be honest, I don't want to bad mouth other people neh but, I think some other nurses or whoever is in the profession, in this government thingy, they are doing jobs that they don't like because she never explained it to me, she just told me I am HIV positive, and no counselling no nothing"* [P: 7]

4.3.5 Theme 5: Raising the HIV-exposed infant

This theme speaks about how the mothers experienced raising their HIV exposed infants, all the aspects involved in comparison to a baby that has not been exposed to HIV. They recounted the different precautionary measures they were forced to take in order to prevent transmission to their infants.

4.3.5.1 Breastfeeding experience

Most of the women interviewed were scared to breastfeed their infants, possibly due to poor insight. They believed that giving breast milk meant giving the baby HIV. Some women bluntly refused to breastfeed because the fear of transmission was too great:

> *"I told myself I am not going to do that. I thought she is telling me nonsense. I told myself I was never going to do it. There is no way that a child can be negative, and I am positive but she is feeding on my breast milk. But I then I sometimes went on the internet and I researched. Even on the internet it says the same thing that was said by the sisters. I realized that there was nothing better than taking my treatment. But sometimes I over-think, I don't know, I just over-think. If she has for instance a flu, I just start searching the internet for symptoms of when an infant is HIV infected, then it*

says a child will have a rash, persistent fever. All those symptoms they mention, I just start seeing all of them on my child." [P: 6]

One of the participants reported how her insight had improved with her second child. She was not as resistant to the idea as she was with her first infant:

"I was very scared with the first one. With this one, I had at least a bit of knowledge, that she won't get infected. Because my breasts were also cracked so I stopped breastfeeding and I came here to the clinic and they said no there won't be a problem. Even if they crack, I must continue breastfeeding." [P: 3]

Participant 7 decided to omit breastfeeding. During her previous consultation, she learnt that not taking her medication and mix-feeding were contributors of transmission of HIV. She was apparently not aware and had assumed that the prophylactic syrup issued was more than enough to keep the infant covered. She admitted that there are days that she forgets to take her tablets:

"I don't want to risk the infant being positive, although I am taking the medication properly. But there are days that I become really busy, for instance now, there is a couple of days I remembered after 12 o'clock that I didn't take my medication." [P: 7]

She expressed how much she loved breastfeeding and how she was saddened by the decision that she was forced to take. She became emotional as she was sharing her reasons behind wanting to discontinue breastfeeding. When asked about her feelings about omitting breastfeeding, she shared:

"I am getting emotional. I thought the medication for the infant, the nevirapine will protect the baby, and that it protects the child when I am breastfeeding as well. Even that itself is not 100%, so why should I risk? I am not going to risk, so I would rather stop." [P: 7]

Participant 8 was appreciative of her ability to breastfeed and recognized the advantages of breastfeeding:

"I love breastfeeding. The reason why I love it is because, firstly, breastfed infants are less likely to be sick. And even if the child is sick or ill, they never refuse the breast. That's why I love breastfeeding." [P: 8]

4.3.5.2 The baby's test results

Despite the mothers' concerns, most of their infants remained negative in the PMTCT programme. The infants were tested at the different intervals stipulated in the HIV guidelines and results were satisfactory for the mothers. They expressed immense relief upon disclosure of the infants' test results:

> *"I was VERY happy. I was very happy that my child is negative because I don't wish that she can go through what I am going through, I don't want that. If she is meant to have it, then she must acquire it on her own when she is grown and has lived her life, I don't want her to get it from me. Because this is my mistake, I don't want her to be affected by it."* [P: 6]

The participants were happy with the results of their infants' HIV status, it was a great relief to them:

> *"It feels so nice, it's one thing that I always long for. Because I feel like I would never forgive myself if my child would be positive. Yes, I am not saying those who have positive children shouldn't forgive themselves but it's by God's will that the child turns out that way, but I am very happy when He keeps protecting my children."* [P: 8]

For some participants, getting these satisfactory results was a form of validation that they have done well in reducing the transmission risk and it was consolation for them to know that they have done well in preventing their infants from taking lifelong medication from infancy:

> *"I was happy because she won't be taking any medication. At least I must be the only one taking medication."* [P: 11]

One of the mothers did not have the joy of celebrating her infant's results as her baby tested HIV-positive. The mother tested negative initially and on delivery she was retested and was positive, unfortunately it was too late and the baby was HIV-positive:

> *"The child also became positive because I wasn't on treatment. It was very painful but there is not much to be done because the child is here and I started with treatment, he is also currently on treatment. He is 6 years now."* [P: 5]

4.3.5.3 Motivators of bringing the infant to the clinic

Bringing infants routinely to the clinic is important because it helps assess and monitor

the infants' development. Apart from visiting the clinic on the allotted appointment date, mothers shared other motivators that drove them to bring their babies to the clinic regularly:

> *"I think it's because I am sick. So, I always want to know if my child is not infected, especially because I am breastfeeding. I want to know if he has not contracted the disease and that he gets all his injections in a proper way. I am sick and I don't want my children to contract what I have."* [P: 2]

The fear of not knowing their infants' current health status was another contributor that the participants reported often. They brought their infants routinely so that they are aware of their current health status:

> *"I become happy because if I stay with him at home and keep him at home, I won't know if there is a problem or if he can be disabled over time, if he doesn't get his immunizations. So that motivates me to always bring him on his dates, so that he can remain well like other children."* [P: 3]

Participant 4 recognized the importance of diagnostic tests that need to be done and this was a driving force for her. She also noted that when she visits the clinic, the service is quick and bearable for her:

> *"What motivates me is the fact that I know it is important for the child to be seen on their date and for special tests to be done. What also motivates me is the fact that, when I get to the window, my child's file is already at the window waiting for me take it. So, they take out the folder the day before and when I come on the given date, I don't sit long, it just flows. It's just important for the child to be brought on their given appointment."* [P: 4]

4.3.6 Theme 6: Novel and unanticipated challenges

With this specific theme, most women reported minimal problems with regards to challenges experienced during their journey in the PMTCT programme. However, as the interviews proceeded, they began to share certain stressors or issues that influenced their adherence to the programme. Challenges varied from work restrictions that influenced their clinic visit, to having multiple children, including ones with disabilities that would also be dependent on the mother. Even though the challenges influenced the mothers' adherence, they showed remorse and regret for the days missed.

4.3.6.1 Limitations to the infant's clinic visit

An issue that was raised often by the participants was having to prioritize work over the clinic visits. As much as they recognized the importance of the clinic visit, they also could not ignore the importance of generating an income in order for them to survive. One participant shared the reasons for not bringing her infant on the allotted appointment date:

> *"As for me the problem, I don't want to lie. As for me I was about to come on the 4th of August but I came today. The problem, I was at work. If I can't go to work, I can't provide for him. So, I have to go to work and then I will find the day off, you see. That's the only problem yah. But even if it's like that, I always try to make another day to bring him yah"* [P: 1]

Participant 3 expressed how fearful she was of the possibility of her status being accidentally disclosed when sending someone with her infant to the clinic:

> *"My current challenge is work. Sometimes I can't get off work to bring my child to the clinic and I can't send anyone else because I'm scared that my status will be accidentally disclosed. Otherwise, I can bring him if I'm off"* [P: 3]

A few participants also highlighted the stigma around HIV still being a huge factor in their treatment journey and feared being seen in the clinic. The fear of other peoples' perceptions limited them from adhering to their treatment. One participant reported that the fear of their HIV status being known was overwhelming in the beginning but over time, she has learnt to accept and adjust.

