

**EXPERIENCES OF MOTHERS ADMINISTERING HIV POST-EXPOSURE
PROPHYLAXIS TO THEIR INFANTS
IN LUSAKA, ZAMBIA.**

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Declaration

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Abstract

Background

Effective Prevention of Mother-to-Child-Transmission (PMTCT) programs require women and their infants to have access to and to participate in a cascade of interventions including antenatal, postnatal and child health services. This includes HIV testing during pregnancy and the use of antiretroviral treatment (ART) with good adherence. HIV-positive mothers should be guided to practice safe childbirth, provide appropriate infant feeding, bring their infants for HIV testing and to administer antiretroviral (ARV) Post-Exposure Prophylaxis (PEP) to their infant's post-delivery, for the prescribed period. Currently contextual information relating to the experiences of mothers administering ARV drugs for prophylactic purposes in Lusaka, Zambia is limited.

The research endeavoured to explore the experiences of mothers administering PEP to their infants in Lusaka, Zambia.

Methods

The study followed a qualitative methodology with a descriptive design to explore the mothers' experiences of administering PEP to their infants. Fifteen semi-structured individual interviews were conducted using open-ended questions. The targeted population were mothers that were required to administer PEP to their infants. Data analysis was guided by Creswell's six-step model of data analysis. The study was approved by the Health Research Ethics Committee (HREC) of the University of Stellenbosch Faculty of Medicine and Health Sciences, the University of Zambia Bio-Medical Research Ethics Committee (UNZABREC) and the Ministry of Health (MOH). Trustworthiness was ensured by following the four principles of credibility, transferability, dependability and confirmability.

Findings

The participants experienced emotional stress and demonstrated a lack of knowledge and understanding about the need for PEP. Challenges experienced by them included difficulties with PEP administration, attending healthcare appointments, cultural and religious influences, lack of partner involvement and stigma and discrimination. Other social challenges that affected the administration of PEP were lack of disclosure to partners for fear of stigma and

discrimination with possible abandonment. However, some participants' own belief in the efficacy of PEP made them continue attending postnatal care.

Conclusion

Most women accepted and understood that PEP reduced the possibility of HIV infection of their infants and accepted it as part of the PMTCT programme. However, several challenges to PEP administration were identified. Administering PEP is emotionally challenging due to fear and apprehension that the baby may become HIV-positive. Although some women are supported in the administration of PEP, lack of knowledge, cultural and religious practices and stigma deter women from continuing to administer PEP. Long waiting times for laboratory results, insufficient supplies of Nevirapine and ineffective counselling were identified as health system barriers to continued PEP administration. Support for women to administer PEP can be enhanced through cultural empowerment, involving partners and family members and the training of healthcare workers.

Key words: Post-exposure prophylaxis, prevention of mother-to-child-transmission of HIV, experiences and mother-to-child transmission of HIV.

Opsomming

Agtergrond

Effektiewe voorkoming van moeder-tot-kind (VMTKT) programme is noodsaaklik vir vrouens en hulle pasgeborenes om toegang tot 'n menigte intervensies, insluitende voorgeboortesorgdienste te kan kry. Dit sluit MIV-toetsing gedurende swangerskap en die gebruik van antiretrovirale behandeling (ARB) met toegewyde nakoming daarvan in. MIV-positiewe moeders behoort ingelig te word oor hoe om veilige kindergeboortes te hê, geskikte babavoeding te verskaf, hul pasgeborenes vir MIV-toetsing te neem en antiretrovirale (ARV) postblootstelling profilakse (PBP) na geboorte vir 'n voorgeskrewe periode toe te dien. Tans is kontekstuele inligting wat verband hou met die ervaringe van moeders wat ARB substansie toedien vir profilaktiese doelwitte in Lusaka, Zambia beperk.

Hierdie navorsing het gepoog om die ervaringe van moeders wat PBP aan hul pasgeborenes in Lusaka, Zambia toedien, te ondersoek.

Metode

Hierdie studie het 'n kwalitatiewe metodologie met 'n beskrywende ontwerp gevolg om die moeders se ervaringe van die toediening van PBP aan hulle pasgeborenes te ondersoek. Vyftien semi-gestruktureerde onderhoude met oop-einde vrae is gevoer. Die teikengroep was moeders wat PBP aan hul pasgeborenes moes toedien. Data analise was gelei deur Crewell se ses-stap-model oor data analise. Die studie is goedgekeur deur die Gesondheidsnavorsingsetiëkkomitee (GNEK) aan die Universiteit van Stellenbosch, Fakulteit van Medisyne en Gesondheidswetenskappe, die Universiteit van Zambia Biomediese Navorsingsetiëkkomitee (UNZABNEK) en die Ministerie van Gesondheid (MVG). Betroubaarheid is verseker deur die vier beginsels van geloofwaardigheid, oordraagbaarheid, getrouheid en bevestigbaarheid.

Resultate

Die deelnemers het emosionele stres ervaar en het 'n gebrek aan kennis en begrip oor die behoefte aan PBP. Probleme met die toediening van PBP en nakoming van gesondheidsorgbesprekings, kulturele en religieuse invloede, 'n gebrek aan betrokkenheid van die saamwoonmaat, en stigma en diskriminasie, is die uitdagings wat deelnemers ervaar het. Ander maatskaplike uitdagings wat 'n effek op die toediening van PBP gehad het, was die gebrek aan openbaarmaking aan saamwoonmaats weens vrees vir verlating, en stigma en

diskriminasie wat verder die gebrek aan ondersteuning van hulle saamwoonmaats bevorder het. Nietemin, sommige deelnemers se eie geloof in die effektiwiteit van PBP het daartoe aanleiding gegee dat hul voortgegaan het om postnatale sorg by te woon. Kulturele en religieuse invloede het 'n rol gespeel in die besluitneming ten opsigte van PBP-toediening wat postnatale bywoning geaffekteer het.

Slotsom

Die meeste vrouens het aanvaar en verstaan dat PBP die moontlikheid van MIV-infeksie kan verminder en dit as deel van die VMTKT-program aanvaar. Nietemin, verskeie uitdagings aangaande die toediening van PBP is geïdentifiseer. Die toediening van PBP is emosioneel-uitdagend weens die vrees en ongerustheid dat die pasgeborene MIV-positief kan raak. Alhoewel sommige vrouens ondersteuning het om PBP toe te dien, het die gebrek aan kennis, kulturele en religieuse praktyke en stigma verhinder dat sommige vrouens voortgegaan het om PEP toe te dien. Uitgerekte wagperiodes vir die verkryging van uitslae, onvoldoende voorraad van nevirapien en oneffektiewe berading, is geïdentifiseer as struikelblokke in die gesondheidsorg sisteem vir die voortsetting om PBP toe te dien. Ondersteuning aan vrouens om PBP toe te dien, kan versterk word deur kulturele bemagtiging, die betrokkenheid van saamwoonmaats en familielede en die opleiding van gesondheidsorgwerkers.

Sleutelwoorde

Postblootstelling profilakse, voorkoming van moeder-tot-kind transmissie van MIV, ervaringe van moeder-tot-kind transmissie van MIV.

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Treatment
ANC	Antenatal Care
CD4	Cluster of Differentiation 4
CIDRZ	Centre for Infectious Disease Research in Zambia
HIV	Human Immunodeficiency Virus
MOH	Ministry of Health
PMTCT	Prevention of Mother-To-Child-Transmission
PEP	Post-Exposure Prophylaxis
UNAIDS	United Nations AIDS Programme
UNICEF	United Nations Children's Fund
WHO	World Health Organization
ZDHS	Zambia Demographic Health Survey

CHAPTER 1

FOUNDATION OF THE STUDY

1.1. Introduction

Human Immunodeficiency Virus (HIV) in sub-Saharan Africa has caused about 90% of AIDS-related paediatric deaths in Africa despite the wide coverage and acceptance of programs to prevent mother-to-child-transmission (PMTCT) (Ngarina, Tarimo, Naburi, Kilewo, Mwanyika-Sando, et al., 2014:1). In the majority of children, HIV-infection is obtained from their mothers through vertical transmission (Ngarina, et al., 2014:2). In order to prevent mother-to-child-transmission during labour, delivery and breastfeeding, mothers should administer antiretroviral (ARV) drugs to their infants' post-delivery, for the prescribed period. The ARV drugs administered to prevent HIV transmission and infection are termed post-exposure prophylaxis (PEP) and are one of the components of the PMTCT programme in Zambia (Republic of Zambia, 2014:15).

HIV-positive mothers are faced with a number of challenges. Challenges observed are the inadequacy of knowledge on how to take care of their infants and the lack of disclosure of their HIV status to their partners (Boateng, Kwapong & Agyei-Baffour, 2013:6). In addition, these mothers should prevent their babies from becoming infected with HIV through administering PEP to their infants after delivery. Good adherence to PEP is necessary to prevent transmission that could have occurred during delivery and postpartum through breastfeeding, especially if the mother is not on lifelong antiretroviral treatment (ART) (Chasela, Hudgens, Jamieson, Kayira, Hosseinipour, et al., 2010:2272). Zambia has adopted option B+ which provides pregnant and breastfeeding mothers with lifelong ART regardless of their CD4 count or clinical stage (UNAIDS, 2016:81).

Many infant deaths in Africa could have been prevented during the postnatal period, which is an important time to follow-up and provide simple measures of preventing mother to child transmission of HIV. Kak, Chitsike, Luo and Rollins (2010:113) state that there is often a major gap in the provision of effective prophylaxis to prevent transmission during pregnancy and childbirth in the postnatal period. Few PMTCT programmes provide support, treatment and on-going care for the infant after discharge that successfully reach mothers and infants. The authors further elaborate that the PMTCT programmes focus on identifying HIV-positive mothers and preventing HIV infection in infants, but less emphasis is placed on follow-up

activities. It is evident that not many studies have focused on the experiences of mothers providing PEP to their infants post-delivery. Consequently, the researcher did not find studies that specifically concentrated on the experiences of mothers who administer PEP to their infants. This has made it imperative to explore the mothers' experiences of administering PEP to their infants.

1.2. Significance of the problem

Lusaka is the largest city and is the capital of Zambia. Lusaka is one of the fastest-developing cities in Southern-Africa. The population projection for Lusaka city by July 1, 2016 was 2 888 575. Lusaka is at an elevation of 1 279 metres above sea level located in the southern part of the central plateau (World population review, 2016:1).

Although Zambia's population is at present growing at a rate of 3.2% per year, the HIV prevalence has dropped and is at 13.5% among adults (World population review, 2016:2-3). The HIV incidence amongst Zambian women aged between 15 and 29 has declined from 1.13% in 2009 to 0.94% in 2011. New paediatric HIV infections have also declined by 55% between 2009 and 2011, from 21 000 to 9 500. There has been an expansion of PMTCT coverage in antenatal clinics by 81%, which has resulted in an increase in HIV testing of pregnant women from 14% in 2005 to 94% in 2010. In addition, the percentage of HIV-positive pregnant women receiving ARVs for PMTCT has risen from 58% in 2009 to 86% in 2015 (United Nations International Children's Emergency Fund (UNICEF) Annual Report for Zambia, 2015:23). Even with the progress that has been made to reduce HIV transmission, the HIV epidemic in Zambia is still one of the nation's major public health problems.

It is recorded that 90% of new HIV infections in Zambia are driven by structural and biomedical factors such as multiple, concurrent sexual partnerships; MTCT; low and inconsistent condom use; low levels of male circumcision; and mobility and labour migration. The socio-economic impact of HIV and AIDS in Zambia is substantial since the people most affected are at the peak of their productive and reproductive lives (Centre for Infectious Diseases Research in Zambia (CIDRZ), 2016:1-2).

The PMTCT guideline of the World Health Organisation (WHO) 2013 has been adopted by Zambia. The guideline recommends two options: (i) lifelong ART should be given to HIV-

positive, expecting and breastfeeding mothers irrespective of their CD4 count or WHO clinical stage (Option B+); and (ii) HIV-positive expecting mothers should take ART during the course of the MTCT risk period (Option B) (WHO, 2013:16). Furthermore, the Zambia Consolidated guidelines (Republic of Zambia, 2016:1), present recommendations that ART be provided to all children living with HIV regardless of their CD4 count and is aimed at promoting early treatment to prevent morbidity and mortality.

According to UNICEF (2012), the impact of HIV/AIDS has continued to haunt the Zambian community. Sex with non-regular partners remains the most common source of infection and accounts for 71% of new HIV infections in Zambia (UNICEF, 2012).

The background highlights the HIV transmission risk for mothers and infants. Further research into this risk would assist in achieving the country's goals. There is a need to improve healthcare services in order to eliminate vertical transmission of HIV from mother to infant.

1.3. Rationale

The timely provision of ARV drugs to HIV-positive mothers has been proven to reduce MTCT of HIV including morbidity and mortality rates (Donahue, Dube, Dow, Umar & Van Rie, 2012:1233). It has been estimated that PMTCT in Africa probably averted about 600 000 infant infections with the provision of ARV prophylaxis for pregnant women living with HIV between 1995 and 2011 (Gopalappa, Stover, Shaffer & Mahy, 2014:5). HIV-exposed infants should receive infant prophylaxis immediately after they are born (WHO, 2013:30). Nevirapine (NVP) should be administered as infant prophylaxis for six weeks to HIV-exposed infants who are breastfeeding if their mothers are receiving ART. Nevirapine (or twice daily Zidovudine) should be given for four to six weeks if infants are receiving replacement feeding (WHO, 2013:30). Replacement feeding is defined as giving an infant exclusive formula milk during the first six months of life. Women who are HIV-positive are informed to breastfeed when replacement feeding is acceptable, feasible, affordable, sustainable and safe (UNICEF, 2010:6). However, the latest WHO 2016 guidelines recommend that women who are on ART can safely breastfeed for up to two years (WHO, 2016:3). In studies done in sub-Saharan Africa, prophylactic ARV drugs for PMTCT used in the third trimester of pregnancy and during breastfeeding, have reduced HIV transmission to 5% or less at 6 months after delivery (Ngarina, et al., 2014:2).

The Sustainable Developmental Goals (SDG) are new universal goals, targets and indicators officially put forward to transform healthcare globally. These include tackling the root cause of poverty and improving the lives of the poor (United Nations Development Programme, 2013:16). One of the SDGs for Zambia is to prevent morbidity and mortality by promoting early treatment of HIV-infected children and reducing missed opportunities for HIV care (Republic of Zambia, 2014:10). Zambia has embraced the four prongs of PMTCT care including primary HIV prevention, prevention of unplanned pregnancies, PMTCT for HIV and the support and care of HIV-infected families (Republic of Zambia, 2014:10).

PMTCT programs are not without challenges. Some of the challenges reported by mothers in a study conducted in Malawi included a lack of knowledge regarding infant ART and fear of disclosure of their own and their child's HIV status (Donahue, et al., 2012:1233). The challenges mentioned in a study conducted in Beira, Mozambique included the discouragement of mothers from seeking care postnatally due to transport costs, inadequate spousal or family support and fear of HIV/AIDS-related stigma and discrimination (Blanco, Micek, Frenkel, Montoya, Karagianis, et al., 2015:1). Clouse, Schwartz, Van Rie, Basett & Yende, et al., (2014:12) support this assertion by stating that pregnant and postpartum women from South Africa face their own unique barriers for PMTCT care in the form of inadequate partner support and anxiety about infant HIV diagnosis. Furthermore, postpartum women who received ART during pregnancy experience a unique change from receiving care for themselves during their pregnancy to having separate appointments for their infant and maternal care after delivery (Clouse, et al., 2014:12). The HIV postnatal transmission risk was reported to be substantial to nearly 100% in a study conducted in Malawi, despite the fact that they offer a PMTCT programme to HIV-infected women (Van der Horst, Chasela, Ahmed, Hoffman & Hosseinipour, et al., 2009:25). In another study conducted in the United States of America (USA), women complained of separate appointments a few days apart for themselves and their babies at the paediatric and adult HIV clinics (Blanco, et al., 2015:4).

The life of an HIV-infected woman and consequently her postpartum HIV care, time and finances, are influenced by the birth of an infant (Boehme, Davies, Moneyham, Shrestha, & Schumacher, et al., 2014:579). Lazarus, Struthers and Violarie (2010:176) write that the understanding and practice regarding their infants' care is influenced by the mothers' experiences, observations and fears. Furthermore, they state that for those mothers who have

not disclosed their own nor their infant's HIV status to family members, starting and continuation of ART posed a challenge (Lazarus, et al., 2010:178). In India, a study by Seth, Gupta, Chandra, Maheshwari, Kumar and Aneja (2014:867) it was discovered that family support plays a key role in the treatment of children when an HIV-infected mother or caregiver is struggling with her own illness, treatment, financial constraints and psychosocial challenges.

It is evident that the accessibility of services alone does not lead to acceptance of and adherence to PMTCT programmes (Colombini, Stockl, Watts, Zimmerman & Agamasu, et al., 2014:914). Although many studies have been conducted on women's involvement in the PMTCT programme (Gorman, Nyirenda & Theobald, 2010:2-3; Kamuyango, Hirschhorn, Wang, Jansen & Hoffman, 2014:335; Sprague, Chersich & Black, 2011:2), few studies have focused on postpartum experiences and more specifically, the administration of PEP to infants.

Currently contextual information relating to the experiences of mothers administering ARV drugs for prophylactic purposes in Lusaka, Zambia is limited. By completing this study the appropriate interventions could be introduced to support HIV-positive mothers administering PEP to their infants. PMTCT programs need to incorporate strategies and objectives for continuous care to guarantee long-term benefits for mother and child.

1.4. Problem statement

Postpartum attrition in the PMTCT programme is of particular concern. Clouse, et al., (2014:12) have reported that in some settings up to 50% of women drop out of care after delivery. The researcher, who is currently working at the Paediatric Centre of Excellence (PCOE) situated in the University Teaching Hospital in Lusaka, has observed that some women who tested HIV-positive in pregnancy did not return for HIV care for the six week postpartum visit and therefore their infants could not receive the appropriate care offered at this visit. On average, the return rate in the three months prior to the onset of this study being May, June and July 2016, was approximately 80%. For optimal management of infants exposed to HIV, this rate should be 100%.

From the researcher's experience, it was difficult to monitor adherence to PEP if mothers did not return for follow-up. Postpartum follow up of HIV-exposed infants is critical in order to ensure adherence to prophylaxis, for monitoring the health of the mother and infant, to identify

infants who may have seroconverted by follow up HIV-testing and to initiate ART timeously. Mothers receive counselling on how to give PEP to their infants and about follow-up appointments, but it is not evident that this strategy is effective. Exploring the experiences of mothers who administer PEP to their infants may provide insight for improved counselling and support systems. Although several studies have highlighted challenges mothers face, challenges related to PEP administration have not been explored. Further, there may be challenges unique to the context of Lusaka, Zambia. With reference to the above discussion, it is therefore important to explore the mothers' experiences of administering PEP to their infants.

