

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.



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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, Lebeso & 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 health 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 (Abteu, 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 (Abteu 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 care 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

Private Bag X 17, Bellville 7535, South Africa

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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 be 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



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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 kukuphonononga 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 aliya 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 iimpemulo 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 kuqinisekisa ukuba yimfihlo. Yonke ingcaciso eqokelelwayo iya kugcinwa ikhuselekile 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 kuqokelelwa ngendlela yokuba, ayiyi kudibana nawe

Zithini ingozi zoluphando?

Zonke iintsebenziswano zabantu kunye nokuthetha ngabanye okanye abanye bathatha 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 banokuzuzisa kulolu 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 uyavuma ukuba yinxalenye yesifundo, kuya kufuneka ugcwalise kwaye usayine ifomu yokuvuma. Ukuba unquma ukungathathi nxaxheba kule sifundo okanye ukuba unqamle ukuthabatha inxaxheba nangaliphi na ixesha, akukho miphumo eya kuhlalulwa 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 wahlangabezana 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



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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



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E-mail: 3153602@myuwc.ac.za

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 aliya 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 zisetyenzisiwe ngokwaneleyo. Ndiyazi ukuba iqela lophando aliya 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 was 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.



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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 leenkukacha, 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 intsholongwane 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



OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

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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.

A handwritten signature in black ink, appearing to read 'Josias'.

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

BMREC REGISTRATION NUMBER -130416-050

FROM LEARN TO ACTION THROUGH KNOWLEDGE

APPENDIX: H



**Health Impact Assessment
Health Research sub-directorate**
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www.capegateway.gov.za

REFERENCE: WC_201905_020
ENQUIRIES: Dr Sabela Petros

University of Western Cape
Robert Sobukwe Road
Bellville
Cape Town
7535

For attention: Ms Linda Velopi

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

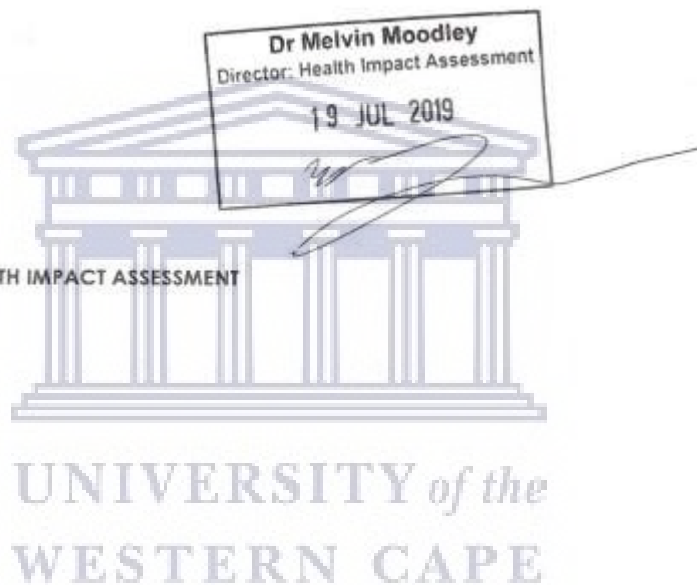
Kindly ensure that the following are adhered to:

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 M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT



APPENDIX: I



LETTER OF CERTIFICATION

Gareth O P H Lowe
9 Lamborghini Avenue
Wierda Park
Centurion
0157
Tel: +27 83 726 6868
Email: gareth_lowe@yahoo.com

5 DECEMBER 2020

To whom it may concern

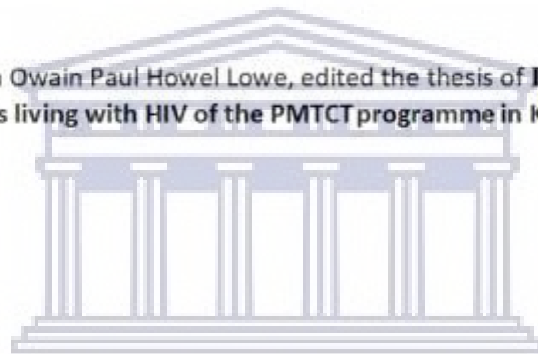
I hereby certify that I, Gareth Owain Paul Howel Lowe, edited the thesis of **Linda Velapi**, entitled "**The experiences of mothers living with HIV of the PMTCT programme in Khayelitsha, Cape Town.**", for language.

Regards

A handwritten signature in blue ink, appearing to read "Gareth Lowe", written over a horizontal line.

Gareth Lowe

Editor



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