> *"I used to be worried that someone might see me, someone that knows me, who might end up talking about me in the community, that they saw me there and all that. But I eventually accepted it and learned that people will always have something to say. I just thought I am going to be concerned about what another person thinks whereas they might have their own journeys to deal with"* [P: 10]

4.3.6.2 Disclosing the mothers' HIV status to the child

During the data collection process, the issue of having to disclose to the infant that the mother is infected surfaced often. Participants reported that they were very fearful of the possibility of informing their babies that they had turned out HIV-positive whereas there were available interventions that could have prevented that outcome during their

infancy. For the participants, this was a motivating factor for them to bring their babies on their appointment dates. Unfortunately for one of the participants, this possibility was an active reality as her child was not only HIV infected, but also deaf. When asked about how she would go about informing her son of her status one day, she said:

> *"It's not going to be easy because he doesn't even speak because he is deaf"* [P: 5]

She went on to recollect the day she found out about her infant's HIV status:

> *"It was very painful but there is not much to be done because the child is here and I started with treatment, he is also currently on treatment"* [P: 5]

Contrastingly, some participants had a less stressful journey. The support they received made the disclosure to their children about their own HIV status a less stressful process. Participant 8 shared:

> *"Honestly, I don't want to lie, my kids are very supportive, I don't want to lie. Even when my appointment date is coming up, I update them and they remind me closer to the time"* [P: 8]

4.3.6.3 Missing the child's appointment

Missing the child's appointment was an unpleasant experience amongst the participants. They had various reasons towards what could prevent a mother from bringing her baby for their routine clinic visit. Even if the visit was missed due to a justifiable reason, it still left the mothers unsettled as they were concerned about the service missed for that specific day. Participant 1 shared how she always feels like there is something important that she has not done when she misses her infant's appointment:

> *"It's a stress you see. Just because you have something on your mind, you are supposed to do but you didn't do. It's like uh…It's like if you offer someone. If you… you have a credit for someone, you get stressed when the day is… yha. So, it's a stress just because you know, you have to go to the clinic and you couldn't even go, so what must I do? All over your bed, thinking about that and today I was like, I am bringing my kid to the clinic, this part is over, yha…So it's like that, yha"* [P: 1]

For one mother, missing an appointment meant missing an opportunity for a vital assessment to be done:

"It doesn't really sit with me because when they are still this young (pointing at her five-month old on the lap), you are always worried. Its like I just want all the tests to be done so that I know he status. Like, I only relax when I know that he is alright. For instance, I will only start to relax once he completes 6 months. I will relax but then again, I must still continue because he virus is contracted in different ways. Despite him getting it from me, he can get it in other ways also" [P: 9]

4.4 Summary

The findings of the study were presented in this chapter. They illustrated how mothers living with HIV experience being in the PMTCT programme. The reviewed findings disclosed how delicate the participation in the PMTCT programme is, highlighting the multiple influencers in the participants' lives that can affect their adherence to the programme. The experiences shared focused on both personal and health care system related aspects. Participants revealed the emotion behind their experiences, which gave the researcher an opportunity to understand the participants' perceptions better. The chapter concluded by sharing how participants would like their treatment process to be carried out, and how it can be improved to ensure their best comfort. The findings were presented in six themes and 18 sub-themes. The findings will be discussed the next chapter.

CHAPTER 5: DISCUSSION, RECOMMENDATION, LIMITATIONS AND CONCLUSION

5.1 Introduction

This chapter discusses the findings of the qualitative study in relation to the literature reviewed. The aim of the study was to explore the experiences of postpartum mothers living with HIV enrolled in the PMTCT programme in Khayelitsha, Cape Town. Six themes emerged during data analysis. This chapter also presents the limitations of the study, recommendations, and conclusion.

5.2 Theme 1: Knowledge of HIV/AIDS and PMTCT programme

This theme describes the participants' knowledge about HIV and the PMTCT programme. Three sub-themes emerged: Mothers' understanding of HIV, Mothers' knowledge regarding PMTCT programme, and Mothers' knowledge regarding reducing ways of transmission.

The findings of the study revealed that participants had very limited knowledge of their condition. Although they knew their status and, in some cases, had been living with HIV for some years, they found the condition difficult to explain. Participants had been informed of their diagnosis and advised on a few precautionary measures to take in order to reduce the risk of transmission to their infants or partners, but they still did not understand their condition. Dlamini and Mokoboto-Zwane (2019) have argued that the adherence to treatment and care is directly affected by mothers' knowledge of their condition and women who have insight regarding their condition are more likely to adhere to ART (Dlamini & Mokoboto-Zwane, 2019). Literature reveals that it would be unrealistic to expect mothers to comply with lifelong treatment and health education provided if they do not recognize the importance of their condition (Masten & Cicchetti, 2010).

As a result of their limited knowledge, some women developed their own understandings and theories regarding the disease. These included beliefs that HIV was genetic; it was a family disease and they had contracted it only because a member in their family was previously diagnosed with it. They also strongly believed that the fate of their children was dependent on their illness. According to Kiene, Dove and Wanyenze (2017), individuals who have recently been diagnosed as HIV positive

encounter a range of psychosocial issues and there is limited information regarding other psychological symptoms that are experienced by individuals following diagnosis and on how coping and other factors may contribute to depressive symptoms. It is essential that such persons be referred to a psychologist who can assist them in recognizing their new reality, which will facilitate improved adherence to treatment (Ramavhoya, Maputle, Ramathuba, Lebese & Netshikweta, 2020). It is the role of health care practitioners to facilitate this referral for psychological treatment.

The population of Khayelitsha, the study setting, is in the low-middle income bracket. Thus, most pregnant women will attend public facilities for their antenatal and post-natal care. They are less likely to have access to sources of information other than those provided by health care workers. Accurate and up to date information from heath care practitioners is vital. Participants were dependent on health care workers for such information. Rasmussen et al. (2018) stated that the health care system and its components influence the success of health programmes. Kate et al. (2019) also found that the probability of MTCT is escalated by factors such as the mothers' high viral load due to poor compliance to ART. Poor adherence is influenced by limited knowledge, understanding, and insight with regards to the importance of treatment, thus increasing the risk of transmission to infants. It is the health care practitioners' responsibility to ensure that mothers are well informed and supported. Poor adherence to PMTCT is not unique to the Western Cape and has been reported elsewhere in South Africa and other African countries including Tanzania, Nigeria and Zambia. Zacharius et al. (2019) highlighted that PMTCT adherence in eastern Tanzania was low compared to previous studies conducted in the country. Male partner support, time on ART, and area of residence were significant predictors of adherence to Option B+ treatment. Efforts to enhance male partner support and involvement and focusing on those on treatment for a longer duration in the PMTCT program may yield more significant outcomes.

Furthermore, in Nigeria, Agboeze, Adedokun, Adeoye and Nwali (2018), state that the main factor associated with poor adherence is the fear of being labelled as HIV positive. This is not surprising as discrimination and stigmatization against people living with HIV is common in our society and remains an important factor mitigating against quality HIV care.

Additionally, in Zambia, the results showed evidence of a difference in adherence levels between pregnant women above 30 years old when compared to those between 15 and 30 years old. Results of the multivariable logistic regression showed that participants older than 30 had a 10% increased chance of adhering to Option B+ compared to those below this age accounting for marital status, occupation, stigma, and level of education though we could not rule out random chance finding (Mukosha, Chiyesu & Vwalika, 2020).