1.5. Research question

The study was directed by the following research question: What are the experiences of mothers administering post-exposure prophylaxis to their infants in Lusaka, Zambia?

1.6. Research aim

The aim of the proposed study was to explore the experiences of mothers administering post-exposure prophylaxis to their infants in Lusaka, Zambia.

1.7. Research objectives

The research objectives were to:

- Explore the experiences of mothers administering PEP to their infants.
- Understand the views of mothers about the administration of PEP to their infants.
- Describe challenges mothers experience in administering PEP.
- Identify suggestions to improve counselling and support for mothers who administer PEP to their infants.

1.8. Research methodology

The research methodology will be discussed briefly under the sub-headings below and will be discussed in detail in chapter three.

1.8.1. Research design

In the current study, mothers' experiences of administering PEP to their infants were explored by applying a qualitative approach with a descriptive design. The approach assisted the

researcher to understand the phenomenon under investigation, to develop new insights and to improve comprehension of the whole (Grove, Burns & Gray, 2013:57). Administering PEP to a baby and living with HIV is a complex and multi-faceted phenomenon. A qualitative design was therefore appropriate in exploring the in-depth experiences of the women affected (Grove, Burns & Gray, 2013:275).

1.8.2. Study setting

The study was conducted in Lusaka, the capital city of Zambia at the University Teaching Hospital (UTH).

1.8.3. Population and sampling

The target population for the current study were mothers administering PEP therapy to their infants. Thirty-five women were diagnosed HIV-positive in the maternal and child health care department (MCH) of the UTH between July and August 2016. Through personal communication with the relevant personnel at the MCH, an average of 9 to 15 HIV-positive mothers attend the hospital monthly for postnatal visits. A purposive sample of 15 women were selected to participate in the study. This study only focused on adult mothers, since there may be specific challenges unique to adolescent mothers. The researcher deliberately selected the participants in order to ascertain discovery of events or incidences (Grove, Burns & Gray, 2013:365). This selection was done to gain a detailed understanding of the experiences of mothers administering PEP to their infants. The hospital staff first obtained permission from possible participants identified before referring them to the researcher. Data saturation was reached when the 15th interview yielded no new information.

1.8.4. Data collection tool

Data was collected during individual interviews by using a semi-structured interview guide (Appendix 4) that was based on the objectives of the study, the literature and the researcher's own experience (Grove, Burns & Gray, 2013:271). Open-ended questions were chosen to allow the participants to answer in their own words, knowing that it was a sensitive issue (De Vos, Strydom, Fouche & Delport, 2013:351).

1.8.5. Pilot interview

A pilot interview was conducted at the University Teaching Hospital with one participant who met the study inclusion criteria. Information collected was included in the main study.

1.8.6. Trustworthiness

Trustworthiness was ensured by following the four principles of trustworthiness described by Lincoln and Guba (1985) in Brink, van der Walt and van Rensburg (2012:172), which are credibility, dependability, transferability and confirmability. Additional discussion of the principles is presented in chapter three.

1.8.7. Data collection

In-depth interviews were undertaken during data collection using the semi-structured interview guide. The researcher conducted one-on-one interviews at a place convenient for the participants. During these face-to-face interviews privacy was maintained to build rapport as the discussions occurred. Interviews were conducted in a separate room within the UTH building but in another department to maintain privacy. The open-ended questions were asked in an informal, conversational manner, in order to allow the participants to talk freely about their experiences. An audio-recorder with a spare one was used in case of technical failure. Field notes were recorded.

1.8.8. Data analysis

Data analysis was performed simultaneously throughout data collection. The researcher listened to the recordings and transcribed the participants' recorded interviews. The data were transcribed verbatim and included visual clues. Data was analysed, organised, and interpreted, using Creswell's six-step technique of data analysis for qualitative research (Creswell, 2014:197-199).

1.9. Ethical considerations

Ethical approval to conduct the study was obtained from the Health Research Ethics Committee (HREC) of the Faculty of Medicine and Health Sciences, Stellenbosch University (SU) in South Africa (SA) on the 24th of June 2016 (reference number S16/04/062). Permission was obtained from the Permanent Secretary, Ministry of Health in Zambia, the Senior Medical

Superintendent for the institution and the Head of Department of the university teaching hospital in Lusaka, Zambia on the 22nd of July 2016. Thereafter, further ethical approval was obtained from the Biomedical Health Research Ethics Committee (BHREC), University of Zambia (UNZA) in August, 2016 (reference number 001-07-16).

In order to ensure the participants understood what was involved and why it was important for them to participate, the purpose of the study was explained at the beginning of each interview. An information leaflet about the study was provided for each participant to read and take home. It was explained that participants may leave the study at any time without any consequences since participation was voluntary. Participants were also informed that responding to every question was not compulsory if they felt uncomfortable with the topic. The researcher complied with all ethical principles throughout the study. These were confidentiality, respect for persons, beneficence and justice. Participants were assured of the confidentiality of data collected and the anonymity of their identity.

1.9.1. Right to self-determination

The fundamental principle of self-determination is based on respect for persons. As mentioned, participants were informed that participation was voluntary. Information about the study was given to the participants using an information pamphlet in the language each participant understood (English, Bemba or Nyanja). They were encouraged to ask questions. All the participants that were eligible to participate in the study were informed that they could leave the study at any time even after signing the consent form (Grove, Burns & Gray, 2013:164). The contact details of the researcher were on the information pamphlet. No participants chose to leave the study.

1.9.2. Right to confidentiality and anonymity

Confidentiality was maintained throughout the study to protect the HIV status of participants by the allocation of participant codes in lieu of personal identification. The participant codes were also used when transcribing the interviews. Data will be locked for safety on a password protected computer and only accessible to the researcher and will remain secured for five years. Permission was obtained from the participants for audio recording during the interviews. Telephone numbers of the study supervisor and the Ethics Committees were readily available in case the participants experienced any problems with the researcher.

1.9.3. Right to protection from discomfort and harm

The researcher ensured the wellbeing of the participants from discomfort and harm throughout the study by the allocation of participant codes instead of their names to ensure confidentiality. Interviews were conducted on the same day they visited the postnatal clinic in a private room. Participants were interviewed in English, Bemba or Nyanja, which are the main spoken languages in Lusaka. During the interviews, none of the participants became emotionally distressed requiring referral to the onsite counselling services, which was available to them if required.

1.9.4. The right to fair treatment and justice

The principle holds that the participants are treated fairly (Grove, Burns & Gray, 2013:164). Participants signed informed consent forms after explaining and describing to them what the study entailed. They were reassured that confidentiality would be maintained. Participants were selected for the study based on the inclusion criteria.

1.10. Operational definitions

To ensure clarity, certain terms were used with a specific meaning in the study as described below.

1.10.1. Experiences

The concept experience refers to information that originates from being personally involved in a happening, state or circumstance (Grove, Burns & Gray, 2013:10).

1.10.2. Post-exposure prophylaxis

Post-exposure prophylaxis (PEP) is preventive treatment with ARV drugs after exposure to HIV, in order to minimize HIV transmission. Infants born of an HIV-positive mother who is on ART should receive NVP as prophylaxis immediately after they are born, until they are six weeks old (WHO, 2013:16). The risk of HIV infection following exposure is reduced by using short-term ART defined as PEP (Sultan, Benn & Waters, 2014:147).

1.11. Duration of the study

Data was collected between August and September 2016. Data collection and data analysis was done concurrently and was completed in November 2016. The final thesis was submitted for examination in December 2017.

1.12. Chapter outline

Chapter 1: Foundation of the study

The chapter portrays the background and motivation for the study. The problem statement, research question, research objectives, research approach, operational definitions and the outline of the study are described.

Chapter 2: Literature review

Chapter two discusses the literature review related to the study.

Chapter 3: Research methodology

Chapter three provides an in-depth description of the research methodology applied.

Chapter 4: Findings

Chapter four discusses the findings of the study which include the analysis and interpretation of the data.

Chapter 5: Discussion, conclusions and recommendations

Chapter five concludes the findings according to the study objectives and recommendations are made based on the scientific evidence obtained from the study.

1.13. Significance of the study

This qualitative study explored the experiences of HIV-infected women administering PEP to their infants, the challenges encountered and suggestions for counselling support that could be provided in the Zambian community, especially in Lusaka. Exploring the experiences from the perspective of mothers provided insight on how to better support them in administering PEP to their infants.

HIV programmes in Zambia are saving more babies from HIV infection with the expansion of Option B+ within the PMTCT of HIV programmes and keeping their mothers alive. The UNICEF Annual Report for Zambia (2015:7) reports that ART coverage for PMTCT were

closer to the 2016 target of 95% as compared to 86% in 2015. However, a 13% increase in MTCT has been observed. Poor breastfeeding practices are thought to contribute to this worrying trend. The Zambia Ministry of Health is planning to assess the cause of the increased transmission rates with the support of UNICEF and other partners (UNICEF Annual Report Zambia, 2015:11). It is important to further improve strategies to prevent and eliminate MTCT in order to reach the Sustainable Developmental Goals (SDGs).

1.14. Summary

In this chapter, a broad orientation has been given on the importance of exploring the experiences of mothers on administering PEP to their infants. The background highlights the risk of HIV transmission from mothers to infants. The methodology applied in the study is described.

1.15. Conclusion

This qualitative study explored the experiences of HIV-infected women who administer PEP to their infants, the challenges encountered and suggestions for counselling support that could be provided in the community of Lusaka, Zambia. Research into how the HIV transmission risk can be further reduced would assist in achieving the country's goals. The next chapter will focus on the literature related to the study topic.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

The literature review in qualitative research provides the researcher with current and scientific knowledge about a phenomenon (Brink, et al., 2012:54; Burns, Grove & Gray, 2011:189). The review further assists the researcher with interpretation of the study findings. This chapter presents literature that provided a background to the study and includes studies on the challenges experienced by women participating in PMTCT programmes. Studies done globally concerning PMTCT of HIV, including sub-Saharan Africa and in Zambia were reviewed. A statement on the need for further research will form the final part of this chapter.

2.2. Electing and reviewing the literature

The literature was reviewed through a process to identify scientific texts that would add value to the study. Scientific studies were searched electronically from PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Google Scholar and Science Direct. Additional literature sources included international and local policies and books. The material selected was not older than ten years, with the exception of the historical review of HIV/AIDS. The key words used during the search were: ‘experiences of mothers’, ‘HIV post-exposure prophylaxis’, and ‘prevention of mother-to-child transmission of HIV ’and ‘mother-to-child transmission of HIV’.

2.3. The relationship between HIV and paediatric deaths

The global epidemic of HIV still affects the lives of millions of children. The spread of HIV disease among children in sub-Saharan Africa has mainly been through MTCT and this has led to infant mortality (Boateng, et al., 2013:2). In 2013, 240 000 children were newly diagnosed with HIV, with the majority of new paediatric infections attributed to MTCT (AVERT, 2015). Ngarina, et al., (2014:2) observed that most of the HIV-positive children were infected as a result of vertical transmission. Ninety per cent of AIDS-related paediatric deaths amongst children who acquire HIV occur in sub-Saharan Africa despite the extensive coverage and acceptance of programmes for PMTCT (Ngarina, et al., 2014:1). Perinatal mortality is highly associated with HIV. Many HIV-infected children who acquire HIV through MTCT without medical intervention will die in the first year of their life (Morsheimer, Dramowski, Rabie & Cotton, 2014:148).

The introduction of PMTCT programs has had benefits. It is reported that in sub-Saharan Africa there was a 60% reduction in new HIV infections among children – from an estimated 270 000 to 110 000, between 2009 and 2015. An estimated 1.6 million new infections among children were prevented between 2009 and 2015 globally as indicated in the End AIDS – Seventh Stocktaking Report (UNAIDS, 2016:16). A few countries have embarked on prevention strategies to reverse the spread of the HIV epidemic. Worldwide, few programmes have been able either to stop and reverse the spread of the HIV epidemic or sustainably scale up HIV prevention programmes to a national level (Poku, 2016:65).

Lowering child mortality in sub-Saharan Africa is challenging due to the high birth rate. The number of births and the under-five population are set to noticeably increase in Africa. One in three children in the world will be born in sub-Saharan Africa and the under-five population will markedly increase (UNICEF, 2012:9). These children need to be protected from becoming infected with HIV. The End AIDS – Seventh Stocktaking Report, reports that PMTCT coverage in sub-Saharan Africa was at 79% in 2015, which means that effective regimens of ARVs was provided to an estimated 1.4 million HIV-positive pregnant women (UNAIDS, 2016:15).

The PMTCT programme in Zambia was initiated in at 1999 to address the burden of vertical transmission of HIV. Since then, much progress has been made by ensuring that women that are HIV-positive have a reduced risk of transmitting HIV to their infants. Infants born to HIV-positive mothers are provided with prophylaxis and those that are HIV-positive are initiated on ART (Zambia Demographic and Health Survey, 2013-14:111). The HIV epidemic is one of the major public health problems in Zambia (CIDRZ, 2014:9). Approximately 10% of deaths among children in Zambia below the age of five are related to HIV. The Zambia National Protocol Guidelines state that an estimated 16.4% of the Zambian population in 2008 were infected with HIV and approximately 80 000 infants born annually are at risk of vertical transmission (Republic of Zambia, 2010:1).

Between 2009 and 2012, more progress has been made in reducing HIV prevalence in Zambia than previously recorded. As reported in the Children and AIDS: Sixth Stocktaking Report, Zambia recorded a 35% decline in the 2012 data in new HIV infections among children under the age of 15 (inclusive of infants), compared with 2009 (UNAIDS, 2013:6). According to the

Zambian Demographic and Health Survey (2015:111), the neonatal mortality for the period 2009 to 2013 was 24 deaths per 1 000 live births. Neonatal mortality is defined as the number of infant deaths in the first twenty-eight days of an infant's life (UNICEF, 2015:16). Further, one in every 22 Zambian children died before reaching the age of one. Moreover, 45 deaths of infants occurred per 1 000 live births in the five years that preceded the census survey. The under-five mortality rate for the same period was 75 deaths per 1 000 live births, meaning that one in every 13 Zambian children did not survive to their fifth birthday (Zambian Demographic and Health Survey, 2015:109).

According to the Millennium Development Goals Report (MDG) (United Nations, 2014:25), Lusaka province showed a significant drop in infant mortality following the provision of PMTCT services. Infant mortality is when a child dies before their first birthday (Zambia District Health Statistics Report, 2013:12). The number of infant deaths declined from 88 per 1000 live births in the year 2000 to 68 in 2010. At the time, the report stated that it was unlikely that the Lusaka province will meet the MDG goal in dropping infant death to 25 deaths per 1000 live births by 2015.

It has been scientifically proven that early ART initiation can reduce neonatal and infant mortality rates. In the case of HIV infection, evidence indicates that ART initiation before 12 weeks of age reduces the risk of HIV mortality by 76% (Morsheimer, et al., 2014:152). According to the Children and AIDS: Sixth Stocktaking Report (UNAIDS, 2013:6), ARV drugs were recommended by the WHO (2013) in the form of Consolidated Guidelines for treating and preventing HIV infection. All HIV-positive expecting and breastfeeding women should use lifelong ARV drugs during the MTCT risk period to prevent HIV transmission. Timely provision of ARV drugs have greatly proven to reduce the morbidity and mortality rate of HIV-positive mothers and their infants and involvement of mothers in PMTCT programs appear to be critical to the lives of infants (Donahue, et al., 2012:1233).

Zambia still faces significant obstacles to scaling up paediatric care. There is inadequate understanding of the benefits of ART and advocacy for the use of ART in children coupled by limited HIV screening practices. These could be some of the contributing factors that hinder mothers from attending PMTCT. The Zambia Consolidated Guidelines (2014:10) state that prevention of severe morbidity and mortality can be reduced by promoting early management of HIV-infected children and preventing missed opportunities.

Several interventions to promote HIV prevention and knowledge about HIV in Zambia have been introduced. The involvement of community leaders and male partners across a broad range of PMTCT programmes have been promoted. Other interventions that have significantly led to increased uptake of PMTCT and child health services include voluntary counselling and HIV testing, prompt provision of HIV test results, ARV prophylaxis for PMTCT and referral of women in need of clinical care. The integration of maternal and child healthcare services and equity in urban and rural healthcare access has had positive consequences for Zambian communities (UNICEF, 2010:10).

2.4. Mother to child transmission of HIV

Antiretroviral-based prevention is a well-established intervention scientifically proven to prevent MTCT of HIV. The Children and AIDS Fifth Stocktaking report (UNICEF, 2010:5) states that MTCT elimination will require adopting a comprehensive approach towards maternal and infant care. A study conducted in Malawi, Lilongwe town has identified that the HIV transmission risk is higher in the first months of life, compared to studies that have indicated that the risk of transmission remains fairly constant even after the first month. HIV transmission can be increased by different factors, such as maternal advanced stage of HIV and breast infection (van der Horst, et al., 2009:24; Sultan, Benn & Waters, 2014:1476).

In 2005, about 15% of HIV-positive pregnant women in low and middle-income countries received ARV drugs for the prevention of MTCT of HIV. The Children and AIDS Fifth Stocktaking Report, reports that the number of HIV-positive women in need of ARV drugs globally was approximately 356 400 or 28% at the time (UNICEF, 2010:3). AVERT (2015) states that four million lives have been saved over the last decade due to the scale up and access to ART. Following the results of several large randomised trials, there is strong evidence that ARVs are effective in preventing HIV transmission (Baggaley, Doherty, Ball, Ford & Hirschall, 2015:159). ART guidelines for HIV infection in infants and children were revised following an accumulation of evidence on the use of ARVs for preventing MTCT by the WHO in 2010. These guidelines represented a different standard of management based on extremely effective procedures. The guidelines emphasised that the safest infant feeding option for HIV-exposed infants is to be breastfed for at least 12 months with appropriate ARV prophylaxis according to the country setting (UNICEF, 2010:5).

Zambia's PMTCT programme has been scaled-up and succeeded in halving the transmission of MTCT between 2009 (24%) and 2012 (12%) through universal coverage (AVERT, 2015:1). HIV prevention programmes in Zambia have a rigorous combination prevention strategy that focuses on the main action points: preventing spread of HIV and unintended pregnancies among women living with the disease; PMTCT of HIV; and appropriate care and support to women, children and families living with HIV. The provision of ARVs for PMTCT and PEP prevent HIV from becoming established in the body should exposure to the virus occur (AVERT, 2015:1).