Participants revealed a limited knowledge of HIV and the purpose of the PMTCT programme. This was demonstrated by the questions which were raised during interviews, such as the importance of exclusive breastfeeding and how to administer the infant's prophylactic medication. Mothers had limited knowledge and insight into how to minimize the risk of transmission to their infants, the main aim of the programme. Questions such as when to introduce solids, concern about their limited maternity leave, and how long the infant would remain HIV-negative highlight the lack of important information which is vital for the continued health of mother and infant. These are principles of the programme that should be discussed with the mother on introduction to the programme. Dlamini and Mokoboto-Zwane (2019) argue that the poor outcomes in the PMTCT programme are linked to poor insight of the mother regarding HIV, ART, and the importance of PMTCT. It is crucial that mothers' insight regarding PMTCT be improved if favourable outcomes are anticipated (Dlamini & Mokoboto-Zwane, 2019).

Poor insight was also highlighted when it came to mothers explaining the ways in which the risk of transmission to the infants is reduced. Some of the participants found it easier to explain how they reduce the transmission risk to their own infant as opposed to how the risk should generally be minimized. The respondents reported that they minimize the risk of transmission through avoiding mix-feeding, recognizing the importance of being consistent with their treatment, as well as the importance of administering the baby's prophylactic syrup. The researcher established from the participants' responses that they had a belief that reducing risk of transmission by a single intervention was sufficient and that it was not necessary to carry out other strategies.

For instance, participant seven, who was distraught after her clinical consultation,

learnt that she was not effectively reducing the risk. She was mix-feeding her baby and she was missing her treatment on certain days primarily because she strongly believed that the Nevirapine prophylactic syrup was more than enough coverage to reduce the risk. The mother stated that she was informed about the importance of administering the prophylactic syrup and breastfeeding the baby, but nothing else was shared beyond that. With an understanding that this section focuses on the discussion of findings, it does not encourage the discussion of individual experiences of the participants, however, in order to better capture the diminished knowledge of the participants and elaborate on the discussion of this theme, the study highlighted the above individual experience.

The risk of HIV transmission to the infant was poorly understood by most participants in this study. These findings are consistent with a study that was conducted in Ethiopia, where mothers living with HIV also presented with poor insight regarding the three critical modes of HIV transmission from mother to child as a result of poor counselling from health care professionals (Abtew, Awoke & Asrat, 2016). Effective reduction of the risk of transmission is the primary focus of the PMTCT programme. In 2016, the WHO envisioned eliminating paediatric HIV infections through MTCT by the year 2020 (Banja & Gebrehanna, 2020). In order to adhere to the goal as set out by the WHO, it is essential that education strategies implemented by health care professionals be improved to facilitate the desired outcomes (Abtew et al., 2016).

5.3 Theme 2: Experience of living with HIV and being in the PMTCT programme

The researcher explored the experiences of mothers in depth. This theme allowed the researcher to “step in” the mothers’ shoes and understand their circumstances as they lived it. The five sub-themes that emerged were: Immediate thoughts after testing HIV positive; Testing HIV positive; Perception about being pregnant and HIV infected; Experience of taking ARVs; and the Mothers’ observation of routine consultation.

Being informed of a new medical diagnosis is for many people an anxiety provoking experience. Participants in this study expressed an immediate sense of fear after learning their new HIV status which was exacerbated by the knowledge of the incurability of the disease (Safeek et al., 2018). This led to a preoccupation with HIV as a disease that is known for its mortality rate; their immediate thoughts were that their time was limited due to acquiring virus. These findings concur with those of

Bruton, Rai, Day and Ward (2018), in whose study participants shared a similar initial reaction of an immense sense of shock and fear of death. Not only were the mothers fearful for their lives, they were just as fearful for the lives of their unborn infants. Participants varied in their response to the information about the diagnosis – from disbelief to acceptance and a sense of betrayal, as partners whom they had trusted had failed to disclose their status. Unsafe sexual practices are great contributors to HIV transmission (Kate et al., 2019).

Some of the participants still needed psychosocial support in accepting and living with their diagnosis. A woman's psychosocial health is vital in adapting to and adopting any new information (Yourkavitch et al., 2018). Yourkavitch et al. (2018) further state that it is important that the psychosocial well-being of patients is stabilised in order to ensure optimal uptake of information, including that of PMTCT.

Of the 11 interviewed participants, eight had tested by means of opt-out testing. Leidel, McConigley, Boldy, Girdler and Wilson (2015) describe opt-out testing as an HIV test conducted where consent for the test is assumed unless the patient specifically refuses it. This is the routine protocol as per the Western Cape Government's (2018) Department of Health guidelines, as soon as pregnancy is confirmed, the HIV test is done. This protocol is important as the majority of HIV diagnoses are made through this process rather than by individual choice (Leidel, Leslie, Boldy & Girdler, 2016). Some of the participants had initially tested HIV negative, but had seroconverted at a later stage, resulting in the transmission of the virus to the infant without the mother's knowledge. These findings correspond with those from a study by Yah and Tambo (2018), which confirmed that HIV remains a threat to new-borns as a result of mothers not being aware of their HIV status and not being on treatment for the duration of their pregnancy. Zorrilla et al. (2018) state that the risk of HIV seroconversion during pregnancy is high among women in South Africa.

The experience of being diagnosed and living with HIV as a pregnant woman and mother was compared to a rollercoaster ride. This was exacerbated by the perceived incompetence of some health care practitioners as they had difficulty in explaining inconsistent test results (e.g. false negative) to participants (UNICEF, 2016).This made it difficult to fully understand the transmission risk.

Fear of HIV transmission and the consequences of this was a significant source of

anxiety for all participants. Some had seriously considered termination of their pregnancy as the thought of raising an HIV positive child was overwhelming. In some countries, abortion is a strategy implemented in attempt to limit the risk of mother-to-child transmission (Chibango & Maharaj, 2018). Mothers expressed fear about having to disclose to the child how they acquired the disease. Termination was seen as a means of sparing the child's potential suffering, although a strong consideration for some was the fact that they would be raising the child on their own. Partner support is vital. Besada et al. (2016) have argued that the involvement of partners in women's reproductive health has a significant influence on the utilization of health care services, including retention of patients in PMTCT services.

The experience of ART initiation was influenced by the amount of information given by health care professionals. On administration of any form of medication, it is the responsibility of the practitioner to educate the patient regarding how to take medication, possible side effects, and how to manage these. ART has numerous side effects some of which, for example, hallucinations, can be frightening. Knowledge helps patients cope with side effects. Not only does the mother have to adhere to her own medication regime, she also has a responsibility to administer medication to her infant if infected. The consequences of non-adherence are serious for mother and infant and the findings of the study have shown that this lack of understanding of the importance of adherence can lead to consequences such as discontinuation of breastfeeding, which in turn may lead to nutritional deficits for the infant. According to Lumbantoruan, Kermode, Giyai, Ang and Kelaher (2018), a women's beliefs about the efficacy of treatment is largely influenced by witnessing satisfactory results from peers that are also on ART. It becomes a challenge for women to take this medication daily for the rest of their lives. A study by Wahyuni, Zulkifli, Thamrin and Arsin (2020) states that patients' compliance with regards to ARV usage and willingness to learn about HIV increased after counselling interventions.

Mothers were asked to share their experience of a routine consultation. They were knowledgeable of the procedures involved with each consultation, but had not enquired about the rationale behind each procedure, with exception of one participant who had asked and received detailed information, which had increased her adherence. Some women had displayed a sense of interest in their baby's health and treatment progress. Patients who are actively involved and are engaged in their own

health and treatment process have better health outcomes (Westman, 2015; Robinson, 2016).

5.4 Theme 3: Support system

This theme describes the support systems that are available to the mother during their PMTCT journey and the participants' perceptions of those that were more or less effective or useful.

Partner support was a key factor in the participants' support system. The male partner (the father of the infant) was valued, however, for most of the participants, the partner's involvement was unsatisfactory. This left the woman alone in her journey, having to cope with the stress of being diagnosed and the awareness of the HIV transmission risk to her infant. This situation is exacerbated when a partner/husband is in denial of his own status and accuses the woman of unfaithfulness and even refuses to practice safe sexual behaviour.

As a consequence, participants have had to be moved from first line ART to the second-line regime due to consistently high viral loads. A patient is initiated on to the second-line regime when there is virological failure, as evidenced by persistent elevated viral load readings (Ssempijja et al., 2017; Shroufi et al., 2019). Elevated viral load may be due to the acquisition of a different HIV strain from a partner, which leads to the rapid deterioration of a previously stable infection (Gillroy, 2020). If the viral load in the source partner, in this case the husband, is higher, there are higher transmission rates (Gillroy, 2020). This has negative implications for the infant as there is increased risk of transmission if the mother is not virologically suppressed and continues to breastfeed.

Despite a nine-year relationship, one participant had not disclosed her HIV status to her partner. She had re-tested during her antenatal visit with her partner, however, this test was negative, a result that confused both herself and the health practitioners. Walcott, Hatcher, Kwena and Turan (2013), state that women usually feel unsafe about disclosing their HIV status to their partners after testing due to fearing their partners' reactions. Most PMTCT programmes perform HIV tests without the partners at the antenatal clinics, this offers very little support and encouragement towards disclosure to male partners (Walcott et al., 2013).

Family support emerged as another critical component of mothers' support systems. As with partner support, family support also plays a huge role in facilitating adherence and linking to care in the PMTCT programme. Family support provides a means of strength for mothers living with HIV and their babies. Some participants had not yet disclosed their HIV status to their families due to the fear of stigmatization and lack of acceptance from their loved ones. For one participant, the only person to whom she had disclosed was her boyfriend, which left her very vulnerable and alone. Another participant had been rejected by her family after disclosing her diagnosis. In a study by Mpinganjira, Tchereni, Gunda and Mwapasa (2020), women also reported that their relatives failed to provide them with the physical, moral, and psychological support that they so much needed, instead they disclosed their HIV status to third parties. Even after the person has accepted their HIV status, these are the things that affect their progress in PMTCT programme and contribute to LTFU (Mpinganjira et al., 2020).

Community support was as important as partner and family support. For some participants, the community services provided more assistance than family or partners. The support participants received from community programmes influenced the way in which they interacted in the PMTCT programme. Postnatal mothers are allocated to a treatment buddy, a person who is a member of the community who follows up on the patients in their homes and on progress with their treatment. Treatment buddies clarify any misconceptions that mothers may have and check that mothers understand information provided by health practitioners. They also motivate their patients to continue to go to the clinic, even if they have missed an appointment date and are fearful of returning and will accompany the mother to the clinic when necessary.

Being in a group with other mothers who were in the same situation was beneficial to some participants. They reported how much they offloaded to each other about current stressors and what they feared most in their children's health. Fatti, Shaikh, Eley and Grimwood (2016) suggest that community-based interventions contribute towards positive health outcome for women living with HIV.

5.5 Theme 4: Health care system experience

In this theme, the researcher describes the experiences of mothers following services rendered to them at the health facility by different health personnel. Participants

shared the practices that they observed, how they were treated, and their feelings about particular practices by facility health care staff. This discussion focuses particularly on the health care system factors and concerns regarding the attitudes of health care workers.

It is revealed in the study that there are divisions at health care facilities that patients visit. Areas are separated according to the conditions for which patients are attending. Participants reported that there are different sections for persons living with HIV, with TB, and for other conditions. They expressed that this separation made them feel very uneasy. For one participant, this separation made her feel stigmatized and uncomfortable, and although she had accepted her status, this type of categorization reawakened her feelings of rejection. Another participant had the experience of a neighbour enquire about the specific clinic section she had visited which could indicate the condition for which the person was receiving treatment, thus further stigmatising the person. This type of health facility division, while perhaps convenient for efficiency, has significant implications for patient confidentiality and even safety.

According to Bond et al. (2019), this practice takes place at a number of facilities in South Africa and Zambia; health care workers in that study reported that the identification of patients living with HIV was increased because of this practice. Bond et al. (2019, p. 87) argued that demarcated HIV services are linked with the risk of identification as well as stigma, but advocate for advantages such as patients receiving more specialized treatment, as well as the opportunity to share similar experiences with other patients. However, Mpinganjira et al. (2020) suggest that patients could possibly be lost to care as a result of stigma resulting from such separation of people living with HIV in health facilities. Participants also reported that they had noted that persons living with HIV (PLWH) had different clinic cards to other patients. This makes PLWH patients easily distinguishable from other patients.

Nurses are the main providers of care in the PMTCT services in sub-Saharan Africa (Mulenga & Naidoo, 2017). Participants concerns regarding the attitudes of health care workers emerged clearly in the findings. Participants experienced that many health care workers showed hostile attitudes towards their patients. This created uncertainty and fear for the participants. Examples included being shouted at if they had missed an appointment or being afraid to ask for information about their

prescribed medication. Rasmussen et al. (2018) have identified this as one of the health care system challenges that limit the optimal uptake of the programme. Nkwabong, Meboulou Nguel, Kamgaing and Keddi Jippe (2018) stated that the effectiveness of the PMTCT programme is dependent on adequate knowledge, positive attitudes, and good practices by those who are offering the service. However, stigma and discrimination by health care personnel remains an area of concern.

5.6 Theme 5: Raising the HIV-exposed baby

This theme discusses mothers' experiences of raising their HIV-exposed but negative babies. Raising a baby is not an easy journey for any mother, but having to raise an exposed baby comes with extra precautions that need to be adhered to, such as strictly exclusive breastfeeding, dealing with the infant's test results, and keeping appointment dates. Although breastfeeding is promoted for all mothers and their infants, participants expressed scepticism about this, especially first-time mothers. The fear stemmed from the belief that the breastfeeding itself would cause the HIV-negative baby to seroconvert. Some mothers refused to breast feed their babies despite the advice given by the clinicians. For them, it did not make sense to feed the baby breastmilk from their own HIV infected bodies and expect the baby to remain negative. The WHO and UNICEF (2018) policy is that a woman who is HIV positive can safely breastfeed her baby without transmitting the virus provided she breastfeeds exclusively and is adherent to ART. This highlights the importance of providing factual and contextual information to women in the PMTCT programme.