Globally, the estimated number of 1.4 million women living with HIV has remained relatively unchanged for the past six years (UNICEF, 2016:4-5). The latest recommendation for HIV prevention, management, care and follow-up services for children, youth and young women called the 'Start Free, Stay Free, AIDS Free' approach, proposes a 'super-fast-track' strategy. Under its new 'Fast Track' strategy, UNAIDS reintroduced the 2011 obligation to eradicate HIV/AIDS as a public health concern by 2030, which is ambitious but timely (Poku, 2016:66). The HIV/AIDS epidemic among women, mothers, infants, adolescents and young girls may come to an end by 2030 (UNICEF, 2016:7).

2.5. Effectiveness of PMTCT programmes

HIV-positive pregnant women and mothers face problems throughout the PMTCT care continuum. These problems are related to the lack of adequate space for counselling and HIV testing and stock-out of supplies (Rujumba, Tumwine, Tylleskar, Neema, & Heggenhougen, 2012:2). Expecting and breastfeeding women and their relatives receive care and treatment through linkages created by the Zambian government. Linkages are services needed by patients that are offered within the hospital settings. Patients and their families are guided through a systematic and effective referral channel. Linkages occur between clinics organized within the hospital or between clinicians, the pharmacy and the laboratory within the healthcare system (Republic of Zambia, 2014:12). Individuals infected with HIV and affected families should be provided with a full package of HIV prevention, problem-solving, management and maintenance services, that extends through early HIV diagnosis and care, controlling opportunistic infections and other comorbid illnesses, namely, commencing, maintaining and monitoring ART (WHO, 2014:3). At birth, the infant should receive ARV (NVP) prophylaxis

and routine immunizations should be provided at the appropriate time. ARV prophylaxis should commence within the first week of birth (Republic of Zambia, 2014:3). Care for infants born to HIV-positive mothers involve infant feeding counselling, early HIV testing and continues until there is no more HIV transmission risk, for example, at the end of breastfeeding. ARV prophylaxis, counselling on ideal infant feeding practices, ART commencement and retention in care for infants diagnosed with HIV and continuation of ART in mothers, are essential components of PMTCT and HIV care (UNICEF, 2016:22).

In 2013, Option B+ was adopted nationwide for the PMTCT programme with the help of Centre for Infectious Diseases Research in Zambia (CIDRZ). This involves providing lifelong ART to expecting and breastfeeding mothers living with HIV irrespective of their CD4 cell count or their WHO clinical staging (Republic of Zambia, 2014:9). CIDRZ is one of the largest independent health research non-governmental organizations in Zambia. The mission of CIDRZ is to improve access to quality healthcare through developing healthcare workers, excellent implementation of research and sustainable public health programmes (CIDRZ Annual Report, 2015:1). CIDRZ offers the PMTCT programme in three of the ten provinces of Zambia (CIDRZ, 2014:12). The Ministry of Health (MOH) has received support from CIDRZ from the beginning of 2014 in the effort to implement Option B+ in health facilities across Zambia. CIDRZ (2015:2), reports that the organization has been working with other counterparts in the MOH, provinces and districts in providing ART to HIV-infected expecting and breastfeeding women. The implementation of Option B+ has saved many babies from HIV infection and kept their mothers alive. In 2015, 86% of expecting women attending PMTCT were provided with ARV treatment which was closer to the 2016 coverage target of 95% (UNICEF, 2015:23).

The Government of the Republic of Zambia (GRZ) is dedicated to promoting child and maternal well-being despite facing significant challenges. In order to promote access and utilization, the government has abolished user fees for all maternal and child health services. Further, the Zambian government has implemented innovative approaches to promote PMTCT by allowing access to social insurance, cash transfers and vouchers for antenatal, maternal, new-born, postnatal and child health follow-up services. The aim of UNICEF programmes is to improve the care provided to mothers and children by supporting the delivery of cost-effective evidence-based interventions at various service delivery levels. Technical assistance

is provided to the GRZ to increase the capacity of facility healthcare workers and community-based agents that provide maternal and child health services (UNICEF, 2010:1).

Despite all the positive interventions and strategic support, PMTCT programmes may still not be as effective as they should be. Braun, Kabue, McCollum, Ahmed and Kim, et al., (2011) have evaluated whether insufficient coordination of maternal and child HIV services could adversely affect early child diagnosis and outcomes in Malawi, while Stringer, et al., (2008) have investigated the monitoring effectiveness of programmes to prevent MTCT in lower income countries. Their study findings have shown that if ARV treatments and prophylaxis as well as follow-up appointments are not adhered to, the interventions to eliminate paediatric HIV would be unsuccessful. The authors explain that inefficient monitoring and ART non-adherence results in higher rates of HIV transmission during labour and delivery as well as late transmission through breastfeeding. These barriers also prevent early HIV diagnosis in children and thus could lead to ill health and death.

2.6. The use of PEP for reducing vertical transmission of HIV

HIV transmission is enhanced by viral, maternal, obstetric, foetal and postnatal factors (Republic of Zambia, 2014: 11). Infants of pregnant women who have not received ART should receive dual or triple ARV prophylaxis since it is evidenced to be more effective than mono therapy (Sultan, Benn & Waters, 2014:148). There exists supporting evidence that the use of ARV drugs decreases the risk of becoming infected with HIV when administered as PEP (WHO, 2013:15). The efficacy of ARV drugs in preventing HIV infection following exposure, for example, occupational exposure, is supported by the effectiveness of ARV drugs in preventing the MTCT of HIV (WHO, 2013:16). Several studies support the efficacy of PEP by showing that vertical transmission of HIV can be decreased for HIV-positive expecting women who have not commenced any ART during their pregnancy. The AIDS Clinical Trials Group (ACTG) 076 showed a reduced incidence of HIV transmission in neonates given six weeks of Zidovudine within 48 hours of delivery (Sultan, Benn & Waters, 2014:1473).

Globally, an expected 150 000 children (aged 0–14 years) were newly infected with HIV in 2015 with about 85% of them living in sub-Saharan Africa. Most of the infections occurred during the breastfeeding period. The prevention of HIV should be aimed at good adherence to

ART by keeping breastfeeding mothers and infants in the PMTCT programme until the end of the breastfeeding (UNICEF, 2016:18).

The high coverage of PMTCT programmes has not resulted in decreasing HIV transmission to infants in all settings. Eradication of vertical transmission of HIV will require multi-pronged approaches to prevent HIV infection amongst women in their reproductive age and improve access and uptake of family planning amongst HIV-positive women (UNICEF, 2010:6).

2.7. Management of HIV-exposed infants

Care for HIV-exposed infants is centred on preventing postnatal HIV transmission by providing PEP, encouraging regular follow-up, HIV screening and maximizing family health and well-being (UNICEF, 2013:17). Infants born of HIV-positive mothers should breastfeed exclusively for the first 6 months of life and be provided with appropriate balanced supplemental foods thereafter. Breastfeeding should continue until 12 months and should only be discontinued once a nutritionally acceptable and harmless diet without breast milk can be provided (WHO, 2013:104). The 2016 guidelines for PMTCT recommend that women breast feed for up to two years (Republic of Zambia, 2016:60). HIV-exposed infants should receive regular follow-up with immunizations and other additional healthy child services (WHO, 2013:106). If the mother is on lifelong ART and virologically suppressed, there is no need to continue PEP beyond six weeks after delivery.

Children younger than 18 months should be tested for HIV within four to six weeks of birth so that those that have been infected could start ART. Infants that are HIV-exposed should commence PEP at birth or whenever HIV exposure is recognized (WHO, 2013:30). NVP should be given for six weeks daily for infants born of mothers who are receiving ART and are breastfeeding. Infants receiving replacement feeding should be given four to six weeks of NVP (or twice daily AZT) (WHO, 2013:30). The Zambia Demographic and Health Survey report (2013:19) indicated that only 73% of infants were exclusively breastfed for the first six months of life, which indicated that complementary foods are often introduced too early in Zambia. HIV testing should be performed according to WHO guidelines that recommend initial serological testing followed by a confirmatory virological HIV test for infants and children under 18 months. For HIV-negative infants and children, HIV testing should be repeated six weeks after breastfeeding ends or when clinically indicated (WHO, 2014:26). In the Republic

of Zambia (2016:57), the latest Zambia Consolidated Guidelines recommends testing an HIV-exposed infant at birth, 6 weeks, 6 months, 9 months, 12 months, 18 months and at 24 months of age.

In addition to the provision of PEP, HIV-exposed infants should also receive co-trimoxazole for treating and preventing opportunistic infections (WHO, 2014:6). Ending AIDS by 2030 requires the implementation of all the above mentioned guidelines (WHO, 2014:6).

2.8. Evidence for PEP

The use of ARV drugs for PEP has been shown to be effective in animal studies (WHO, 2014:16). This is supported by retrospective studies investigating the efficacy of PEP for occupational HIV exposure and data from studies showing lower vertical transmission rates with the use of PEP for PMTCT (Sultan, Benn & Waters, 2014:1472). Sultan, Benn and Waters (2014:1472) report that viral replication and dissemination of HIV infection can be prevented with early initiation of ART, since it takes 72 hours for HIV to be detected in the regional lymph nodes, up to five days to be detected in blood and eight days to be detected in the cerebrospinal fluid. The 2013 WHO consolidated guidelines provide evidence-based recommendations that PEP is suitable for all populations and for all categories of exposure (WHO, 2014:16).

Fowler, Coovadia, Herron, Maldonado and Chipato, et al., (2015:3), conducted a prospective study on breastfeeding and discussed implications for practice in four African countries, which showed a significant reduction in HIV transmission when prolonged infant NVP was provided. The authors further discussed the safety and efficacy of NVP among HIV-exposed infants whose mothers are counselled to stop breastfeeding at six months and confirmed the importance of the continued use of NVP prophylaxis throughout the breastfeeding period to prevent HIV infection.

2.9. Specific recommendations for the use of PEP

In order to attain good results of adherence for infants taking PEP, the choice of ARV drugs for infants should be based on safety and efficacy (WHO, 2013:13). The duration of taking PEP has an impact on the efficacy it provides in preventing HIV transmission in HIV-exposed infants (WHO, 2013:11). Additional factors that may influence PEP efficacy include the

timing of the commencement of the drug, the level of risk of exposure and possible treatment resistance. Given these concerns, PEP may never be viewed as completely effective (WHO, 2013:16). Moreover, women should be informed that ART prophylaxis is only effective through good adherence (Boateng, et al., 2013:2). It has been reported that adherence to completion of prescribed courses has been a challenge in general and reported completions are currently suboptimal (WHO, 2014:20). Acceptance of and adherence to PMTCT therapies requires that healthcare providers clearly explain the importance of being adherent to PEP to the mother and the consequences of non-adherence (Colombini, Stockl, Watts, Zimmerman, Agamasu & Mayhew, 2014:914).

Women must be assisted to overcome obstacles that decrease adherence to ARV treatments such as stigma and fear of disclosure to their partners, in order to prevent HIV transmission and infection from mother to infant during labour, delivery and breastfeeding (Colombin, et al., 2013:914). PMTCT is being practiced to reduce HIV infection among infants and efforts by the Zambian government to support the programme have been introduced with the assistance of partners. CIDRZ has reported that despite the availability of ART services throughout Zambia, gaining sustainable control of the HIV epidemic requires adherence to life-long treatment and care. Despite clinics offering care services, there has been increasing congestion and long waiting times, causing patients not to return for follow-up (CIDRZ Annual Report, 2015:15).

There is scientific evidence through a study conducted by Boateng, et al., (2013:5) that the benefit of effective counselling is good adherence. Clients are counselled so that they have good knowledge and understand the benefits of adhering to ART and the issues relating to PMTCT. AVERT (2015) indicated that there is a need to explore whether poor retention rates in treatment and care for the infant is due to a lack of knowledge, through conducting more research. Boateng, et al., (2013:1) observed in a study conducted in Ghana that gaps in the mother's knowledge, attitudes and perceptions of ART influenced decisions to adhere to PMTCT. This further emphasises that women need to be adequately counselled on the benefits of PEP and practices that will optimise treatment efficacy.

2.10. Challenges of PMTCT programmes

Women and children have faced disproportionate exposure to HIV infection due to several barriers in accessing services. As a result, PMTCT services are not fully utilized. More children are diagnosed with HIV early in their lives, but they do not return for test results and treatment initiation. Effective follow-up of HIV-infected pregnant women and their babies is lacking due to poor health systems (UNICEF, 2010:2). Moreover, healthcare system barriers such as inconsistencies between Ante-natal Care (ANC) and paediatric ART clinics, affect timely paediatric ART initiation (Boender, Sigaloff, Kayiwa, Musiime & Calis, et al., 2012:7). In South Africa, Sprague, Chersich, and Black (2011:6) noted that there is poor data management in PMTCT programmes. The authors report that some participating sites had no technical means of capturing data and that data was manually recorded and mostly of low quality.

WHO (2014:26) states that breastfeeding is a challenge if not well discussed with an HIV-positive breastfeeding woman. Women should be informed about the risks and benefits of on-going breastfeeding so that the use of PEP is not redirected to suppress the benefits of on-going breastfeeding while HIV transmission is unknown (WHO, 2014:26). The latest WHO guidelines (WHO, 2016:3) state that HIV-positive women should be supported to be fully adherent to ART and to continue breastfeeding for up to 2 years or more.

Cultural influences dictate how women and men negotiate sexual behaviour (UNICEF, 2010:4). Some women in the Zambian society may not decline their partners sex or insist on condom use due to strong patriarchal beliefs (AVERT, 2015:4). This makes women vulnerable to contracting HIV during pregnancy and the breastfeeding period.

According to a study conducted at a primary healthcare facility in Johannesburg, South Africa, women initiating ART during pregnancy have a high dropout rate. About 50% of women drop out of care particularly post-delivery (Clouse, et al., 2014:12). Kalembo and Zgambo (2012:1) in their study investigated the challenges to successful implementation of PMTCT of HIV-1 programmes in sub-Saharan Africa in order to understand the causes of loss to follow-up. The authors report that the high attrition within PMTCT programmes are likely to contribute to mortality. It is estimated that 20-28% of mothers are lost to follow-up during antenatal care, up to 70% four months after delivery and near to 81% at six months after delivery. These findings are also documented in reports by UNAIDS (2010) and WHO (2011). Only 52% of

the women in a study in Nigeria who entered the PMTCT programme completed the entire cascade of services being offered, which included prenatal care, delivery and at least one infant follow-up visit (Said, 2014:18).

Rujumba, et al., (2012:5-6) conducted a study in Eastern Uganda aimed at listening to health workers and gaining lessons for reinforcing the programme for the prevention of PMTCT of HIV. The authors observed that the continuity of drug supply to health facilities was a challenge to PMTCT adherence. Some of the study sites reported running out of HIV test kits and NVP for mothers and babies, which demands that the mothers be referred to the larger centres and hospitals where drugs are more readily available. Generally, the process of going to one clinic and then being referred to another large centre or hospital are very costly for women and their families. According to Blanco, et al., (2015:4), adherence in a study conducted in Mozambique was poor because mothers were given separate appointments, a few days apart, for themselves and their babies at the paediatric and adult HIV clinics.

Koye and Zeleke (2013:3) conducted a study in North West Ethiopia and indicated that one of the causes for HIV transmission through MTCT was home deliveries. Additional factors were the lack of maternal PMTCT interventions, mixed infant feeding, rural placement and late admission of HIV-exposed, but unprotected infants to a health facility.

Healthcare workers interviewed in a study conducted in Eastern Uganda by Rujumba, et al., (2012:6), stated that they needed more training on PMTCT to update their knowledge and skills. The participants emphasised the importance of on-going training regarding current developments and information in PMTCT. The same study indicated the need for sufficient healthcare workers to minimize the increasing workload in the PMTCT programme.

2.11. Challenges experienced by women participating in PMTCT programmes

Several challenges experienced by women participating in PMTCT programmes have been reported in studies and are briefly summarised here.

2.11.1. Lack of knowledge about ART

Some of the challenges to adherence reported in the literature include the lack of knowledge regarding infant ART and fear of disclosure of their own and the child's HIV status (Donahue,

et al., 2012:1233). Further, a lack of knowledge regarding safe infant feeding has also been reported (Van der Horst, et al., 2009:25).

According to a study conducted by Negashl and Ehlers (2016:1) in Ethiopia, after implementation of the PMTCT programme in 2012, about 50% of pregnant women did not access PMTCT services, which might have been due to the women's lack of knowledge. Katirayi, Namadingo, Phiri, Bobrow and Ahimbisibwe, et al., (2016:4) reported in a study conducted in Malawi that adherence challenges were triggered after birth, since women did not see the need for continuing attending ART care after delivery due to feeling healthy and the concern about taking lifelong treatment.

2.11.2. Disclosure and fear

Lazarus, Struthers and Violarie (2010:176) assert that babies' care and treatment is subject to the mothers' personal experiences, thoughts and practices despite being informed about PMTCT. Non-disclosure of a mother's and the infant's HIV status to family members presents a challenge to the initiation and continuation of ART. Buregyeya, Naigino, Mukose, Makumbi and Esiru, et al., (2017:5) write in a qualitative study conducted in Uganda that breastfeeding and pregnant women had disclosure challenges to their partners about ART, which affected adherence.

2.11.3. Lack of spousal support

The challenges highlighted in a study conducted in Beira, Mozambique, included that mothers were discouraged from seeking care postnatally due to transport costs, inadequate spousal or family support and fear of HIV-related stigma and discrimination (Blanco, et al., 2015:1). Clouse, et al., (2014:12) support this by stating that pregnant and postpartum women from South Africa face their own unique barriers for PMTCT care in the form of inadequate partner support and anxiety about the infant's HIV diagnosis. Buregyeya, et al., (2017:5) reports that a lack of transport and other family commitments were challenges that contributed to non-adherence to PMTCT.

According to a study in North India by Seth, Gupta, Chandra, Maheshwari and Kumar, et al., (2014:867), the family plays an essential role in the management of an infant when an infected mother or caregiver is stressed with her own illness, therapy, financial constraints and

psychosocial factors, in addition to dealing with an HIV diagnosis. A study conducted in Alabama, USA has identified that HIV-infected women, throughout the postpartum period, experienced high levels of stress about the care of the infant and financial implications (Boehme, et al., 2014:579).

Secka (2010:64) has conducted a study in Gambia on male involvement in care and support during pregnancy and childbirth. The study shows that there are certain reasons why men do not escort their partners to the clinic. Some of the reasons are due to the men's job responsibilities, long waiting times at the clinic, the large age difference between husband and wife as in many instances older men marry younger girls and who feel ashamed to escort them to the clinic. Another study in Kenya by Aluisio, Richardsonb, Bosireg, John-Stewart and Mbori-Ngacha, et al., (2011:6) investigated male antenatal attendance. Involvement of partners in PMTCT programmes were associated with decreased infant HIV infection and increased infant survival rates. When the husband/partner is involved in the PMTCT programme, the danger of vertical spread of HIV reduces by 40%.