Participants who were breastfeeding found fulfilment in this and experienced a special type of connection and bond with their infants while breastfeeding. In a study by Ghure, Taran, Arora and Shaw (2018, p 383.) about knowledge, attitudes, and perception regarding breastfeeding practices among mothers, 99,2% of the mothers interviewed reported that they thought breastfeeding increased mother-baby bonding. Other beliefs about breastfeeding were that breastfed babies are less likely to be sick due to the immune boosting components of breastmilk. This has been corroborated by evidence; infants that are exclusively breastfed have less chances of being sick and have a better immune system (Endalamaw et al., 2018). In order for mothers to safely breastfeed, they need to ensure that the feeds are exclusive, they are virologically suppressed, and they continue to give the baby the prescribed prophylactic syrup

(WHO, UNICEF, 2018). For mothers who are unable to breastfeed, in some cases due to non-adherence, significant psychosocial support may be needed.

According to the Western Cape Government's (2018) Department of Health consolidated guidelines on HIV care, HIV-exposed babies are tested using a PCR test at specific time intervals: birth, 10 weeks, 12 weeks if the baby is high risk, 9 months, 18 months and 6 weeks post cessation of breastfeeding. The study revealed that, even though mothers understood that the PMTCT interventions were to ensure their baby remains negative, upon disclosure of the baby's negative results, they were extremely grateful for this news. A mother expressed how happy she was that her baby's results were negative by revealing that she was more grateful that her child was spared from taking lifelong medication and would not suffer because of her status. One participant who had initially tested negative, had been diagnosed with HIV late in her pregnancy and had transmitted the virus to her unborn infant. Haas et al. (2017) state that a large number of babies become HIV infected are a result of mothers who were not initially diagnosed as HIV infected. The current Western Cape Government's (2018, p8) consolidated guidelines on HIV care provide for regular follow up testing for women who initially tested negative.

Motivating factors for mothers to remain linked to care included regular check-ups to ensure that their babies have not been infected while breastfeeding, understanding the importance of routine testing, and the recognition that this offered the best chance of their children being "normal", or as stated by one participant "so that he can remain like other children".

Prendergast, Essajee and Penazzato (2015) state that, while babies born to all HIV-positive mothers are susceptible to acquiring the infection, women who become infected with HIV during pregnancy or while breastfeeding have an exceptionally high risk of passing the infection to their new-born child. The interaction of HIV with other infections and the indirect effects of HIV, such as poverty and maternal illness, also contribute to poor outcomes for new-borns. In addition, Rowan et al. (2018) agree with the above point and state that confusing information about feeding choices for HIV-infected women, combined with the provision of commercial infant formula in poor communities with high infant mortality rates, has resulted in losses for breastfeeding in general and has had a spill-over effect on the breastfeeding behaviours of non-HIV-

infected mothers and infants as well.

5.7 Theme 6: novel and unanticipated challenges

This theme discusses the challenges experienced by mothers in the PMTCT programme; such challenges have the potential to restrict the effectiveness of the programme. These include limitations that restrict mothers from bringing the child to the clinic, the preparation in order to disclose HIV status, and experiences after the child's appointment has been missed.

Fitting in clinic appointments for participants who were employed was particularly challenging and this was one of the main reasons for missing appointments. These findings concur with those of Kyaw et al. (2017), who reported that women who had to return to work soon after delivery had difficulty in attending regular PMTCT follow-up appointments. Fear of health practitioners' attitudes towards mothers after missing an appointment made participants more reluctant to return. Fear of stigma was also a factor; mothers with HIV-exposed babies were sent to a separate room to mothers who did not have exposed babies, which increased the risk of being identified as a PLWH. It was also difficult emotionally as participants were concerned that if they missed appointments, not only them, but also their infants would be disadvantaged.

One of the major decisions that mothers living with HIV have to consider is when and how to disclose their status (and that of their children where relevant) to their children. Participants in this study were fearful about this, particularly one participant who knew that her infant was infected. A cross-sectional study by Van Estland et al. (2019) shows a low proportion of children knowing about their HIV status. The older the age of the child was strongly associated with disclosure. That study found a less stringent need for caregivers to disclose the child's HIV status to the child when ART was tolerated well and no condition-related difficulties were experienced. Van Estland et al. (2019) also highlighted that disclosure can only be beneficial when there is a supportive social structure. Non-disclosure can indicate a sub-optimal social structure, which could negatively affect adherence and viral suppression. In order to successfully address disclosure, the complex social context needs to be considered. When families are in a good space, there is no pressing need to start the disclosure process. However, these circumstances positively enable the disclosure process. Targeting these families for disclosure interventions and the support of families to reach such an enabling

environment can therefore be especially successful.

Furthermore, Sariah et al. (2016) note that the disclosure process is found to be a complex process. They state that perspectives regarding disclosure in children infected with HIV varied among healthcare providers in terms of their role in the process, clear national guidelines, and appropriate standardized training for paediatric disclosure. Consistent with Sariah et al. (2016), Appiah, Kroidl, Hoelscher, Ivanova and Dapaah (2019) in their study revealed that healthcare providers reported difficulties during disclosure because mothers mostly fear blame, social stigma, the child's negative emotional reaction when informed, and have concerns about the child being too young and immature to understand the HIV condition.

For one participant, her older children, who had previously been on the PMTCT programme, were more accepting of her HIV status, so much so that they are involved in her treatment journey. The children had expressed fear about the possibility of their mothers' death but had been reassured. Children can also support parents they share this journey with. A study by Visser and Hlungwani (2020) reported that mothers who disclosed their HIV status to their children received significantly more emotional and instrumental support from their children compared to mothers who did not disclose.

It is essential that health care workers listen empathically to mothers' challenges of adherence to the clinic appointments. According to Terezam, Reis-Queiroz and Hoga (2017), empathy displayed by nurses contributes to mothers being comfortable in returning to the clinic on a regular basis.

5.8 Recommendations

The recommendations emanating from this limited qualitative study are grouped into four areas: practice, education, service issues and further research.

5.8.1 Recommendations for nursing practice:

MTCT is the most common cause of paediatric HIV infection in the sub-Saharan Africa. Retention in care in the PMTCT programme remains a critical challenge even though access to ARV treatment and the PMTCT programme has improved.

5.8.1.1 Evaluate efficacy of the MTCT programme

Participants displayed limited knowledge with regards to HIV, the PMTCT programme

and its principles. This study submits that the facility develops a strategy to assess the effectiveness of the programme, with specific reference to mothers' knowledge and understanding of the programme and adherence to it. Health information and education should be focused, contextual, practical, and with a clear rationale for the information and advice.

5.8.1.2 Provision of support mechanisms

Community health centres are places people go to seeking help, however, psychological needs also need to be attended to at these facilities. The health care professionals need to ensure that patients get sufficient counselling sessions until they can be confidently discharged from the sessions. The study recommends an improvement and enhancement of the existing support systems to ensure psychosocial well-being of the mothers in the PMTCT programme.

5.8.2 Recommendations for nursing education

5.8.2.1 Continuous staff training and development

Health care workers need to undergo training each time updates are released. This is to ensure that they are up to date with the latest practices. This will help them to avoid disclosing an incorrect diagnosis to patients. They also need to be considered for training on how to engage the patients and provide constructive health education that can be beneficial to patients.

5.8.3 Recommendations for nursing policy

5.8.3.1 After-hour clinic services

The study recommends that the facility develop a system that will allow working mothers to be accommodated. It could implement a morning clinic, whereby mothers can bring their babies before the clinic routine commences and they could then be issued with proof that they were at the clinic should they run late. The facility could also have an option of implementing a similar system during the afternoon or liaising with mothers and allocating dates on days that are most suitable for them.

5.8.3.2 Courtesy and redress (Batho Pele Principles)

Participants reported that the attitude of staff was very unpleasant and they were reluctant to attend the facility. In some instances, participants would get medication or

health education and would be too scared to ask for clarity on the instructions given. The staff need to be proficient with regards to the manner in which they address patients seeking help at their facilities. It is their duty to not violate any of the patients' rights and to practice within ethical standards. If the staff still acts inappropriately, this needs to be addressed at the highest disciplinary level by management. The facility should also discontinue with the segregation of patients based on their conditions. This practice facilitates stigma and discrimination, it is neither right nor ethical. All patients have the right to be treated equally.

5.8.3.3 Removal of distinguishing and possibly stigmatizing structures and practices

Apart from the demarcation at the facilities, participants also reported that their clinic cards, entrance doors, and folders are different from other patients'. This made participants very uncomfortable. Mothers reported that they felt identifiable with this distinguishable component. Bond et al. (2019) confirms that the demarcated HIV services are linked with the risk of identification, which contributes to patients' discomfort. Participants reported that it would make them feel better if everyone attending the clinic was issued with the same clinic cards and for it to be only the consulting practitioner that is aware of the patient's HIV status.

5.8.4 Recommendations for further research

The study recommends that further research be conducted as this study was focused on one area of Khayelitsha. A comparative study would give a clearer reflection on the PMTCT programme. Furthermore, the study recommends a quantitative study in order to understand the experiences of mothers as this will enable a bigger sample to be part of the study. The study also recommends further exploration of the experiences in the PMTCT programme between mothers in the private and public sectors.

5.9 Limitations of the study

As a limited qualitative study located in one health facility in Khayelitsha, Cape Town, these findings are not generalizable, but may be transferable to similar settings. The facility where the study was conducted is a public community health centre, therefore the experiences of mothers accessing private health cafe may be different.

The practices reported in interviews might have been influenced by recollection bias and/or the temptation to offer socially desirable answers. Lack of diversity of

participants might not be a true reflection of the reality, rendering the findings ungeneralizable. Therefore, caution needs to be applied when interpreting and generalizing study findings to other areas by considering possible variations influencing factors at all levels.

5.10 Conclusion

This study aimed to explore the experiences of postpartum mothers living with HIV in the PMTCT programme in Khayelitsha, Cape Town. It described how women experienced the journey of living with HIV in the PMTCT programme and revealed the women's knowledge, support structure, their experiences in the health facility, the challenges they experienced and their recommendations on how to improve their own treatment experience. Apart from the personal factors, the study disclosed that health care system factors also contribute towards a mother's experience of and adherence to the programme, with specific reference to staff attitudes and the service rendered.

It is clear from this study that the PMTCT programme is critical for mothers in providing support, promotion of adherence, and reducing the risk of MTCT. Retention in care in the PMTCT programme remains a critical challenge even though access to ART and the PMTCT programme has improved. Women need to be empowered and encouraged to be participative individuals in their own and their baby's health. If women are adequately educated, they will be more motivated to carry out the health advice provided because they will understand the necessity better. Health care workers need to be held accountable for their actions that affect mothers' compliance in the programme.

The results of this study demonstrate the intricacy of living with HIV in a disadvantaged and marginalized community like Khayelitsha and the exceptional challenges that HIV-positive pregnant women face. It goes past unfolding distinct barriers to participating in the PMTCT programme and explains a dynamic analysis of actual and perceived risks in the home, community, and clinic that begins when a woman is diagnosed with HIV at her first ANC visit. This risk analysis is unique to each woman and can change throughout the course of her pregnancy, informing her engagement in the PMTCT programme. This study reveals the day to day realities that mothers living with HIV in Khayelitsha must negotiate, especially dynamics with male partners, making it challenging to follow PMTCT counselling and interventions provided at the clinic.

Engaging the community to actively address social factors outside of the clinic environment, ongoing patient-tailored counselling for HIV-positive mothers, and increasing male involvement are key to the success of PMTCT programmes in Khayelitsha and similar locations.

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APPENDIX: A

UNIVERSITY OF THE WESTERN CAPE

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E-mail:*3153602@myuwc.ac.za*

INFORMATION SHEET

Project Title: ***The experiences of mothers living with HIV of the PMTCT programme in the Khayelitsha district of Cape Town***

What is this study about?
This is a research project being conducted by Linda Velapi from the University of the Western Cape. We are inviting you to participate in this research project because your experience can help develop new information on how to improve health services of the PMTCT programme. The purpose of this research project is to explore the experiences of HIV positive mothers who are currently enrolled in the PMTCT programme in the Khayelitsha district of Cape Town, which is one of the areas known to have high prevalence of HIV-infected mothers. The researcher will employ face to face interviews as a data collection technique.

What will I be asked to do if I agree to participate?
You will be asked to share your experiences regarding being in the programme and any challenge that you experience. The interview will be approximately 45-60 minutes and will take place in a private consultation room in the health care facility. The interview will recorded.

Would my participation in this study be kept confidential?
The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity the responses you give during the interview will be anonymous. Your participation in this study will not infringe upon your privacy. The identity of all the people participating in the study will be kept confidential. Each participant will be assigned code numbers/names that will be used on all research documents, this is to ensure confidentiality. All information collected will be kept safe in a locked file cabinet in the personal possession of the researcher, and used only for the purpose of the research. If we write a report or article about this research project, your identity will be protected.

What are the risks of this research?
All human interactions and talking about self or others carry some amount of risks. However, there are no physical risks anticipated in participating in the study. Should you feel distressed at any time the interview may be paused or terminated, and if required you will be referred to a counsellor. We will nevertheless minimise such risks

and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. You may decline to answer any or all questions and you may terminate your involvement at any time.

What are the benefits of this research?
There are no monetary, materialistic or direct benefit to the participants. However, it is hoped that the information obtained from this research study, will provide useful information to improve the service, outcomes and adherence in the PMTCT programme. We hope that, in the future, other people might benefit from this study through improved understanding of the experiences of HIV-positive women in the PMTCT programme.

Do I have to be in this research and may I stop participating at any time?
Your participation in this research is completely voluntary. The choice of taking part in the study is entirely up to you, but you may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you agree to be part of the study, you will be required to complete and sign a consent form. If you decide not to participate in this study or if you stop participating at any time, no disadvantages will be inflicted on you and you will not be required to state reason for your change of interest

What if I have questions?
This research is being conducted by **Linda Velapi**, a student at the University of the Western Cape. If you have any questions about the research study itself, please contact Linda Velapi at 0837670924 or email 3153602@myuwc.ac.za.
If you have any questions about the research itself, please contact **Prof. Patricia Mayers** at The School of Nursing, University of the Western Cape, her telephone number is +27 (021) 959 1723.
If you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Professor Patricia Mayers (D.Phil)
Associate Professor emeritus
School of Nursing, University of the Western Cape
Private Bag X17, Bellville 7535
pmayers@uwc.ac.za

This research is approved by the University of the Western Cape's Senate Research Committee and Ethics Committee and it is approved by the Department of Health.