2.11.4. Stigma and discrimination

Another major challenge that appears to have a disproportionate bearing on women is stigma. HIV-positive pregnant women experience HIV-related humiliation when pursuing maternal health care. Stigma is a detrimental or demeaning trait that an individual owns that diminishes the person's position in the society. Thus, an individual or group is perceived as being different, unwanted and often denigrated (Land & Linsk, 2013:3). Land and Linsk, (2013:4) has further explained that silence and denial generates barriers to treatment and expands poor health outcomes for people diagnosed with HIV. In some extreme cases, people with HIV/AIDS in the United States and other countries around the world have been attacked when disclosing their health status and advocating for medical care. Research by the Global Network of People Living with HIV has found that some women could not receive adequate information to prevent vertical transmission or be retained in care due to stigma. Other women are denied access to PMTCT services due to fear of violence or desertion by male partners and community-level isolation or discrimination (UNICEF, 2016:23).

Reports by WHO, UNAIDS and UNICEF (2011:145-146) show that if couples who together attend health facilities for antenatal care and PMTCT and who have been counselled and tested as a couple, less potential for blame and judgement among themselves occurs.

PMTCT programmes can only be successful if stigma-reduction strategies are implemented. The effect of stigma on maternal, neonatal, and child health outcomes should be acknowledged. Turan, Bukisi, Onono, Holzemer and Cohen (2011:1118) state that women are more scared of the negative influences of stigma and discrimination from their male partners. Stigma from male partners is bound to have a more profound effect on women than any other persons because these are the closest persons to them.

A study conducted in Ghana, West Africa, reports that although 99% of men and 98% of women are aware of HIV and AIDS, strategies to reduce HIV-stigma have lagged behind (Boateng, et al., 2013:2). Despite the awareness of HIV/AIDS in Zambia, stigma and discrimination still exist for HIV-positive people in some communities (Republic of Zambia, 2014:10).

Gorman, Nyirenda and Theobald (2010:2) conducted a study in a rural district of Malawi and discovered that ART adherence was impeded by stigma and discrimination. The authors mentioned that women were scared of abuse and divorce after partner disclosure.

2.12. Conclusion

Elimination of vertical transmission of HIV is possible. Research evidence shows that PMTCT programmes have been widely implemented internationally and in Zambia and has led to improved maternal and infant outcomes. There is evidence supporting the efficacy of PEP provided to HIV-exposed infants in order to prevent HIV transmission that may have occurred during labour and in the postnatal period through breastfeeding. However, in the context of PMTCT mothers may experience several challenges including a lack of knowledge, non-disclosure and a lack of support. Many studies have focused on the challenges experienced by women who participate in PMTCT programmes, but none specifically focused on the provision of PEP. The research methodology that was used to explore the experiences of mothers administering PEP to their infants will be discussed in Chapter 3.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction

This chapter discusses the research design and approach, the selection of participants, the techniques for data collection and data analysis in detail.

3.2. Aim and objectives

The aim of the proposed study was to explore the experiences of mothers administering post-exposure prophylaxis to their infants in Lusaka, Zambia.

The objectives set for the study were to:

- Explore the experiences of mothers administering PEP to their infants;
- Understand the views of mothers administering PEP to their infants;
- Describe challenges mothers experience administering PEP; and
- To identify suggestions to improve counselling and support for mothers who administer PEP to their infants.

3.3. Study setting

A specific place or places where data is collected is called a research setting (Brink, et al., 2012:59). The research was undertaken in a natural setting. A natural setting is defined as an environment that has not been manipulated or changed for the sake of the study (Grove, Burns & Gray, 2013:373).

Collection of data was done at the University Teaching Hospital (UTH) in Lusaka city, Zambia. A large number of women and infants receive care at this hospital. As a referral hospital, the UTH provides primary and secondary care for a large number of Lusaka residents. The hospital has a total bed capacity of 1 868 and it provides both outpatient and inpatient care. Lusaka city has a population of close to 2 million people. Women of child bearing age make up about 20% of the population. The highest fertility rate globally was recorded in Zambia at 6.2 births per woman (World population review, 2016). Rural women were recorded as having about three children more than urban women (Zambia Demographic and Health Survey, 2013-2014:67). Women are referred to the UTH from urban and rural areas.

The data collected represents the opinions of study participants within one hospital, selected since the hospital provides Option B and Option B+ treatment strategies. A neutral venue for participant interviews was carefully selected before the onset of interviews by the researcher after consulting with the unit manager. This room was separate from where PMTCT care is provided. The researcher ensured that the recorder was in good working order prior to the interviews with a spare one in case of technical emergency. Extra care was taken by inviting participants in advance so that they were not disturbed in terms of missing their appointments or losing their place in the queue. Participants were identified by hospital staff taking care of postnatal mothers and their infants before referring them to the researcher.

3.4. Research design

A research design is defined as a framework for the conduct of the study that maximises control over factors that could interfere with the study's desired outcome (Burns, Grove, & Gray, 2012:42). The study adopted a qualitative approach due to the nature of the topic, with a descriptive design. Data were collected from the participants by conducting semi-structured individual interviews.

The choice of the research design and data collection was based on the research aim and objectives of the study. Qualitative research is a way of gaining insight through discovering meanings. It is a means of discovering and exploring the depth and richness of data. According to Grove, Burns and Gray (2013:23), a qualitative study is an interactive, subjective, holistic approach used to describe life experiences. The insights gained from these individual interviews were used to describe the experiences of mothers that attended postnatal care at the UTH.

The descriptive design was used to describe situations. It is open, flexible and inductive in nature as this allowed the participants to openly talk about their feelings and thoughts about their lives. The logic of the inductive approach begins with the researcher who gathers thorough information from participants and then formulates categories and themes. Thereafter, the existing literature about the topic is compared with the themes, which are then developed into broad patterns, theories or generalizations (Creswell, 2014:65).

De Vos, et al., (2013:65) explains that the researcher is directly involved in the setting, interacts with the people and is the key instrument when data is collected through examining documents,

observing actions and questioning participants. The authors further explain that the researcher ascribes meanings to the participants' every day accounts by using the descriptive approach. The purpose of the approach allowed the researcher to spend time with the participants, observe, listen and ask questions during the in-depth interviews. Descriptive research allows the researcher to picture specific details of a situation, social setting or relationship, and focuses on "how" and "why" questions (De Vos, et al., 2013:96).

3.5. Population and sampling

A population is the entire group of persons or objects that meet the criteria the researcher is interested in studying (Brink, et al., 2012:131). All HIV-positive mothers who were administering PEP to their infants at the time of the study were involved in the research. Thirty-five women were diagnosed HIV-positive in the Maternal Child Health (MCH) care of the UTH between July and August 2016. An average of nine to 15 HIV-positive mothers attended the hospital monthly for postnatal visits.

The sample size and the sampling approach were determined by the purpose of the study and the depth of information needed (Grove, Burns & Gray, 2013:371). The criteria of selecting the sample was established from the research problem, the purpose, the literature and the conceptual and operational definitions. A total of fifteen participants over the age of 19 years were selected using the inclusion criteria. This study only focused on adult mothers, since there may be specific challenges unique to adolescent mothers. The size of the sample was determined by the principle of saturation. The idea of saturation comes from grounded theory which means that the researcher stops collecting data when the categories (themes) are saturated. This is when fresh data no longer provides new insights or reveals new properties (Creswell, 2014:191). Data saturation was reached with the 15th interview when no new information was mentioned.

Purposive sampling aimed to include women from rural and urban settings, those with prior experience in providing PEP and those that did not. The sampling method allowed for the inclusion of women of 19 years and above of different language backgrounds. Participants were drawn from the population of mothers receiving routine postnatal care at the UTH. The aim was to enrol HIV-positive mothers administering PEP to their infants and receiving HIV care in accordance with Zambian national guidelines.

Saturation of data was achieved with the fifteenth participant, since this interview provided no new information (Grove, Burns & Gray 2013:371). The selected participants provided the researcher with a deeper understanding of the topic under study, since they had experience concerning the administration of PEP.

3.5.1. Inclusion criteria

Inclusion criteria are characteristics a participant must possess to be part of the population that teaches the researcher a great deal about the central focus or purpose of the study (Grove, Burns & Gray, 2013:353). In this study the inclusion criteria were HIV-positive mothers:

- over the age of 19;
- who had been caring for an HIV-exposed infant since birth; and
- who had experience in administering ART to an infant within the past three months.

As previously mentioned, this study only focused on adult mothers, since there may be specific challenges unique to adolescent mothers. The World Health Organization (WHO) describes adolescence as the period between 10 and 19 years (WHO, 2013:13). In order to limit recall bias, mothers who had administered ART within the past three months were selected. The Zambia Consolidated Guidelines state that HIV-exposed infants should receive NVP prophylaxis from birth for at least 4-6 weeks (Republic of Zambia, 2014:15). Participants were therefore recruited at the 6-week postnatal visit.

3.5.2. Exclusion criteria

Exclusion criteria are characteristics that can cause a person or element to be excluded from the target population and justification should be provided for excluding participants (Grove, Burns & Gray, 2013:353). In this study, women who were administering ART to an infant, but involved in another study, were excluded to prevent participation fatigue and those younger than 19 years.

3.6. Data collection tool

Systematic gathering of information relevant to the research purpose or specific objectives of the study is called data collection (Grove, Burns & Gray, 2013:45). The interview guide was designed according to the objectives of the study as stated in chapter one (Appendix 4). The

researcher was completely involved by perceiving, reacting, interacting, reflecting, attaching meaning and recording the data obtained (Grove, Burns & Gray, 2013:268-269). The questions in the interview guide were linked to the purpose of the study. Data was collected through exhaustive dialogues using a semi-structured interview guide to allow for probing of views from the participants. The researcher used a calm and non-threatening language in the thought-provoking questions to probe for information (Grove, Burns & Gray, 2013:272). Detailed exploration was increased by using probing questions to follow on the main questions. Brink, et al., (2012:158) define probes as prompting interrogations that inspire the respondent to elaborate on the subject. As interviews continued, new questions arose from the answers that were provided by the participants. There was more time created for detail exploration as the interviewer and the participant developed a rapport that allowed a free flow of communication between them. The method allowed the interviews to flow, while confirming that the content was focused on the critical concerns of the study and permitted exploration of unexpected and potentially significant responses framed from the experiences of the participants themselves (Grove, Burns & Gray, 2013:424-425). Participants were encouraged to provide descriptions of their experiences, such as feelings and any other memories encountered.

3.7. Pilot interview

A pilot study helps the researcher recognize and address some of the problems that may be encountered during the research process, make adjustments about the instrument or re-assess the achievability of the study (De Vos, et al., 2013:237). A smaller scale version of the main study is a pilot study (De Vos, et al., 2013:237). In the context of qualitative research, a pilot interview was conducted in order to refine the interview guide questions and the interviewing skills of the researcher such as listening, reflecting, probing, paraphrasing and summarizing (Grove, Burns & Gray, 2013:343).

One participant was interviewed in the pilot study who met the inclusion criteria. The study supervisor evaluated the interviewing skills of the researcher and provided advice. No changes were made to the interview guide as all the questions were clear. The data collected was included in the analysis.

3.8. Trustworthiness

Trustworthiness in qualitative research is the ability of the methodological approach used to capture the reality of those being studied (Ngarina, Popene, Kilewo, Biberfeld & Ekstrom, 2013:3). Trustworthiness in this study was the ability to capture the reality of those mothers who are HIV-positive and administered PEP to their infants. Trustworthiness was ensured by following the four principles of trustworthiness described by Lincoln and Guba (1985) in Brink, et al., (2012:172). Guba's model was used for trustworthiness of qualitative research to establish and maintain overall trustworthiness. The model has been used extensively by qualitative researchers.

The researcher's worldview affects how data is collected and interpreted. In order to control self-bias, the researcher engaged in self-reflection (Polit & Beck, 2008:146). The researcher worked on the PMTCT programme prior to the study as a study coordinator. During this process, referred to as reflexive thought, the researcher explores personal feelings and experiences that may influence the study and integrates this understanding into the study (Burns & Grove, 2003: 379). Reflexivity involves conscious self-awareness by the researcher who explores personal feelings and experiences that may influence the study so that the researcher does not integrate these feelings into the study. As an individual, the researcher brings to the inquiry a unique background set of values, and a social and professional identity that can affect the research process (Polit & Beck, 2008:334). Despite the researcher's fluency in the languages English, Nyanja and Bemba used during the interviews, language and cultural barriers were taken into consideration knowing that certain expressions may have different meaning in different languages. Qualitative research involves making meaning and interpreting data and the researcher takes an important role in the collection of the data.

The criteria to ensure trustworthiness are discussed in more detail below.

3.8.1. Credibility

Confidence in the truthfulness of the data and the interpretation thereof was achieved by ensuring credibility (Brink, et al., 2012:172). Trustworthiness was ensured through selecting only those participants who met the inclusion criteria and by following the interview guide. The researcher ensured that the participants accurately understood the questions and the research that was being conducted. Applying the strategy of credibility ensured truth-value (Polit & Beck, 2008:562). Assurance in the truth of the data collected was established through

the techniques of peer debriefing and member-checks. The researcher verified the accuracy of qualitative findings through member-checking (Brink, et al., 2012: 172). The researcher took the transcriptions of the interviews back to the participants and allowed the participants to confirm the accuracy of the information on their next clinic visit and phone calls. Member checking was also done during the interviews by asking the participants whether she understood correctly by rephrasing and summarising. Peer-debriefing was done by reviewing the interview transcripts with the supervisor. Creswell (2014:202) describes peer-debriefing as a process that involves finding a peer who evaluates and enquires about the research process so that the interpretation resonates with other people and not only the researcher.

The researcher worked on the PMTCT programme prior to the study as a study coordinator. The participants were referred from the postnatal clinic by professional nurses who requested permission from them before referring them to the researcher. This consequently allowed the researcher to have knowledge of the context and background of the programme and further helped the researcher to collect rich data. Creswell (2014:202) explains prolonged engagement as a way that the researcher develops an understanding of the phenomenon under study and conveys detail about the site and the people that lends credibility to the narrative account.

3.8.2. Transferability

Transferability was aided by the detailed description of data collection and data saturation (Brink, et al., 2012:173). The researcher ensured that sufficient information of the research study was available to allow other readers to apply the findings of the study in another setting. Transferability was pursued during data collection until data saturation occurred when the information provided by participants became repetitive and no new themes emerged. Transferability refers to the analogy of generalizing and the ability to relate the findings to other contexts or to other participants (Brink, et al., 2012:173). Generalization was not the aim of this qualitative research, but a detailed understanding of the participants' experience. In order to improve transferability, a purposive sample was used. Purposive sampling maximises the range of information by conscious selection of participants in terms of their knowledge of the phenomenon under investigation and other background characteristics (Brink, et al., 2012:173).

3.8.3. Dependability

The term dependability refers to the stability of data over time (Brink, et al., 2012:173). Guba and Lincoln (1985) in Brink define dependability as the extent to which similar results would be attained if the study were repeated. To support dependability, the researcher ensured that the methods were described in sufficient detail by maintaining a step-by-step “audit trail”. The researcher has all raw data stored so that it is available for review if requested. As the study progressed, the researcher documented the information, the conclusions on which each decision was based and the reasoning behind each decision (Polit & Beck, 2008:80). The supervisor functioned as an auditor to make sure that the information given by the participants was accurately captured. In order to address dependability more directly, the researcher used a digital recorder to ensure that all the information provided by the participants were recorded (Shenton, 2004:71). The details of the interviews were recorded, documented and sent to the supervisor for verification. Brink, et al., (2012:127) explains that dependability entails an audit. The inquiry auditor who is generally a peer determines whether the process and procedures used by the researcher in the study were acceptable. The supervisor closely supervised every stage of the study. The method of data analysis in Creswell, (2014:197) was used. Agreement was reached between the researcher and the supervisor on the identified themes.

3.8.4. Confirmability

Confirmability refers to the potential for accuracy of data in terms of correctness, significance or importance. Confirmability establishes that the data collected represents the information provided by the participants and that the interpretations of the data are not influenced by the researcher’s imagination (Brink, et al., 2012:173). The researcher kept all data safe for further analysis and provided enough substantiation that the findings and their interpretation were grounded in the data through making use of verbatim participant quotations. The recorded data reflects the participants’ voices and not the bias or perceptions of the researcher (Brink, et al., 2012:173). This helped to ensure that the findings were a genuine reflection of the experiences and ideas of the interviewed participants (Shenton, 2004:72). After transcribing the participant interviews, the data was verified by the participants through member-checking to ensure that the data was transcribed accurately.

3.9. Data collection

A systematic gathering of information relevant to the research purpose or the specific objectives, questions or hypotheses of a study is defined as data collection (Grove, Burns & Gray, 2013:45).

Collection of data commenced after ethical approval was granted from the University of Stellenbosch, University of Zambia Bio-Medical Research Ethics Committee (UNZABREC) and Ministry of Health (MOH). Approval was also obtained from the institution, the UTH and the Head of Department. Data collection started on the 15th of August and concluded September 30th 2016 when a total of 15 women were interviewed. The participants were identified by the professional nurses who provided postnatal care and requested permission from the mothers before referring them to the researcher. The researcher worked as a study coordinator where she was actively involved in enrolling mothers into the PMTCT programme. However, the researcher was not involved in the care of mothers who were enrolled in the PMTCT programme at the time of data collection. The researcher is currently working at the UTH. The study participants were mothers that came for the 6-week postnatal visit.

3.9.1. The interviews

An introduction of the study topic was given to the participant and the objectives explained to gain permission. Upon agreement, the participant was requested to sign the informed consent form indicating willingness to participate in the study. To ensure participant's confidentiality, the researcher applied participant codes instead of their names.

An interview according to Grove, Burns and Gray (2013:271), is defined as a two way verbal communication between the researcher and the participant and during this interrogation information is provided. In-depth individual interviews were the most appropriate technique, since HIV infection carries a lot of stigma. Data was collected by conducting one-on-one interviews by the researcher herself.

The researcher made sure that participants did not miss their appointments or lost their place in the line. The researcher built a rapport with the respondents as data was being collected, and this built trust and revealed information with ease. Some questions from the interview guide

led to other ideas and information as the participants spoke freely. The interview guide used is attached in Appendix 4. The interview was recorded using a digital voice recorder to ensure that all data was captured.

The researcher devoted some time to organising the venue for the interviews. The venue was a private neutral place isolated from the main postnatal clinic, namely an examination room at the institution. The researcher sat alongside the interviewee to avoid talking across the desk. The researcher switched off her personal cell phone and requested participants to do so or put their cell phones on silent mode in order to minimise possible interruptions (Grove, Burns & Gray, 2013:272-273).

During the interview, the researcher used techniques such as nodding the head and making sounds indicating interest to encourage the participant to continue talking. Each interview lasted for approximately 25 to 45 minutes. The researcher received training in qualitative interviewing during the research methodology module which was completed successfully at Stellenbosch University and also received additional training in interviewing and data analysis in qualitative at Lusaka Apex Medical University, Lusaka. The open-ended questions were asked in an informal, conversational manner, in order to allow the participant talk freely about her experiences. Participants were interviewed in the language of their choice, Nyanja or Bemba. Participants also spoke English during the conversation if they so wished.

No imbursement was provided to the participants, for example, compensation for travel expenses, since the participants were not inconvenienced in any manner (e.g. they did not miss their usual transport due to staying longer for the interview). No participants needed to be referred for counselling during the interviews.

3.10. Data analysis

Data analysis was conducted to give meaning to the data collected and this was achieved by reducing and organising the data collected (Grove, Burns & Gray, 2013:46). All information collected from the participants through interviews were analysed by way of gathering and generating the collected data into themes. The researcher was completely immersed during the face-to-face interviews in order to facilitate the process of data analysis. The interviews were recorded using a digital recorder. The researcher listened to each recording before making

transcriptions. Interviews were transcribed verbatim in MSWord. The transcriptions included laughter and pauses. A wide margin was left on the transcript for coding and categorising. The descriptive data analysis was done using Creswell's six-step model (Creswell, 2014:197-199). The data was transcribed by the researcher manually and key words were identified representing the codes. The steps are listed below:

3.10.1. Step 1. Organizing and preparing data

During this step, the researcher got a sense of the whole by thoroughly listening to the recordings and carefully writing down the ideas. This involved transcribing interviews, scanning and sorting out material gathered from the participants. Each participant's transcription was numbered to maintain their anonymity. Information from the participants was gathered by carefully listening to the recordings a number of times so that the content of a particular experience could be captured. This included writing notes on anything unusual or interesting. This first step allowed the researcher to become immersed in the data (Creswell, 2014:197). The researcher sent the transcribed interviews to the supervisor.

3.10.2. Step 2. Reading through all the data

The underlying meaning of the participant's was captured by listening to recordings thoroughly and repeatedly and writing down the thoughts in the margins. The researcher also used debriefing sessions, by reviewing the transcripts with the supervisor. Debriefing is defined as seeking ears of peers who have similar status outside of the study in either the method or the phenomenon being studied. These people should be able to discuss with the researcher each step of the process and have a general understanding of the study (Brink, et. al., 2012:172).

3.10.3. Step 3. Coding the data

Coding of data is defined as the progression of organising the data and marking words demonstrating a category (Creswell, 2014:198). The researcher chose to code the data by using key words. These codes identified were close to the words that the participants expressed. Tesch's method in Creswell, (2014:197-199) includes eight steps in the coding process of data analysis and these steps are described in the Table below (Table 3.1).

Table 3.1: Tesch's eight (8) steps in the coding process of data analysis as applied in the study.

1	All the transcriptions were read carefully and thoughts that came to mind written down.
2	For each transcript, the researcher asked: What is this about? Meanings and thoughts were written down.
3	After all the transcripts were reviewed, topics were listed and similar topics grouped to form a framework.
4	Each topic was abbreviated as a code. Using the list of codes, the researcher again re-read the transcripts and wrote the codes next to the appropriate parts in the narrative. While doing this, the researcher explored whether new topics were identified.
5	Similar topics or those that relate to each other were grouped into categories/sub-themes and named using the most descriptive wording. Overlapping topics were merged where possible to reduce the list of topics.
6	Categories were further condensed into main themes.
7	Data related to each category were identified and placed separately in order to begin preliminary analysis.
8	Data were recoded where needed.

The supervisor and the researcher discussed the formulated topics and agreed upon their meaning. This helped to organise the emerging categories and ensure the rigor of the study.

3.10.4. Step 4. Generate a description of the setting and themes

The researcher took the list of emerging themes and sub-themes and compared them with the data collected to ensure that important data were not left out. The main study themes and sub-themes are presented as headings and subheadings in the findings chapter of the study (Creswell, 2014:199-200). Contextual information relating to each theme was identified and themes arranged in a logical order for presentation.

3.10.5. Step 5. Presenting themes in a qualitative narrative

The themes and sub-themes are presented in a table in chapter 4. The essence of each main theme and sub-theme are described and supported by participant verbatim quotations to generate a thick description of the data.

3.10.6. Step 6. Interpretation

The researcher draws meaning from the findings of data analysis through interpretation in qualitative research (Creswell, 2014:244). The meaning drawn may result in lessons learned and information to compare with the literature or personal experiences. This involves asking questions such as “what are the lessons learned?” The researcher compiled a written account of the interpretation that emerged from the data analysis and verified it with the supervisor. By doing this comparison, the researcher made suggestions about the findings. Conclusions and recommendations are provided in chapter 5.

3.11. Summary

Chapter 3 presented the research methodology and explained how data was collected. The data collection tool and data collection methods have been described. Ethical procedures have been explained as applied during the recruitment of participants, data collection and analysis. Trustworthiness of the research has been discussed. The descriptive method of data analysis of Creswell has been explained. Chapter 4 presents the research results.

CHAPTER 4

FINDINGS

4.1. Introduction

The experiences of mothers administering HIV post-exposure prophylaxis to their infants in Lusaka, Zambia are presented in chapter four. Fifteen participants were individually interviewed and a portion of an interview is attached (Appendix 5). Section A describes the biographical data and section B the themes induced from the data analysis of interviews. The themes and sub-themes are listed in table 4.1. The biographical data are presented in a narrative format.

4.2. Section A: Biographical data

The participants were mothers who were administering ART to their infants at the time of the study. Nine participants were married, two were divorced, one was separated from her partner and three were single mothers. The participants' ages ranged from 20 to 42. The participants each had two to four children. Participants were from within and outside Lusaka city, since UTH is a referral hospital. Regarding the employment status, three participants were employed during the study period and 12 unemployed.

4.3. Section B: Themes

To facilitate understanding of the research findings, themes were induced from the participant's accounts of their experiences. Seven main themes emerged (Table 4.1).

Table 4.1. Themes and sub-themes

Themes	Sub-themes
4.3.1 Emotional responses	Apprehension Self-reproach
4.3.2 Knowledge and understanding of PEP	Sources of information Misconceptions about PEP and breastfeeding
4.3.3 PEP administration practices	Hiding Burden
4.3.4 Healthcare appointments	Time consuming Behaviour of healthcare workers
4.3.5 Partner involvement	Support Abandonment
4.3.6 Cultural and religious influences	Family roles and support Belief systems and customs Religious beliefs (faith healing)
4.3.7 Stigma and discrimination	Disclosure Healthcare settings

4.3.1. Theme 1: Emotional responses

The participants expressed several emotional responses towards being HIV-infected, the possibility of transmitting the virus to the infant, providing PEP and breastfeeding. For some participants it brought fear, worry and a sense of guilt realising that it would be their fault if their child became HIV-positive. Other negative emotional reactions were negative feelings associated with HIV, the stigma attached to it, as well as anxiety and concern about confidentiality. The sub-themes identified were apprehension and self-reproach.

4.3.1.1. Apprehension

Participants expressed fear associated with the transmission of HIV to their infants. Some participants experienced constant fear even while they administered post-exposure prophylaxis.

I am fearful of losing my baby even if I am giving Nevirapine. (Participant 2)

Many were fearful of their infants becoming infected with HIV, being abandoned by their husband or partner and being stigmatised by society. They were also afraid of how their partners would react upon disclosing their HIV status to them. One of the participants

mentioned visiting a mother who was caring for an HIV-positive baby and expressed fear that she would find herself in similar circumstances:

I am really scared of losing any of my children, nursing an HIV-positive baby is also a nightmare. The constant admissions into hospital. (Participant 6)

Participants expressed fear that their infants might become HIV-positive. Notwithstanding the constant fear, participants volunteered to have their infants tested for HIV, despite knowing that there was a possibility that the infant may test HIV-positive.

I didn't want the baby to turn out positive. The baby was tested today and I pray she turns out negative. (Participant 9)

It is scary to have the baby tested but it is better to know. (Participant 12)

The time between when the healthcare workers took a blood sample for HIV testing from the infant and when the results were given was an emotionally draining period since it could take three weeks to a month.

[T]he time delay between the testing and collection of results and medications is too much, need to be reduced. (Participant 12)

Some participants were very worried about the side-effects of NVP (the drug given to the infant for PEP) they thought they had observed in their infants, while others were not worried at all since they did not observe any side effects. One participant explained that the times when her baby had developed a high temperature, she thought that it was a side-effect of NVP. She was also worried that the high temperature may be the presenting signs and symptoms of HIV infection. These symptoms made the participant consider stopping the treatment:

With fever I would feel like stopping giving the baby the Nevirapine, thinking it was because of the Nevirapine.; [F]or me I thought I felt that the drugs were either going to prevent my baby from the HIV or damage her. (Participant 3)

Many participants were aware that high adherence levels were needed in order to prevent HIV transmission. They were therefore worried when their babies did not swallow all the NVP:

The baby doesn't swallow all the medication... it is scary to keep waiting for the results when you know that the baby never swallows all the medication at times. I don't want to be told that the baby is positive. (Participant 1)

A lack of knowledge perpetuated fears related to the medication NVP. Participants felt that no clear instructions were given about the times of administration and what a mother should do in case of vomiting or spitting. Some participants were worried about the duration of breastfeeding and the continued risk for HIV transmission it poses. One participant expressed fear of being bitten by the infant whilst breastfeeding:

When the baby bites you when they are teething. The fear of the baby getting HIV has always been there especially when she bites because of the itchy gums. You scared of the baby swallowing your blood. (Participant 11)

One participant described the administration of medication as a sensitive procedure where there was a need to be aware of who was in the immediate environment. Being extra careful was a burden, because depending on who was around, she would have to administer the medication in the privacy of her bedroom.

I used to hide the medication in the baby bag, it was quite a burden, I had never shared my HIV status with anyone I was not comfortable with. (Participant 6)

Another participant explained that being seen giving the medication daily to a healthy baby was associated with HIV within the community. Most of the participants feared discrimination. One participant mentioned how she feared that her husband, family and friends would eventually discover that she was HIV-positive:

My mother-in-law stayed with us. I had to lie and a bit of explaining with the number of times I go to the hospital. (Participant 6)

Participants who were administering PEP to their infants seemed to be very apprehensive and tended to manage their emotions alone. This might have been mitigated by increased support and understanding of HIV and PEP. Some participants felt that they would have benefited

from being assisted to accept the diagnosis. Participants appreciated counselling related to acceptance of the diagnosis and information about NVP.

Oh yes, when I was told the results that I was HIV-positive, I was really devastated it took long for me to accept, it took some time for me to move on with everything. The counsellors never stopped reassuring me. But I have moved on now, my children have made me accept as well. (Participant 3)

4.3.1.2. Self-reproach

Some participants expressed feelings of guilt and self-blame. They experienced feelings of guilt when giving NVP and felt responsible for the suffering of the infant, even before knowing the HIV status of their infants. Feelings of guilt and self-reproach also emanated from experiences of not adhering to the advice of healthcare providers during previous pregnancies.

[H]elp was offered to me, but I chose to ignore it. I did not want others to know, it was so foolish of me. I should have composed myself enough to do the right thing... I lost my three babies probably because of being HIV-positive or because of not following what the nurses told us from the antenatal clinics. (Participant 6)

Some had feelings of guilt due to the realisation that they were not completely adherent in administering PEP to their infants. The concern of one participant was that missed dosages would lead to reduced drug efficacy and the child would become HIV-positive. She expressed this in the following statement:

I wonder when I am in the line...; Waiting for results is like judgment day, my baby missed some dosages. (Participant 6)

Participants who admitted to not being adherent to giving their infants NVP, expressed feelings of self-reproach that was mostly due to feeling responsible for the ‘suffering’ of their infant. Conversely, those who reported to be adherent expressed appreciation for receiving PEP. Feelings of self-reproach were not present with participants who had successfully administered PEP before. They narrated that administering PEP was an efficient intervention since their children were uninfected and therefore benefited from receiving PEP:

The medication, is good because it is preventing the baby, it is good because it is preventing my baby from HIV. The elder sister to this baby I breastfed her for six months and now she is five and she is negative, even this one she is okay. I have been breastfeeding her and she is also fine. (Participant 2)

4.3.2. Theme 2: Knowledge and understanding of PEP

Some of the participants interviewed were sceptical about the efficacy of PEP. They did not understand why they were giving NVP and as a result they viewed it as being pointless. The reasons for their doubt appeared to be a lack of knowledge and understanding, as well as a misconception on the need for providing PEP and the benefits thereof. The misconceptions that the researcher discovered during the individual interviews seemed to contribute to the problems mothers encountered when administering NVP such as a lack of correct information. Many of these misconceptions were due to conflicting information received from different sources. Participants received information from their church pastors, mother-in-law's and family members, healthcare workers and friends. Two sub-themes emerged under this main theme namely sources of information and misconceptions about PEP and breastfeeding.

4.3.2.1. Sources of information

The dominant number of participants seemed misinformed when they responded to the questions on the challenges experienced in administering PEP to their infants. During counselling sessions, healthcare counsellors conducted group counselling sessions though results were provided individually. HIV counselling and testing for the mothers and infants was done routinely by healthcare workers. PEP counselling was done to all mothers at the postnatal clinic. However, mothers also received information on care for themselves and their infants from other sources. It was evident that they received information from various sources and that many participants relied on and trusted information from family and friends.

I hear from friends that the medication results in complications. (Participant 9)

From the concerns that the participants presented, the researcher noticed that there may have been women who were not informed of PEP by healthcare workers, which resulted in missed opportunities for providing PEP. One participant reported that she was not informed about the drug NVP, despite being found HIV-positive during her antenatal visit. She was unable to start administering NVP to her infant, since she was not informed about the measures available to

prevent the transmission of HIV/AIDS in her current pregnancy. She only started giving NVP a few days after she delivered the baby when she was admitted to the hospital due to being referred from the local clinic for not feeling well. This may influence the trust that participants have in the advice from healthcare workers.

I did not realise that I needed to give the baby Nevirapine and since I had no clue, I did not ask them why I wasn't given. (Participant 7)

Participants who were not adequately informed by healthcare workers and who had difficulty accepting their HIV status were more prone to believe and follow the advice from other sources. These sources were mostly inaccurate. Some participants had inadequate information due to fear of asking the healthcare professionals.

You know what, I had the resources and power of helping my other two children not to get the HIV virus, but due to ignorance, I found myself following the wrong advice from other people. (Participant 6)

I was scared of being scolded at by health professionals. The instructions are scribbled on the bottle. At times the amount changes and is not visible enough to read. (Participant 11)

Other participants narrated that it took time for them to accept their HIV status. This affected the way they embraced the idea of giving PEP to their infants and how open they were to the advice of others. Participants generally trusted the information given to them by healthcare workers. They were informed that NVP was a drug given to help prevent HIV transmission.

I know that the drug should be given to the baby, it just prevents. (Participant 12)

Despite the scepticism of some of the participants, others discovered that the information provided by healthcare workers about PEP were beneficial. A few participants forwarded reasons for not administering NVP such as not being informed by healthcare workers, while others had no complaints regarding a lack of information. Other sources of information confused participants. However, at the time of the interviews, most of the participants could identify that the information provided by healthcare workers were correct and that the other sources were not. They continued to return for follow-up to receive the NVP during the postnatal period, despite minor complaints.

4.3.2.2. Misconceptions about PEP and breastfeeding

Misconceptions arose from different sources of information. Some participants narrated how they were misinformed in their previous pregnancies that PEP was poisonous and this led them to reject the use of NVP.

I did not have proper evidence of what I heard from people... Women said that the medications were poisonous. (Participant 4)

Other participants were correctly informed that NVP reduced the chances of their infants becoming infected with HIV. Although some were sceptical about the efficacy of NVP, they believed that it had positive benefits. One participant gave medication because she believed that once the medication was administered, it would help the baby grow. The perceptions of some participants were that PEP was unnecessary since their infants were healthy. One participant believed that since her baby looked healthy, there was no need to give the drug:

The baby looks healthy, why give the Nevirapine? (Participant 2)

Some participants seemed to have a lack of understanding of the benefits of NVP and this was expressed through answers such as:

I know that the baby won't get sick when I give Nevirapine... I give the medication because I am given. (Participant 7)

In addition to this, some participants did not have enough knowledge about the benefits of NVP and were concerned about drug-related side-effects. The administration of NVP was associated with cancer and diarrhoea. These misconceptions influenced the willingness of the mothers to give NVP to their babies.

I am told by friends that these drugs cause cancer of the liver, these drugs are so strong, and ward 6 has a number of children with cancer. (Participant 9)

Conversely, other participants had no complaints in connection with the side-effects of the drug:

I never experienced any side-effects or saw any side-effects with the baby. I never experienced any problems with the drugs to tell you the truth. (Participant 3)

Some participants accepted the administration of PEP without complaining and appreciated the benefits of using it. They did not have misconceptions about PEP. Other participants demonstrated knowledge that PEP must be administered correctly to prevent HIV transmission.

But there are rules to be followed about the giving of the drugs. (Participant 8)

A strong assertion by participants was that transmission of HIV was possible even when a baby was receiving NVP. Although PEP is not completely effective, some participants felt that there was only a 50% chance of protecting the child from HIV if they gave PEP. These participants were misinformed about the effectiveness of PEP and it may have been the cause of their apprehension that the infant may become infected with HIV.

It is a 50-50 chance that the child would come out HIV negative when medication is administered. (Participant 3)

Breastfeeding and the administration of PEP are closely related since both affect HIV transmission. Many participants mentioned breastfeeding in the discussion of PEP. The majority of participants knew that it was possible to reduce transmission of HIV if a mother practiced exclusive breastfeeding. Most of the participants chose to exclusively breastfeed up to six months. At the time of data collection, WHO guidelines recommended six months exclusive breastfeeding and that breastfeeding can continue for one year for women who are HIV-positive and are on ART. However, one participant was misinformed that she could breastfeed as long as she wanted. Further, she was not informed on how an HIV-positive woman could practice safe breastfeeding. Other participants chose exclusive breastfeeding for the wrong reasons and not as the best option for an HIV-infected mother because of their financial situations. They reported that formula feeding was too expensive.