APPENDIX: B

UNIVERSITY OF THE WESTERN CAPE

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IPHEPHA LENKCUKACHA

Isihloko seproject: ***Amava oomama abaphila ne-HIV kwinkqubo ye-PMTCT kwikliniki yesithili eKapa***

Lungantoni oluphando??
Le projekthi yophando eyenziwa nguLinda Velapi waseYunivesithi yeNtshona Koloni. Sikumema ukuba uthathe inxaxheba kule projekthi yophando kuba amava akho anokunceda ukuphuhlisa ulwazi olutsha malunga nokuphucula iinkonzo zezempilo ze-PMTCT. Injongo yale projekthi yophando kukuphononongа amava omama abane-HIV ababhaliswe kwangoku kwiprogram ye-PMTCT kwikliniki yesithili eKapa. Umphandi uza kuqhagamshelana nabajongene nodliwano-ndlebe nabajongene nodlelwane njengendlela yokuqokelela idatha.

Ndizokubuzwa ntoni ukuba ndiyavuma uthatha inxaxheba?
Uya kucelwa ukuba wabelane ngamava akho malunga nokubekwa kwiprogram kunye naluphi na umngeni onalo. Udliwano-ndlebe uza kuba malunga nemizuzu engama-45-60 kwaye iya kwenzeka kwindawo yokubonisana yabucala kwiziko lempilo. Udliwano-ndlebe luya kubhalwe ngezwi. Igama lakho aliyi kubonakaliswa kwirekhodi. Ukuba uphando luya kupapashwa, ilizwi lakho liza kusetyenziswa kuphela kwipapasho yophando xa unikeza imvume yaloo nto.

Ingaba ukuthabatha kwam inxaxheba koluphando kuzigcinwa kuyimfihlo?
Abaphandi bazama ukukhusela ubuni kunye nobume begalelo lakho. Ukuqinisekisa ukungabonakali kwakho iimpendulo ozinikiweyo ngexesha lo dliwano ndlebe kuya kuthiwa. Ukuthatha inxaxheba kwakho kule sifundo akuyi kuphula umthetho wakho wobumfihlo. Ubuni bonke abantu abathatha inxaxheba kwisifundo baya kugcinwa ngasese. Umntu ngamnye oza kuthatha inxaxheba uya kunikwa iinomboro ze-khowudi / amagama azakusetyenziswa kuwo onke amaxwebhu ophando, oku ku-kuqinisekisa ukuba yimfihlo. Yonke ingcaciso eqokelelwayo iya kugcinwa ikhusele-kile kwikhabhinethi yefayile ekhethiweyo kwi-personal possession yomphandi, kwaye isetyenziswe kuphela ngenjongo yophando. Ukuba sibhala ingxelo okanye inqaku malunga nale projekthi yophando, isiza sakho siya kukhuselwa. Ulwazi luya kuqoke-lelwa ngendlela yokuba, ayiyi kudibana nawe

Zithini ingozi zoluphando?
Zonke iintsebenziswano zabantu kunye nokuthetha ngabanye okanye abanye batha-tha ubuninzi beengozi. Nangona kunjalo, akukho mingcipheko emzimbeni

ekulindelekileyo ekuthatheni inxaxheba kwisifundo. Ngaba kufuneka uzive ux-inezelekile nangaliphi na ixesha udliwano-ndlebe lunokumiswa okanye lupheliswe, kwaye ukuba kufuneka ukuba uthunyelwe kumcebisi. Kodwa siya kunciphisa ingozi enjalo kwaye senze ngokukhawuleza ukukunceda ukuba unamava, unengqondo okanye ngenye indlela ngexesha lokuthatha inxaxheba kulolu phofu. Unokwenqaba ukuphendula nayiphi na imibuzo okanye yonke imibuzo kwaye unokuphelisa uku-bandakanyeka kwakho naliphi na ixesha.

Zithini inzuzo zoluphando?
Akukho mali, izinto eziphathekayo okanye inzuzo ngokuthe ngqo kubathathi-nxaxheba. Nangona kunjalo, ithemba ukuba ulwazi olufunyenwe kulolu pho nonongo luya kunika ulwazi oluncedo ukuphucula inkonzo, iziphumo kunye nokunamathela kwinkqubo ye-PMTCT. Sithemba ukuba, ngokuzayo, abanye abantu banokuzuza ku-lolu cwaningo ngokuqonda okuphuculweyo kwamava abafazi abane-HIV kwinkqubo ye-PMTCT.

Ndinyanzelekile ukuba ndibeyixalenye yoluphando okanye ndingayeka nanini na?
Ukuthatha inxaxheba kwakho kule phando ngokuzithandela ngokupheleleyo. Uku-khethwa kokuthatha inxaxheba kwisifundo kuphelele kuwe, kodwa ungakhetha ukuba ungathathi nxaxheba kukho konke. Ukuba uthatha isigqibo sokuthatha inxaxheba kulolu cwaningo, unokuyeka ukuthatha inxaxheba nanini na. Ukuba uya-vuma ukuba yinxalenye yesifundo, kuya kufuneka ugcwalise kwaye usayine ifomu yokuvuma. Ukuba unquma ukungathathi nxaxheba kule sifundo okanye ukuba un-qamle ukuthabatha inxaxheba nangaliphi na ixesha, akukho miphumo eya kuhlawulwa kuwe kwaye awuyi kucelwa ukuba uchaze isizathu sokutshintsha kwakho umdla.

Ndithini xa ndinemibuzo?
Olu phando luqhutywa ngu**Linda Velapi**, umfundi kwiYunivesithi yeNtshona Koloni. Ukuba unemibuzo malunga nokuhlola ngokwayo, nceda uqhagamshelane noLinda Velapi ku-0837670924 okanye i-imeyile 3153602@myuwc.ac.za.
Ukuba unemibuzo malunga nale sifundo kunye namalungelo akho njengomncedisi wophando okanye ukuba unqwenela ukubika nayiphi na ingxaki oye wah-langabezana nayo ngokumalunga nophando, nceda uqhagamshelane:

Prof Jennifer Chipps
Head of Department: School of Nursing
University of the Western Cape
Private Bag X17
Bellville 7535
jchipps@uwc.ac.za
Tel: +27 21 959 3024

Prof Anthea Rhoda
Dean of the Faculty of Community and Health Sciences
University of the Western Cape

Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Olu phando luya kuvunywa yiKomidi yeNtshona Koloni yeNkcazo yoPhando neKomiti yezoLawulo. Kuya kuqinisekiswa

APPENDIX: C

UNIVERSITY OF THE WESTERN CAPE

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CONSENT FORM

Title of Research Project: ***The experiences of mothers living with HIV of the PMTCT programme in a district clinic in Cape Town***

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that audio recordings need to be made during the interview. I understand that the audio-recordings will be kept for the duration of the research project and will be destroyed once their use is exhausted. I know that when the research team labels my recordings they will use a code and not my real name. I agree that the information I give can be used for presenting research findings; for further analysis in future research projects and/or for teaching purposes.

I agree/ do not agree to take part in the research study (underline correct answer).