One participant had some knowledge that HIV could be transmitted through breastfeeding during the postnatal period due to information provided to her during the antenatal period by healthcare workers. However, her own experience made her decide what worked the best for her:

I would advise the women to stop breastfeeding at six weeks, to worry less. At six weeks as for me it's the best time to stop breastfeeding. No worries of biting. Should give Nevirapine and stop as advised. I prefer after six weeks when you are told the results. It is scary to give

HIV to an innocent baby, because Nevirapine or no Nevirapine the baby can still get HIV.
(Participant 6)

Another participant felt that she did not have enough information about the safety of breastfeeding and the possibility of HIV transmission. Although she understood that PEP can be effective, she still had a fear that HIV will be transmitted to her infant through breastfeeding:

I want to understand that Nevirapine is safe and proven that it can protect the baby from getting the virus when you exclusively breastfeed. (Participant 10)

Some participants therefore had misconceptions, while others had accurate knowledge and understanding of PEP and breastfeeding. Participants narrated receiving information about the benefits and utilization of PEP through counselling at antenatal and postnatal visits. They appreciated the support given to them through information offered in relation to saving their babies lives. Some participants recommended that personalised, fair and correct information about PEP should be provided during counselling and that this information should be presented in a manner that is compatible with women's beliefs and health literacy levels. Participants further recommended that continuous counselling should be given not only during antenatal clinics but also during the postnatal period.

4.3.3. Theme 3: PEP administration practices

Participants expressed how they administered PEP to their infants and some of the challenges related to PEP administration. Participants faced different challenges such as not knowing how to read the instructions on how to give the medication.

With the support from their partners, some participants were able to give PEP to their infants without any issues. Participants who had disclosed their HIV status were less likely to report having problems administering NVP. Some participants were willing to continue giving their infants NVP, but had no freedom to do so since they had not informed their partners. Others thought that giving NVP to their infants was a burden since the act of giving medication was a constant reminder of HIV infection. There were no challenges mentioned with respect to the frequency of giving PEP, which should be administered as a once daily dose. The sub-themes that were induced were: hiding and burden.

4.3.4.1. Hiding

Many of the participants admitted that they chose to hide the administration of PEP from their family members, friends and partners. Some participants confessed removing the medicine label from the bottle while others stated that they did not give the NVP as prescribed because they did not want to administer it in front of their family members.

At first I would remove the label from the bottle and I would give the medicine to the baby when I was alone. (Participant 6)

Participants found it difficult to adhere to treatment and postnatal appointments when they continued hiding the administration of NVP to their infants, since they had not disclosed to family, partner and friends.

Giving of the medication is really a challenge to me, and a burden in other ways. This time I have been extra careful though I still haven't told any of my family members, I did not want to miss any opportunity. (Participant 6)

Nevirapine was administered by some participants in secrecy even in their own home. One participant narrated how she hid the administration of PEP. She explained that neighbours and friends were curious to know what medication was being administered, since they were coming into her house as early as 07:00 in the morning.

'What type of medication are you giving the baby' she would ask me, I don't like their behaviour; one just has to be careful who one tells. (Participant 10)

Conversely, other participants never hid the medication from their partners or household members and it was easier for them since they often received support from them.

4.3.4.2. Burden

The constant thought of having to give NVP was expressed as a burden by most participants. It was a larger burden for those who felt that they did not have clear instructions. Almost every participant expressed remembering to give the medication on a daily basis as a concern.

I did not want to forget to give the medication... it was always on my mind. (Participant 6)

Disclosure of their HIV status seemed to affect how participants perceived the burden of administering PEP. One participant complained about the stress that is constantly there trying to remember to give the baby the medication, since she had not disclosed to her family. Another participant narrated what a burden it was to continually tell lies because she had not informed her family about her HIV-positive status:

I had challenges telling her the truth. There are times when I would want my stepchild to give the medication to the baby. And I would just instruct her and not tell her what it was. She is a grown-up girl. One day I told her that it was medicine for diarrhoea, please give the baby when she wakes up. I was the only one who could give the medication. (Participant 10)

For participants who had disclosed their HIV status, family members shared their burden by reminding them to give the medication in case they forgot or taking on some responsibility for administering PEP. Participants who were administering NVP for a second time to another infant, expressed that the burden and hiding of medication from others was temporal, since the NVP was only administered for a short period of the baby's life.

I give the baby the medication every day, only once a day. This is temporary when the results come out I will know whether to continue or not. I am positive that this baby will be HIV-negative as well. (Participant 7)

Participants narrated how they were instructed to give the NVP syrup to their infants. Some participants were knowledgeable about the importance of administering the medication on time and on how important it is to follow instructions. They mentioned that healthcare workers explained to them how to read the instructions that were written on the label on the bottle. Some participants complained that it was difficult to go back for further clarification when the instructions received were unclear. Certain healthcare workers were not approachable enough for participants to feel comfortable going back to ask for clarification. The behaviour of the healthcare workers discouraged participants to return for medication refills or further clarification when a problem was encountered. Other participants felt that it would have been easier for them to understand how to administer NVP if it was demonstrated to them. They complained that they were just told to read the instructions themselves on the medicine bottle. Some of the participants were provided with a pre-marked syringe to help them remember the dosage.

I was told to give early in the morning every day. Once a day using the syringe that was already labelled. (Participant 9)

The strictness of adhering to medication administration times placed an additional burden on the mothers. Despite this, the importance of giving medication timeously was understood by most of the participants.

If you are told to give at 07:00 hours this has to be followed for medication to work. I do understand that medications work well once given on prescribed times and not giving anytime that suits you. (Participant 10)

Although some participants viewed administering PEP as a burden, others expressed relief at giving it themselves. One participant who was assisted by her mother to administer PEP to her infant described it as a satisfying experience when she gave the medication herself. She expressed a sign of relief to be giving the treatment herself, since she could make sure that all the medication was taken by the infant.

I give the baby in the morning like I was told, early in the morning... I normally give around 7 am. When I wake up I give, since my mum left. (Participant 9)

Despite the constant thought of having to remember to give PEP, negative HIV results brought extreme happiness to participants. All the participants were grateful for their infants having HIV-negative results.

4.3.4. Theme 4: Healthcare appointments

The purpose of antenatal and postnatal care is to fulfil the holistic well-being of the woman and her family. Attendance of antenatal and postnatal clinic appointments provides for early detection and treatment of any complications and enables support with regard to breastfeeding, birth spacing and immunizations. In addition, HIV-exposed infants need to attend regular follow-up appointments. On average the infant is supposed to return to the clinic on six scheduled visits. The infant's PEP initiation will depend on the ARV drug regimen taken by the mother (Republic of Zambia, 2016:7). With option B+, PEP is commenced at birth. The child is scheduled to return for further care at six weeks, nine, twelve, eighteen and twenty four months and then they continue with care at their respective local clinics.

Some participants expressed difficulty in attending appointments due to work commitments. Participants related their motivation to adhere to hospital appointments to reassurance received from healthcare workers. The motivation to keep attending hospital appointments included the benefits of attending regular postnatal visits and staying healthy. Some participants mentioned being unhappy in relation to hospital appointments and complained that time was being wasted while waiting for service. The two sub-themes induced were: time consuming and the behaviour of healthcare workers.

4.3.4.3. Time consuming

Most of the participants complained that healthcare appointments were time consuming. They wanted to be reviewed in the shortest possible time, but expressed that this was a challenge in the healthcare facilities. Long waiting times was stated as a barrier to accessing quick and efficient postnatal care by some participants. They felt that the clinic was disorganized and that this contributed to time being wasted.

Other participants felt that the distance covered from their respective homes was never taken into consideration by healthcare workers. Participants had the expectation that those coming from far should be attended to first, but this was not the case. One participant considered changing the point of care to private practitioners so that her infant could be immunized and receive NVP merely to avoid the queues and in order to receive integrated care. However, she questioned the safety of the vaccines provided by private practitioners and recognized that she would have to pay a fee for a private consultation.

Surgeries [private practitioners] are quicker within the compound, but I wonder how safe their vaccines are and you have to pay. (Participant 11)

The fact that there were long queues and that mothers had to wait for services and treatment discouraged some participants.

There were long queues – baby still too small, those that were to receive vaccines and results were put in the same line, takes time to have one's turn. Babies who were successfully immunized and whose HIV tests were done for the first time still go back to line up for supply of NVP (Participant 12)

Another participant complained that it was also costly travelling from her home to the UTH, since she stayed on the outskirts of Lusaka. The transport fee affected her ability to frequently attend hospital care visits. The participant relied on her husband or family for transport money to attend clinic appointments. Complaints did not only come from those participants that came from afar but also from participants who thought queuing in the same line just for the replenishment of medication was time wasting. This discouraged participants, since they knew that they could have received the services (including the medication) all at once. The participants felt that there was no system in place at the clinic during postnatal care, to differentiate those receiving results from those who were attending routine infant follow-up.

I came to get more medications only and I have to be in the line. (Participant 12)

Conversely, some participants narrated how efficient the antenatal and postnatal services were. They explained how they looked forward to receiving their infant's results from healthcare workers. For some participants, the initial counselling session at the antenatal clinic brought a feeling of trust towards healthcare workers. This may be because they received sufficient information regarding their health concerns and the management of their infants.

The advice from the hospital is always the best... prevention of HIV to the baby. As for me, I started a long time ago, when I was told a long time ago that I had to take the ARVs to protect the unborn baby. (Participant 10)

From the working mothers, one participant cited how difficult it was for her to get permission from work to attend hospital appointments, especially because the healthcare appointments for herself and her baby were separate.

It was not easy to get permission from work, I used to get permission for myself and now I have to get permission for me and the baby... Not easy to get permission from work to go for hospital. (Participant 5)

Drug stock-outs contributed further to the time being spent on healthcare appointments. Participants mentioned that a number of times the hospital could not supply them with enough PEP and that the medication that was dispensed only lasted a few days. Some participants had to request permission to attend follow-up clinic appointments from work and others from their partners. Depending on the permission granted, mothers became reluctant to pursue the

administration of post-exposure NVP. The difficulty of attending the clinic more frequently and the implications of being absent from work and transport costs discouraged participants.

Only medicine for four days was given at times and I was required to get permission twice within a week to get back to the hospital for more medicines. (Participant 3)

Participants felt that they did not have enough information about other services offered at the postnatal clinic, such as when to return their infants for an HIV test. Participants suggested that mothers should be well informed about the services that are relevant to their needs. Despite the complaints forwarded by the participants regarding the services, their HIV care and the care of their infants were immediate needs. This was regardless of their location and the situation that they found themselves in. Participants agreed to adhere to the PMTCT programme in order to prevent HIV transmission to their infants and mentioned that time spent at the hospital was worthwhile when they thought about the health benefits for their infants.

4.3.4.4. Behaviour of healthcare workers

Most of the participants complained about the behaviour of the healthcare workers. These complaints included that HIV results were given in an uncaring and non-sympathetic manner. This also happened during routine infant follow-up and during pharmacy visits for medication replenishment. Participants mentioned that healthcare workers talked to one another about HIV results without considering patient confidentiality. One participant narrated how she overheard healthcare workers talking amongst themselves:

'This is amazing we do not have positive results today. HIV is being phased out. These babies taking ARV's will be losing weight very soon, they look quite healthy when still young and sucking.' (Participant 3)

Participants stated that the healthcare workers used sign language such as drawing a plus sign in the air that put women in an uncomfortable position when they went for regular infant follow-up visits. The participants perceived discriminatory sign language as being ascribed to those who were HIV-positive.

Nurses would give each other signs, a certain way of communication amongst themselves referring to HIV-positive mothers. (Participant 3)

Some participants stated not having any problems in relation to the services received from healthcare workers. They narrated how the information received helped them improve on the care of their infants. One participant who worked at the UTH had a positive perception of the healthcare services.

I work here at UTH and I have never had any problems. (Participant 5)

Stigmatising behaviour by healthcare workers was therefore a challenge mentioned by some participants. Further, healthcare workers were not always perceived as being empathetic and approachable. Negative experiences may have resulted in some mothers not attending their PEP follow up appointments.

4.3.5. Theme 5: Partner involvement

Some participants involved their partners in the care of the infant, while others did not. Participants were uncomfortable to disclose about the administration of PEP, mostly in fear of abandonment and were forced to hide the infants' medication. Participants who never revealed their HIV status to their partners disrupted their ability to administer PEP. Some participants also mentioned that their partners refused to test for HIV. The sub-themes induced were support and abandonment.

4.3.5.1. Support

Some participants expressed a lack of emotional support from their male partners, which made it difficult for them to adhere to giving PEP to their infants. Mothers were forced to hide the medications and consequently, the infant did not receive a dosage if the partner was present. A participant in an abusive relationship narrated how difficult it was to adhere to giving the PEP. The situation was so vulnerable that she could not reveal the reasons for giving PEP to the baby to her partner and family.

There were times when I woke upset with myself and my husband and the disease... my overall decision was to prevent my baby from being infected. (Participant 1)

One participant was subjected to impersonal and abusive language from an exploitative husband and family. She complained that the pre-existing home conditions and the uncaring, impersonal, abusive behaviour of her husband were unbearable. She was angry at her husband

for his lack of caring and for infecting her with HIV. This behaviour prevented her from telling other family members about her HIV status and prevented her from adhering to hospital appointments. Other participants mentioned that their partners were uncaring and unsupportive.

I was upset with him for infecting me with the disease and not caring about all of us.

(Participant 9)

The father of my baby never wanted to hear anything about HIV. Every time I spoke about HIV he would leave home and threatened never to come back. He left and stayed with another woman. He gets so aggressive. (Participant 10)

Some participants narrated about incidences of violence with their partners that started or worsened immediately following HIV disclosure.

My husband would shout on top of his voice and call me all sorts of names when there was a misunderstanding, especially when he was drunk, it was difficult to ask for transport money or a lift for the clinic. (Participant 10)

Some women who chose to disclose to their partners and family members experienced positive attitudes. Participants whose partners went with them for couples counselling and testing received good support from their partners. These experiences resulted in good attendance to the postnatal clinic.

Oh yes my husband and my mother were always with me, my husband would drop us at the clinic, but my mum would always be there, I was sick that I needed support when walking. (Participant 9)

4.3.5.2. Abandonment

Some participants related experiences of being abandoned by their partners, while others vaguely spoke of fear of being abandoned and verbally abused by their partners. There was seemingly no partner support for some participants. Asking husbands to go for HIV testing was to risk abandonment.

It was really difficult for me. You know it's confusing, you want to do something good and your husband is moving in with another woman. He stays with another woman. (Participant 6)

My husband does not care. He will leave me. (Participant 3)

One participant explained that she was unsuccessful convincing her partner to have himself tested for HIV so that he could understand the care involved for the infant. The participant narrated how difficult it was for her to provide information about PEP to her husband, since she was not sure what his reaction would be. She wondered why her husband was so defensive when asked to undergo a HIV test. This prevented her from adhering to PEP administration, since she could not give NVP to her infant in front of him.

It is really unfortunate, that my husband was in a position not to listen... I think he knew that he was positive, that was why he was so defensive, and you know he knew that he was positive even before we got married. (Participant 6)

Some participants therefore mentioned that there was a lack of emotional and physical support from their partners in the caring of their infants. In some cases, the lack of support was due to the decision to not disclose.

4.3.6. Theme 6: Cultural and religious influences

In the Zambian context, husbands and mother-in-law have traditionally played vital roles in the care of expectant mothers and infants. The family plays a pivotal role in the culture of child nurturing. Grandmothers were mentioned as very influential individuals during the interviews. Personal beliefs and the influence of the extended family played a significant role in the decisions made by participants. Participants appeared to have different personal beliefs about the administration of NVP and the impact that it would have on their infants. Some of them indicated that they believed in traditional medicine.

Zambia is not an exception where conventional medicine sometimes is in conflict with traditional beliefs, spiritual beliefs and religious practices. These cultural and religious influences may influence women's day-to-day general practice that may or might not benefit the infant's health. Some participants were convinced about spiritual healing and reported that they strongly believed in what the pastors (religious leaders) said about HIV. The participants reported that these religious leaders could treat and heal HIV. The sub-themes that were identified included family roles/support, belief systems/customs and religious beliefs.

4.3.6.1. Family roles and support

A few participants reported that they had to get permission from their partners or household members to attend follow-up clinic appointments and this made them feel uncomfortable. Some participants lied about their movements when attending clinic appointments. A few participants mentioned that in their culture a small baby should not leave the house until they are three months old. The grandmothers played a key role in the care of the infant. The decision to attend clinic appointments was influenced by what the family said.

But my mother-in-law believes in staying indoors until the baby is three months old.
(Participant 6)

Baby is too small to go out... I had to explain and lie to my in-laws because they would want to know the purpose of the visit to the hospital. (Participant 9)

Moving around in public with a baby below the age of three months is unacceptable behaviour for some cultures in Zambia. It is also uncomfortable to use public transport with a small infant. Some participants booked a private cab to drive them to the clinic, while others mentioned using public transport. In the culture, the mother is expected to stay home and accept instructions from their mothers or mother-in-law's. This had led to some participants remaining obedient and not attending clinic appointments. One participant was scared that her family might distance themselves and withhold support if they find out that she is HIV-positive. She said she would do anything possible to prevent others from knowing her status. Postnatal mothers are given a six day appointment if the mother had any complications during delivery that needed close management and then the routine scheduled visits would be specified. One mother opted not to attend the six day visit appointment to avoid suspicion from family members:

I didn't go for the one week appointment. I was told the baby was too young... my mother-in-law escorted me when the baby was six weeks, she told me that the baby was too young to be moving around with her in public. (Participant 11)

In certain cases where the mother had disclosed her HIV-positive status, other household members such as partners and grandmothers assisted with administering NVP to the infant.

4.3.6.2. Belief systems and customs

Participants' personal beliefs, especially their belief regarding the efficacy of PEP, contributed to an increased self-motivation to give the NVP. Women's personal beliefs played an important role in decision-making such as how important it was to give NVP to their infants in preventing transmission of HIV. One participant stated that she was self-motivated to continue giving PEP as it was her duty to take care of her baby. Most of the participants understood the probability of HIV transmission to the infant and that they should adhere to giving medications in order for it to be effective. One participant said:

I strongly believe that the baby will be HIV-negative, since I give the medication without missing a dosage. (Participant 2)

Furthermore, participants expressed their own ability to make decisions relating to their personal beliefs. One participant who had six children lost her first three children before she accepted to administer NVP to the other three surviving HIV-negative children. The HIV negative results for the children she administered NVP to motivated her to continue going to the hospital for the current infant. This participant confessed that she initially did not give the NVP to the infant, although it was given to her at the hospital. Moreover, she thought that she lost her first three children due to witchcraft.

I didn't want to give Nevirapine because I never believed that Nevirapine worked, I didn't give my first three children... I did not accept my HIV-positive status, and when I lost my children I thought it was witchcraft. (Participant 6)

The participant further reported not being consistent with the administration of the NVP. From her point of view, the medication was effective even when she was not completely adherent.

The medication has saved my other three surviving children, and I have given the medications sometimes through cheating. (Participant 6)

Some participants in the study held traditional beliefs and consulted with diviners (spiritualists). Cultural belief systems play a major role in the women's lives in Zambia. It was discovered that some participants trusted in traditional herbs to soothe the infant's colic pain. Even when they were told not to, since the herbs may interfere with the action of NVP, they expressed doubt and gave preference to the herbs.

I have the temptation to go for herbs... the herbs can help my baby to stay healthy because I used herbs for appetite on my babies before. (Participant 3)

Participants recommended that the women's adherence to PEP could be improved if PEP services involve cultural and religious leaders. Involving these cultural and religious leaders may provide them with accurate information in order for society to understand the prevention of HIV transmission to infants. The cultural leaders who are familiar with community settings may help eliminate doubts in the minds of mothers about the drugs given for the prevention of HIV transmission and warn them against using substances that may interfere with the efficacy of the drugs.

4.3.6.3. Religious beliefs

Some participants shared that family members held the opinion that HIV was a demonic disease that could only affect those that were demon-possessed. The participants expressed fear and mistrust regarding the taking of PEP, which was also negatively associated with demons. Participants proved that they were not demon-possessed by seeking spiritual intervention. These negative beliefs led some participants not to administer NVP to their infants while they were seeking spiritual intervention. They confessed seeking spiritual intervention from overnight prayers. This calls for the entire congregation to gather and pray for the entire night.

We used to go for overnight prayers and believed that the anointing water and oil were going to cure us. (Participant 3)

Participants heard about healing that occurred, as testified by other HIV-positive individuals. Other participants relayed past experiences of believing that they were cured of HIV and other illnesses through prayers. This gave them hope that they were going to be healed. These religious influences prevented some participants from adhering to PEP, while others were not influenced by the unsubstantiated rumours.

It is mere hearsay. People have been testifying that when pastors pray for you, you get healed from the HIV virus. (Participant 10)

While some participants strongly believed that PEP would be effective, other participants' feelings oscillated between believing that PEP would work and other beliefs such as traditional

medicines. Despite the conflicting messages from family, friends and church pastors, some of the participants believed in PEP. They were committed to making sure that their infants were prevented from being infected with HIV despite diverging information provided to them. Due to the strong religious beliefs in the community, participants recommended the involvement of religious leaders in the PMTCT programme as it may improve the success of PEP.

4.3.7. Theme 7: Stigma and discrimination

Stigma and discrimination were identified as a continuous challenge. It was very obvious that stigma and discrimination were extensive in families and communities, which forced women to desist from every practice that revealed their HIV status. Much of the stigma was associated with misconceptions about HIV and the administration of NVP to the infants. Stigma and discrimination led to participants making decisions of either continuing/adhering to or discontinuing treatment. The sub-themes that were identified included disclosure and healthcare settings.

4.3.7.1. Disclosure

Some participants stated that they hid their HIV status from their families, partners and friends for fear of discrimination. Other participants indicated that they had told somebody and believed that disclosure and acceptance of the diagnosis was important. Some women had disclosed to one or two members of their family. Participants related instances where infants were given NVP within the house setting without the knowledge of the father and this had an impact on their clinic attendance and medication administration.

I did not know how to tell my husband. As such I was in constant fear because I could not guess how he was going to react. I kept quiet and pretended that everything was fine.
(Participant 7)

Some participants never disclosed their HIV status to their partners due to fear of desertion. Other households consisted of more family members, which made it difficult to disclose because of a lack of trust. Participants had to hide the reason for attending clinic appointments after delivery to avoid suspicion.

Yes I had a caesarean section, so like now when it was time for giving medication, I had to come up with a plan so that my cousin doesn't become inquisitive. (Participant 1)

Other participants disclosed to their families and expressed relief of what felt like a burden. They thought that it was the best that a mother could do to help support the adherence to PEP.

Okay it is good to disclose but disclosing is fine because when you disclose you are at peace now. (Participant 2)

Another participant confessed that it took her a year to inform her family that she was diagnosed HIV-positive during her antenatal visits. She did not want family members to know about her status. However, during this period, she continued taking ART to prevent HIV transmission to her baby. After delivery, she continued giving her infant PEP. Another participant withheld the disclosure of her status from family members and her partner due to the negative opinions the family she was living with had about HIV. Some participants even kept their HIV status a secret in previous pregnancies. Participants postponed the disclosure of their HIV status because of fear of being abandoned by their partners and because of this, disclosure was not done promptly. Participants claimed that it would have been better if there was no stigma or discrimination. Disclosure of their HIV status to partners and families seemed to improve communication and adherence to postnatal PEP. Voluntary disclosure of their HIV status to their partners was therefore imperative in the administration of PEP.

4.3.7.2. Healthcare settings

Stigmatizing attitudes from healthcare workers and a lack of confidentiality manifested within hospital settings. Some participants complained about the unprofessional behaviour of some of the healthcare workers, while other participants complained about a lack of confidentiality.

During the antenatal period, participants who received positive HIV results were told to wait longer, since the initial ARV supply needed to be dispensed to them. The participants whose results were HIV-negative were given their results first and this allowed them to go home early. Conversely, other participants were happy with the services received during the antenatal hospital visits and mentioned that they got their results on time.

You are given a section where to sit and given the HIV-positive results when everybody else has left. (Participant 10)

Some participants felt uncomfortable, since they were told about NVP administration within hearing distance of others. Participants also felt that confidentiality was compromised when

they were called out of the general waiting room where everybody else sat waiting for results. One participant narrated how uncomfortable she felt when called out from the crowd where everybody else was seated waiting for results:

At the clinics, you are told to sit in a waiting space before being given the results. When you are many, a counsellor would come out and call out names, giving the papers carrying the negative results and after that she tells them to go. An announcement will be made for those remaining not to leave until results were given to remain seated.

(Participant 10)

Although some participants complained about the lack of privacy and confidentiality when results were communicated, other participants did not perceive being called out as a lack of confidentiality.

All those I didn't give the results follow me... isolated from the rest of the patients, I was taken out of the group and given the results in a private place. (Participant 13)

Further complaints were received from some participants about the manner in which pre- and post-test counselling was provided. They felt that receiving pre-test counselling in a group made them uncomfortable. In general, complaints were about the lack of privacy and the long waiting periods for post-test counselling.

Another participant explained what happened in the postnatal ward in the hospital where they received treatment before discharge. The settings were different though the impact was the same. It was perceived to be embarrassing and discriminating.

All those giving medication to your babies in the morning, do so now. (Participant 3)

Procedures for HIV-negative and HIV-positive patients differed and the way in which the healthcare workers communicated results came across as discriminatory. The participants perceived the behaviour of healthcare workers in different ways. Participants attended the services despite these discriminatory acts and processes.

4.4. Summary

Chapter four described the findings according to the seven themes identified. The findings outlined the experiences of mothers administering PEP to their infants. Some participants had inadequate knowledge about PEP. Fear of HIV transmission to the infant was emotionally draining for the mothers. The other themes identified were PEP administration practices, health care appointments, partner involvement, cultural and religious influences and stigma and discrimination. Chapter 5 describes the conclusions, suggested recommendations and identifies the limitations of the study.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1. Introduction

The previous chapters stipulated the objectives of the study and presented an in-depth literature review that provided a background to exploring the experiences of mothers administering PEP to their infants. The research methodology and data analysis for the purpose of the study were described. This was followed by a presentation of the findings. From the data collected, themes have been elaborated in chapter 4 and these are emotional responses, knowledge and understanding of PEP, PEP administration practices, healthcare appointments, partner involvement, cultural and religious influences, and stigma and discrimination. This chapter includes the discussion of the findings, conclusion and recommendations for the study.

5.2. Discussion

The aim of the study was to explore the experiences of mothers administering PEP to their infants in Lusaka, Zambia. The findings of the study will be discussed in relation to the objectives. The researcher explains and discusses what was found under each objective.

5.2.1. Objective 1: To explore the experiences of mothers who are administering PEP to their infants

Themes related to the women's general experiences of administering PEP are discussed.

5.2.1.1. Emotional responses

One of the most prominent themes related by the participants were emotional responses such as fear and apprehension. Many participants expressed fear that their infants would become HIV-positive. This fear was exacerbated if they missed a dose of PEP or if the infant did not swallow the prescribed volume. However, some participants feared HIV transmission even when they were given PEP as prescribed and expressed fear about having to nurse an HIV-positive infant. In the context of PMTCT, a study conducted in urban Mozambique found that women were reluctant to seek care for their children. They believed that HIV was a fatal disease and that their children were going to die, despite intervention (De Schacht, Lucas, Mboa, Gill, Macasse, et al., 2014:7).

5.2.1.2. Knowledge and understanding of PEP

The present study identified gaps in the knowledge and understanding of participants regarding the administration of PEP and the risk of HIV transmission. Participants were generally knowledgeable about PEP but lacked understanding in certain areas, namely the dosage of the NVP syrup, since it changed with every visit. Some participants questioned the effectiveness of PEP. Only one participant who was referred from an urban clinic to UTH was not aware of the PEP services, although she had knowledge that HIV could be transmitted from the mother to the baby through different modes, including breastfeeding. A study conducted in Nigeria at an antenatal clinic found that women knew about PMTCT services being offered by the local health facilities and they were aware that HIV could coexist with pregnancy (Lamina, 2012:99-100).

The dominant understanding of participants in this study was that it was possible to reduce transmission of HIV if a mother practiced exclusive breastfeeding. A study in Ghana found that the majority of the respondents perceived that MTCT of HIV/AIDS was possible, a small percentage did not consider that as a possibility, while others did not know if MTCT of HIV was possible (Boateng, et al., 2013:1478). Lamina (2012:100) records that a number of respondents were not aware about MTCT of HIV. The authors further narrated that some respondents knew that vaginal delivery and breastfeeding were modes of HIV transmission. Onono, Cohen, Jerop, Bukusi and Turan (2014:5) showed that most of the women in rural south Nyaza, Kenya had some knowledge about HIV/AIDS and knew about MTCT of HIV and that the infant could be infected with the disease.

In the present study, some participants were misinformed about breastfeeding and administration of PEP; they expressed ignorance about safe breastfeeding. This finding is similar to a study by Ndubuka, Ndubuka, Li, Marshall and Ehiri (2013:4) that stated that although infant feeding counselling was offered as part of the PMTCT programme, not everyone benefited from it. Ndubuka, et al., (2013:3) discovered that 56.3% of respondents in Gaborone, Botswana thought that the infant could become infected with HIV when breastfed and 88.4% were worried about infant feeding options and AIDS-related stigma. Other respondents had sufficient information about PMTCT and breastfeeding. Negash and Ehlers (2016:3) in Addis Ababa, Ethiopia indicated that outcomes for PMTCT programmes would improve if more information about infant feeding was given to mothers.

Although it seemed that women in the present study and PMTCT programmes in general have insufficient knowledge of HIV transmission and infant feeding, the literature show that information is being provided. Muluye, Woldeyohannes, Gizachew and Tiruneh (2012:4) in the study conducted in Gondar Town, Northwest Ethiopia, reported that only four (1.9%) of the respondents said that they had never received advice on infant feeding at all. One hundred and twenty-two of the respondents indicated that nurses, counsellors, the mass media, their families and their friends, respectively had counselled them on infant feeding. This also relates to the findings of the present study, where it was discovered that participants received information from various sources, which could lead to confusion. In addition, the provision of information does not equate to understanding and the way information is communicated may need improvement.

5.2.1.3. PEP administration practices

Based on the participant narratives, the researcher observed that some of the participants had questions about the PEP administration times and dosages. Some participants in the present study said that they did not know how to read the instructions on how to give the medication to their infants. Others felt that no clear instructions were given to them for giving the NVP to their infants, specifically the times of administration and what a mother should do in case of vomiting or spitting. In a study conducted by Falnes, Tylleskarl, Manuela, Manongi and Engebretsen (2010:8) in Tanzania, several of the mothers stated that they had received insufficient information about PMTCT during group counselling. It was discovered that most clinics had group information about PMTCT for antenatal mothers. Due to time constraints, the information was given hastily and the mothers had little opportunity to interrupt with questions if they did not understand. Hence, the same may be happening in Lusaka, Zambia, which explains the participants' lack of knowledge. Participants in the present study also mentioned that the healthcare workers were not approachable for them to ask questions if there was anything they did not understand.

Some participants did not experience challenges with respect to the frequency of giving PEP. Others thought that giving NVP to their infants was a burden, since the act of giving medication was a constant reminder of being HIV-positive. In a systematic literature review of studies conducted in sub-Saharan Africa by Gourlay, Birdthistle, Mburu, Iorpenda and Wringe (2013:4), it was revealed that several psychological barriers to adherence and PMTCT uptake

were present. Women at antenatal clinics were taken by surprise and expressed hopelessness and denial of their HIV status and worried about their condition, death or handling the side effects and lifelong treatment. These same barriers may prevent women from adhering to PEP administration for their infants.

Administration of medication was reported as a sensitive procedure where there was a need to be aware of who was in the immediate environment. With the support from their partners and family, some participants were able to give PEP to their infants without any concerns. Being extra careful was a burden, because depending on who was around, a mother would have to administer the medication in the privacy of her bedroom. Sibanda, Bernays, Weller, Hakim and Cowan (2015:5) conducted a study in Harare, Zimbabwe and found that the community did not have a positive attitude towards HIV-positive people who were often laughed at or ridiculed. Women who were not ready to disclose their HIV status experienced difficulties in giving medicine at home, even to people who lived in the same crowded room, in order to avoid stigma. In the present study, one participant explained that being seen giving the medication daily to a healthy baby was associated with HIV within the compound. Most of the participants feared discrimination. These challenges led to participants not adhering to the administration of PEP.

In the present study, participants who had disclosed their HIV status experienced less challenges administering NVP. However, some participants were willing to continue with giving their infants NVP, but had no freedom to do so since they had not informed their partners. These results are similar to a study conducted by De Schacht, et al., (2014:8) in rural and urban Mozambique, where it was discovered that the main caregiver appreciated family support as facilitating access to HIV care during follow-up visits. Those women who did not have any emotional or social support, experienced difficulties in accessing care.

5.2.1.4. Healthcare appointments

Some participants were not satisfied with the way healthcare services were organised during appointment times and this was noted as a barrier to postnatal care and receiving PEP. Participants further criticised the manner in which antenatal pre- and post-test counselling were being conducted by the healthcare professionals. At one of the primary healthcare facilities where the women underwent HIV testing/antenatal care, privacy was not maintained at all,

which made group HIV pre-test counselling challenging. The same challenges of infrastructure and healthcare settings were mentioned by Nuwagaba-Biribonwoha, Mayon-White, Okong & Carpenter (2007:271) in their study conducted in Uganda. Pre- and post-test counselling was done in groups followed by individual information about PMTCT during antenatal appointments. It was reported that some women avoided the counsellors at the clinics and this was thought to be because group HIV pre-test counselling made confidentiality difficult. Kalembo and Zgambo (2012:3) relates that a study conducted in Uganda and Kenya mentioned that one of the reasons leading to loss of clients in the PMTCT program was constraints of space for counselling, since it compromised privacy and confidentiality.

Long waiting times were stated as a barrier to accessing quick and efficient postnatal care by some participants. They felt that the clinics were disorganized and that this contributed to time wasting. Care and treatment in Mozambique was reduced due to long waiting times at healthcare facilities reportedly due to an insufficient number of healthcare providers. Mothers had a distinct process for collection of medication at the pharmacy that identified them as HIV-positive. The author's further state that there was a need for multiple clinic visits often over a long duration of time to receive test results and care (De Schacht, et al., 2014:8). The above mentioned findings are similar to what was reported by participants in the present study.

5.2.1.5. Partner involvement

Another key theme that emerged was partner involvement. Some participants with partners mentioned that they received support from their partners in addition to receiving support from family members. The support was mostly in relation to being reminded about giving medication to their infants. In Uganda, a study conducted by Nuwagaba-Biribonwoha, et al., (2007:271) revealed that participants received adequate support to help them manage with the HIV disease and care.

Some male partners in the present study also supported their spouses or partners financially to attend antenatal clinics. Participants stated that they were at times accompanied by their grandmothers or partners to access hospital care. However, in most cases, male involvement was lacking. Kalembo and Zgambo (2012:3-5) shared results of studies conducted in South Africa and Malawi and in both studies discovered that a lack of paternal support, relocation, and other socioeconomic factors such as poverty, affected the ability of families to adhere to the PMTCT follow-up program.

The present study demonstrates that participants whose partners went with them for couples counselling and testing received good support from their partners. Positive male support was reported in the study conducted in eastern Uganda (Byamugisha, Tumwine, Semiyanga, & Tylleskar, 2010:4). The study noted that male partners who knew and disclosed their HIV sero-status were four times more likely to get involved in the PMTCT programme compared to those male partners who feared to disclose their HIV status.

Aluisio, et al., (2011:6) demonstrated that male partner involvement significantly lowered the risk of HIV infection amongst HIV-exposed infants and improved HIV-free survival. On the contrary, Morfaw, Mbuanbaw, Thabane, Rodrigue and Wunderlich, et al., (2013:4) reported that antenatal care was perceived to be a woman's activity and it was thus shameful for a man to be found in such a setting. This cultural barrier, without any other external influence, demotivated men from attending antenatal care and becoming involved in PMTCT.

In the present study, some participants spoke of their fear of being abandoned and verbally abused by their partners. Asking a partner or husband to undergo an HIV test was to risk abandonment. Hampanda (2016:2604) discovered in a study conducted in Zambia that increased violent events such as Intimate Partner Violence (IPV) were common in Zambia. The study established that among HIV-infected women in sub-Saharan Africa, IPV victimization from a husband negatively affected safe infant practices and PMTCT adherence. In the present study, disclosing their HIV-positive result was to risk verbal and physical abuse for some women.

5.2.1.6. Cultural and religious influences

It was noted that cultural and religious influences played a major role in the women's lives in Zambia and hence the theme. In the present study, family played an important role in the culture of child upbringing. Personal beliefs and the extended family influenced decisions made by the participants to attend postnatal appointments. Grandmothers were mentioned as being influential individuals in the rearing of an infant. In Mozambique, grandmothers, healthcare workers and caregivers from communities that opposed and mistrusted conventional medicine, were often obliged to follow instructions given from traditional healers for fear of being abandoned by their partners (De Schacht, et al., 2014:8). The present study discovered that some women trusted in traditional herbs to soothe their babies' colic pain, even when they

were told not to by healthcare workers. They expressed doubt and gave preference to the use of herbal medicine, as the information was received from family.

5.2.1.7. Stigma and discrimination

Stigma-related barriers to administering PEP can be divided into four categories relating to the participants themselves, their partners, the community, and the health system. Stigma and discrimination were identified as challenges in the present study. Women desisted from every practice that showed their HIV status.