I agree to be audiotaped for this research project. ☐

I do not agree to be audiotaped for this research project. ☐

If you have any questions please feel free to contact Linda Velapi (The researcher) on 083 767 0924 or Prof. Pat Mayers (The supervisor) on 021 959 1723

Participant's name…….
Participant's signature……
Date……

APPENDIX: D

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
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INCWADI YESIVUMELANO:

Isihloko: ***Amava oomama abaphila ne-HIV kwinkqubo ye-PMTCT kwikliniki yesithili eKapa***

Ndiye ndacaciselwa ngoluphando ngolwimi ediluqondayo. Ndiye ndalifumana ithuba lokubuza yonke imibuzo malunga noluphando, futhi ndifumene iimpendulo ezaneleyo kwimibuzo ebendinayo, kunye nezinye inkcukacha ebendizifuna. Ndiyavuma uthatha inxaxheba koluphando. Ndiyayiqonda ukuba andinyanzelwa uba yinxalenye yoluphando. Ndiyaqonda ukuba igama lam aliyi kutyhilwa kumntu. Ndivumelekile ukuba ndingathathi nxaxheba kwaye ndinelungelo lokuyeka nanini na, ndinganikanga zizathu. Ndiyaqonda ukuba iirekhodi ezirekhodiweyo ziya kugcinwa ixesha lokuphanda iphrojekthi kwaye ziya kutshatyalaliswa xa zisetyenziswe ngokwaneleyo. Ndiyazi ukuba iqela lophando aliyi kusebenzisa igama lam langempela kwii-audio-rekodi zam. Ndiyavuma ukuba ulwazi olunikelayo lungasetyenziselwa ukuveza iziphumo zophando; ukuhlalutya kwakhona kwiiprojekthi zophando kunye / okanye kwiinjongo zokufundisa.

Ndiyavuma / andivumi nokuthatha inxaxheba kwisifundo sophando (gxiba impendulo echanekileyo)

Ndiyavuma ukuba ilizwi lirekhodwe kule projekthi yophando. ☐

Andivumi ukuba ilizwi lirekhodwe kule projekthi yophando. ☐

Ukuba unemibuzo nceda ukhululeke ukuqhagamshelana noLinda Velapi (umphandi) ngo-083 767 0924 okanye u-Prof. Pat Mayers (umphathi) kwi-021 959 1723

Igama lomntu othatha inxaxheba:……

Tyikitya:……

Umhla:……

APPENDIX: E

University of the Western Cape

Private Bag X17, Bellville 7535, Cape Town, South Africa

Telephone :(021) 959 3309 or (021) 959 2271

Contact details: Researcher. Linda Velapi:

Supervisor: Professor Pat Mayers. E-mail: pmayers@uwc.ac.za

Interview guide

Introduction

Thank you for being willing to share your experience with me. As per the information sheet, this study is about the experiences of women in the postpartum period (the first few weeks and months after birth of your baby) of living with HIV and being in the PMTCT programme.

Main question: Please share your experience as a mother living with HIV and being in the PMTCT programme.

Prompts

Can you tell me about your understanding of HIV and AIDS?

Can you tell me about your understanding of the way in which a mother can transmit the virus to her baby?

How can the risk of transmission to the baby be eliminated/reduced?

What can you do as a mother to protect your baby from contracting the virus?

Until you joined the PMTCT programme, had you ever come across the term "PMTCT"? And if so, what do you understand by it?

Can you explain the care that you and your baby receive when you come for a follow up visit?

Please share with me your experience during your last clinic visit. For example, what as your experience from time you came entered the building until you left? What made you satisfied/dissatisfied with the service received?

Have you been able to attend the follow up visits on the appointment date? Please tell about attending and any challenges that you have experienced in attending

What encourages you to bring the baby for the next follow up visit?

In your opinion what are the advantages and disadvantages of being in the PMTCT programme?

Can you tell me about the support that you receive from family / health center staff?

Is there anything you would like to suggest to the healthcare workers which could improve your experience?

Thank you for giving me your time. I appreciate this.

APPENDIX: F

University of the Western Cape

Private Bag X17, Bellville 7535, Cape Town, South Africa

Telephone :(021) 959 3309 or (021) 959 2271

Contact details: Researcher. Linda Velapi:

Supervisor: Professor Pat Mayers. E-mail: pmayers@uwc.ac.za

Udliwano-ndlebe

Intshayelelo

Siyabonga ngokukulungele ukwabelana nawe ngamava akho. Njengokwiphepha leenkcukacha, olu phofu lithetha ngamabhinqa kwixesha lokugqibela emva kokubeleka (iiveki ezimbalwa zokuqala kunye neenyanga emva kokuzalwa kosana lwakho) nokuphila ne-HIV kunye neenkqubo ze-PMTCT.

Umbuzo oyintloko: Nceda uqhagamshelane namava akho njengomama ophila ne-HIV kwaye ube kwinkqubo ye-PMTCT.

U-khuthaza

Unokundixelela malunga nokuqonda kwakho ngeHIV ne-AIDS?

Ngaba ungandixelela malunga nokuqonda kwakho indlela umama angayifaka ngayo intsholngwane kwintsana yakhe?

Umngcipheko wokudlulisela intsholongwane kwisana lungancitshiswa njani?

Yintoni ongayenza njengomama ukukhusela umntwana wakho ukuba angabinayo intsholongwane?

Ngaphambi kokuba ujoyine inkqubo ye-PMTCT, ngaba uye wafumana igama elithi "PMTCT"? kwaye ukuba kunjalo, uqonda ntoni ngalo eligama?

Ngaba ungazichazela unyango olwenzelwa wena kunye nosana lwakho xa ufika kwiklinikhi?

Ndicela undicacisele ngamava akho ngexesha lokutyelela kwekliniki yakho yokugqibela, uziva njani ukususela ngexesha ofike ngalo kude kube lixesha ophume ngalo? Yintoni eyenza uneliseke / unganeliseki ngenkonzo efunyenweyo?

Ngaba uye wakwazi ukuya ekulandelelweni kokulandelelana ngomhla owanikwa ngawo? Ndicela undixelele ngokuya kunye neyiphi na imingeni oye wafumana kuyo.

Yintoni ekukhuthazayo ukuba uzise umntwana wakho ngosuku olunikiweyo?

Ngombono wakho yiyiphi inzuzo kunye nokuphazamiseka kokuba kwinkqubo ye-PMTCT?

Ndicela undixelele malunga nenkxaso oyifumanayo kusapho lwakho na kubasebenzi bezentlalo / zezempilo?

Ingaba kukho into ongathanda ukuyicebisa kubasebenzi bezempilo abanokuphucula amava akho?

Ndiyabonga ngokundinika ixesha lakho.

APPENDIX: G

UNIVERSITY of the WESTERN CAPE

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10 May 2019

Ms L Velapi
School of Nursing
Faculty of Community and Health Science

Ethics Reference Number: BM19/1/36

Project Title: The experiences of mothers living with HIV of the PMTCT programme in a district clinic in Cape Town.

Approval Period: 02 May 2019 – 02 May 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

BMREC REGISTRATION NUMBER -130416-050

APPENDIX: H

Western Cape Government
Health

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REFERENCE: WC_201905_020
ENQUIRIES: Dr Sabela Petros

University of Western Cape

Robert Sobukwe Road

Bellville

Cape Town

7535

For attention: Ms Linda Velapi

Re: **The experiences of mothers living with HIV of the PMTCT programme in a district clinic in Cape Town**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following person to assist you with any further enquiries in accessing the following sites:

Khayelitsha (Site B) CHC	**Mr David Binza**	**021 360 5207**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

Dr Melvin Moodley
Director: Health Impact Assessment
19 JUL 2019

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

APPENDIX: I

Lowe's
Editing Services

LETTER OF CERTIFICATION

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5 DECEMBER 2020

To whom it may concern

I hereby certify that I, Gareth Owain Paul Howel Lowe, edited the thesis of **Linda Velapi**, entitled "**The experiences of mothers living with HIV of the PMTCT programme in Khayelitsha, Cape Town.**", for language.

Regards

Gareth Lowe

Editor