Much of the stigma was associated with misconceptions about HIV and the administration of NVP to their babies. Despite the discouraging effect of stigma, participants decided to continue giving NVP and to attending the postnatal clinic. Some participants found it difficult to adhere to administering the PEP when they had not revealed the reasons for the baby needing NVP to their partners and family. Osman, Unkels, Aliyu, Musa & Mathew, et al., (2014:4) discovered that pregnant women in sub-Saharan Africa did not have the confidence to disclose their HIV sero-status to a partner due to the fear of negative reactions they would face from their husbands and this obstructed progress in PMTCT.

Nearly all women had disclosed to one or two members of their families and partners about their HIV status. They chose to only disclose to close family members or partners for fear of being discriminated against due to undesirable communal beliefs about people living with HIV. Some households consisted of more family members or extended family, which made it difficult to disclose because of a lack of trust.

The fear of discrimination from their families, spouses and friends made some participants hide their HIV status. Kalembo and Zgambo (2012:3) relate to studies that were conducted in Malawi and Mali, indicated that stigma and fear of disclosure of their HIV-1 status were some of the reasons discouraging PMTCT attendance. Women in a study conducted in Zambia revealed that they feared the reactions of a partner or husband. They preferred not to know their HIV status because they believed that a woman's infection and pregnancy would cause a chain of deaths postpartum starting with the baby, herself and then her husband. Women also feared, believing that they would be ignored, isolated, and openly disgraced and blamed. Women not only feared the response of their families but also seclusion, denunciation, humiliation, and they believed that they would be ignored. Other women feared being blamed by relatives for

transmitting HIV to the partner, even if he was the one who was infected first (Kalembo & Zgambo, 2012:3). Hampanda (2016:2600) state that infant feeding practices depends on cultural norms, meaning that a new born baby had to be breastfed. Further, the fear of HIV-related stigma prevented HIV-infected women from practicing safe infant feeding, particularly if they had not disclosed their HIV status to a family member.

In the present study, some participants were afraid of being deserted by their partners following disclosure of their HIV status. Many were reluctant to disclose their HIV-positive status because they feared others would gossip about them. They were scared of how their partners would react upon revealing their HIV status to them. Many were fearful of being abandoned by their husband or partner and being stigmatised by society. They had to make excuses to get permission to attend the clinic to avoid suspicion. Colombini, et al., (2014:4) explains that fear of discrimination was the main factor influencing women's behaviour not to disclose their HIV status.

5.2.2. Objective 2: To understand the views of mothers about the administration of PEP to their infants

The focus of this study was to gain a better understanding on the views of mothers regarding the administration of PEP to their infants in order to improve postnatal care. It was therefore important to explore and understand the beliefs, concerns and feelings of women about administering PEP.

Some participants felt that they received sufficient information regarding their health concerns and the management of their infants. Most of the participants understood the probability of HIV transmission to the infant and that they should adhere to giving medication in order for it to be effective. This knowledge influenced their views that PEP is effective and will ensure that they have an HIV-negative baby, which further affected their motivation to adhere to PEP. Participants' personal beliefs regarding the efficacy of PEP increased their self-motivation to give the NVP to their infants. A study conducted in the rural south-eastern USA reported that HIV-positive mothers had the desire to increase their life expectancy and their motivation to attend clinic appointments included wanting to stay healthy for themselves and their children (Boehme, et al., 2014:578).

A good experience at the clinic motivated the mothers to administer PEP and led to them having a more positive view. Participants found counselling at antenatal and postnatal clinic visits beneficial. The motivational talks received from healthcare workers encouraged mothers to attend regular postnatal visits. Participants related their motivation for adherence to the reassurance received from healthcare workers during counselling and hospital appointments and wanting to enjoy the benefits of being healthy. Similarly, a study conducted in Tanzania, narrated that mothers viewed the PMTCT programme favourably after being informed about the benefits of the PMTCT programme (Falnes, et al., 2010:8). Most of the participants had a positive perception of the healthcare services.

Some participants relayed negative views such as constant fear and worry about the side-effects of NVP. Administering PEP was a problem for some participants due to misconceptions that NVP was poisonous. This arose from different sources of information. Certain participants, who had experience administering PEP to babies following previous pregnancies, reported that these misconceptions had led them to reject the use of NVP for their other children. One participant in the present study viewed the healthy looking infant as one who did not need PEP. In other studies, it was also discovered that the phenomenon of appearing healthy made people to stop the treatment. Ngarina, et al., (2013:4-5) found that some women who felt relatively well, did not contemplate that it would be harmful to stop their treatment. Women may stop PEP administration due to similar views that their infants are healthy.

Some participants had feelings of guilt realising that they were not completely adherent in administering PEP to their infants. One participant expressed concern about missed dosages that would lead to reduced drug efficacy and that the infant would become HIV-positive. Some women were influenced by cultural and religious beliefs that did not benefit their infant's health. They were convinced about spiritual healing and reported that they strongly believed in what the pastors (religious leaders) said about HIV. The participants reported that these religious leaders could treat and heal HIV. This influenced their administration of PEP

5.2.3. Objective 3: Describe the challenges mothers experience in administering PEP

A few challenges were identified in the administration of PEP. Insufficient drug supply issued by the clinic was mentioned as a challenge, since it would not last until the next clinic visit. Some participants who reported challenges with ART adherence personally agreed that the

immediate postpartum period posed unique challenges to PEP administration, such as the difficulty to obtain permission from work to attend hospital appointments, especially because the healthcare appointments for the mother and the baby were separate. Depending on the permission granted, mothers became reluctant to pursue the administration of PEP. Getting permission from employers was a marked challenge for some participants and they expressed difficulty in attending appointments due to work commitments. Some participants had challenges in requesting permission to attend follow-up clinic appointments from work and for others from their partners. Other participants faced challenges such as not knowing how to read the instructions on how to give the medication. Receiving information from various sources also posed challenges. It was evident that participants received information from various sources and that many participants relied on and trusted information from family and friends.

Knowledge gaps with some participants who could not understand why they were giving NVP due to inadequate PMTCT counselling was a marked challenge. The study indicated that some participants did not have enough knowledge about the benefits of NVP. The administration of NVP was associated with cancer and diarrhoea. Falnes, et al., (2010:2) in a study conducted in Tanzania, showed that mothers and counsellors had low levels of knowledge about PMTCT. Mothers were inadequately counselled and this was observed by their lack of knowledge about PMTCT, which further impeded the use of the service.

Mothers experienced challenges when it came to maintaining the duration of breastfeeding and the continued risk of HIV transmission. They did not know when to stop breastfeeding. The challenge was that messages from different sources confused them, which led them to the practice of mixed-feeding. In some cases, participants chose to exclusively breastfeed due to formula feeding being too expensive and not because they were well-informed of the benefits of exclusive breastfeeding. Sprague, et al., (2011:3) discovered that one of the weakest aspects of PMTCT interventions was counselling women on infant feeding. They emphasised the need to explain infant feeding options and counsel mothers effectively during the early postnatal period on the implications of feeding choices.

Stigma and discrimination in families and the community forced women to hide from the practice that showed their HIV status in the present study. Barriers to administering PEP were directly related to crowded housing conditions. Ngariana, et al., (2013:7) reported that societal

stigma such as neighbours' closely observing and gossiping about the signs of HIV has caused women to shy away from postpartum practices that may identify them as being HIV-positive. Some participants from the present study appreciated the benefits of receiving counselling during antenatal and postnatal visits. However, some participants were concerned about confidentiality and privacy.

The other challenges observed during the present study were related to non-disclosure about why the infant needed daily NVP doses. Participants had challenges when administering NVP to their babies within the house setting without the knowledge of the father or partner due to non-disclosure. Non-disclosure further led to participants hiding the reason for attending clinic appointments after delivery to avoid suspicion and desertion from their partners. Ngarina, et al., (2013:6) had similar findings where women tried to conceal their practice of PMTCT. Osman, et al., (2014:4) asserted that women's fear of disclosure to partners could be alleviated by inviting male partners and involving them in the uptake of PMTCT. Other reasons that contributed to challenges were associated with a lack of emotional support from some male partners, abusive relationships and the fear of how their partners would react upon disclosure. Turan, et al., (2011:1118) reported that women in rural Kenya were fearful that stigma would cause them to lose their friends or even break up their relationships. It was a challenge to provide information about PEP to their husbands/partners since they were not sure of their reaction.

Another challenge was that mothers were fearful of their infants becoming infected with HIV. Participants experienced fear, worry and a sense of guilt realising that it would be their fault if the child became HIV-positive

Health system related challenges observed were shortage of space for counselling. Participants felt that confidentiality was compromised when they were called out of the general waiting room where everybody else sat waiting for results. Nuwagaba-Biribonwoha, et al., (2007:271) state in a study that was conducted in Uganda, that confidentiality was not maintained during group HIV pre-test counselling. Long waiting times were stated as a challenge to accessing quick and efficient postnatal care in the present study. Most of the participants mentioned that attending healthcare appointments were time consuming. Length of appointments and long waiting queues are barriers to seeking care and adequate ART adherence (Boehme, et al., 2014:578; Ngarina, et al., 2013:7).

Most of the participants complained about the behaviour of the healthcare workers. These complaints included the uncaring and non-sympathetic manner in which HIV results were provided. Healthcare workers talked to one another about HIV results without considering patient confidentiality and used sign language, such as drawing a plus sign in the air, which was perceived as discriminatory behaviour.

5.2.4. Objective 4: Identify suggestions to improve counselling and support for mothers who administer PEP to their infants

Participants suggested that efforts were needed to improve the way healthcare professionals' relayed information to antenatal and postnatal mothers, which included HIV counselling and the administration of PEP. Some participants recommended that targeted, non-discriminatory and precise facts about PEP should be provided during counselling and that this information should be presented in a way that was compatible with women's beliefs and their health literacy level. Messages of encouragement for HIV-infected and affected individuals should be considered in the information. Participants suggested that counselling should be focused on specific individual needs. They also suggested that some healthcare workers such as counsellors should be supervised to make sure correct information was being relayed to the women. Onono, et al., (2014:7) indicated that poor counselling resulted in demotivated mothers who felt that the counselling focus was on the baby and not on them, which subsequently resulted in them not showing any behavioural change with regards to PMTCT. Healthcare workers needed support to improve their communication, counselling and support skills.

In addition, some participants recommended that healthcare workers undergo training to improve their interpersonal relationships with clients. This is in relation to the way they educate mothers so that they would understand why they should be giving NVP to their infants. One participant suggested that follow-up of mothers and identification of HIV-exposed infants could be strengthened by using maternal records from the postnatal department by extracting phone numbers and addresses from the contact information sheet. Other recommendations included HIV outreach clinics and home-based counselling, testing, and follow-up for HIV-exposed infants, although mothers were still worried about how to overcome stigma from their neighbours. Said (2014:17-18) reported that implementation of follow-up could help

prevent/avoid postpartum HIV transmission, improve the overall compliance to medications and infant outcomes.

Arrangements for supportive services should be made before hospital discharge for women continuing PEP for their infants. Participants recommended that attempts should be made to involve husbands/partners in the PEP program. They further advised that cultural leaders be involved to relay the PEP message to the community. They suggested that policy makers in government should focus on paediatric services being offered in the country such as PEP. They emphasized the need to ensure adequate supply of NVP so that mothers are not sent home without enough supplies. Another solution suggested was that mothers should be assisted to accept their HIV diagnosis, and thereafter, accept PEP administration. Further, disclosure should be facilitated or emphasised by healthcare providers.

5.3. Limitations of the study

The topic under investigation relates to HIV/AIDS which is a sensitive theme characterised by stigma and discrimination. Some participants mistrusted the researcher since they thought the researcher was a person wanting to find a way of stealing their babies or that the aim was to expose their status. The researcher involved the professional nurses providing postnatal care to explain the purpose of the study to the participants and reassured them that confidentiality would be maintained.

The study was conducted at one hospital, the UTH with a relatively small sample size. Generalising the findings to the whole of Lusaka city should be done with caution since the views and challenges presented by the mothers that attended the UTH at the time of the study could be different since UTH is a referral hospital. The group of women attending the postnatal clinic at the time of the study and their responses may or may not reflect that of other women giving NVP to their infants. Further, only mothers who attended postnatal clinic appointments were included in the study and therefore those who did not attend regular follow-up were excluded.

Although it was assumed that the participants would answer honestly, the presence of the researcher might have influenced them to answer questions in a manner in which they thought they should be answered. Participants may have answered differently to what they actually

practiced to please the interviewer. The researcher tried to overcome this limitation by explaining to the participants that all information collected will be confidential and anonymous.

The other limitation was related to the limited availability of published literature on the experiences of mothers administering PEP to their infants to make a meaningful comparison using the findings of this study.

5.4. Conclusions

Several challenges existed regarding administering PEP to infants born of HIV-positive women. Participant-related challenges influencing administration of PEP included emotional responses such as worry and fear. The lack of knowledge and understanding of PEP were discovered as challenges in this study. Participants were not well-informed and were confused due to varying sources of information. Cultural and religious influences played a major role in decision-making regarding PEP administration, which affected postnatal attendance. Some participants stated that they lacked support from male partners, family and healthcare workers. Other challenges included stigma and discrimination manifested through fear of disclosure of their HIV-positive status.

The way the services were organised, hindered women from approaching healthcare workers to ask for clarification with regard to medication administration. Participants experienced stigma from healthcare workers' behaviour and the way pre- and post-test counselling was done. The study was guided by the following research question: 'what are the experiences of mothers administering PEP to their infants in Lusaka, Zambia?' The researcher concludes that the women generally accepted the PMTCT programme and understood that PEP reduced the possibility of HIV infection.

5.5. Recommendations

With reference to the study findings, the researcher suggests focused attention on cultural empowerment, partner and family involvement and training of healthcare workers. HIV-positive mothers should be encouraged to continue giving their infants' NVP, the recommended drug, throughout the required period in order to promote child survival. There are still misconceptions about the drug being given to infants. Not all women understand and appreciate the services being rendered because of a lack of information. Information transfer

can be achieved through continuous provision of counselling and aggressive marketing of PEP and PMTCT services that should involve men and families, cultural and church leaders. Not all people listen to the radio, neither do they own television sets, therefore the need to empower other avenues with information such as traditional leaders and healthcare workers. UTH is a referral hospital and information that was received from the participants in the study reflect that some healthcare workers did not provide PMTCT health information relevant to the people. The researcher strongly recommends measures to strengthen the way health information is provided via training of healthcare workers.

5.5.1. Recommendation 1: Cultural empowerment

With the supported evidence from the research study, policymakers could provide strategies to improve the infant PEP health intervention. The rules of conduct and integrated system of acquired values and beliefs which delimit the range of accepted behaviour in any given society is defined as culture (Secka, 2010:57). Tribal leaders could socially enforce laws to punish men that abandoned their partners after sharing their HIV status. This will alert other men intending to abandon their families to refrain from doing so. The reported incidences of fear of abandonment when pregnant women shared their HIV results with their husband/partner, deserves special attention.

Community and tribal leaders should be engaged in a follow-up or referral and feedback system after the birth of a baby from an HIV-positive woman. The mother-infant pair should be followed-up postpartum by trained counsellors and community workers. PEP could be implemented in the community for HIV-exposed infants by involving family decision makers in the preventive and curative care processes which could help children receive the services they deserve (De Schacht, et al., 2014:11).

5.5.2. Recommendation 2: Partner and family involvement in PEP services

Women that disclosed their positive HIV status received help from their partners, mothers and other family members. Participation in making decisions that surrounded effective administration of PEP was influenced by these key nurturers. Family are in the forefront in decision-making and can be used in the fight against MTCT. There is need for family members to be involved in the infant PEP services. Akinpelu and Oluwaseyi (2014:4) have recommended that the benefits and the need for men's involvement in antenatal care be better

explained to them. Cultural beliefs and social norms influencing male involvement in antenatal and postnatal care should equally be explained to men. WHO, UNAIDS and UNICEF (2011) reports that the HIV/AIDS epidemic updates show that if couples were counselled and tested together, the health sector's progress towards universal access would be achievable, since there would be less potential for blame and discrimination among themselves.

5.5.3. Recommendation 3: Training of healthcare workers to deliver culturally sensitive care.

The knowledge of counsellors and healthcare workers regarding the prevention of MTCT of HIV needs to be explored. There should be supervision to ensure that effective counselling is delivered according to acceptable standards. Healthcare workers and counsellors should undergo training on how to effectively communicate with patients or women receiving infant PEP care. HIV counselling is done by all health workers depending on what level the patient is receiving care. Abteu and Awoke (2016:106) suggested that well-planned and delivered PMTCT services should include the provision of precise information in order to ensure the elimination of HIV transmission. The researcher strongly recommends that the poor access to sound medical information due to rushed counselling sessions be addressed in the scientific literature.

A strategy to address and understand the impact of the diverse culture relating to health issues in Lusaka, Zambia is required. Culture played a vital role in determining the level of health information to be relayed to the participant, family and the community. Madeleine Leininger's theory can be recommended as a framework for healthcare workers to use to ensure provision of culture-sensitive information. Leininger's theory helps discover clients' care needs (Leininger's Theory of Culture Care Diversity and Universality, 2008:2). Leininger's theory further narrates that care expected to be given to community is rooted in culture.

5.5.4. Future research

There is need for further research to help society understand that HIV transmission from a mother to an infant can be eliminated. The following areas could be explored:

- Exploring how male partners can be encouraged to undergo HIV testing and assist in PEP service delivery.

- Exploring how to relay PEP/PMTCT information in a culturally sensitive way following an HIV diagnosis.

5.6. Dissemination

The researcher will share the findings of the study with the personnel and management of the paediatric and adult centre of excellence during their academic meetings at the University Teaching Hospital, Zambia. These are departments that are directly involved with the management of HIV-positive mothers. These results will be shared with the Ministry of Health so that they could be disseminated in training manuals. The findings of this study will be presented at a nursing/midwifery conference and an article will be published in a peer-reviewed journal.

5.7. Conclusion

The findings of the study in relation to the study objectives have been discussed. Experiences of mothers administering PEP to their infants have been narrated. The findings reveal that administering PEP is emotionally challenging due to fear and apprehension that the baby may become HIV-positive. Although some women have support to administer PEP, lack of knowledge, cultural and religious practices and stigma deter some women from continuing to administer PEP. Long waiting times for results, insufficient supply of NVP and ineffective counselling have been identified as health system barriers to continued PEP administration. The study recommends cultural empowerment, partner and family involvement and training of healthcare workers.

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Appendices:

Appendix 1: Ethical approval from Stellenbosch University



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

Approval Notice Response to Modifications- (New Application)

24-Jun-2016
Lusaka, Mildred M

Ethics Reference #: S16/04/062

Title: Experiences of mothers administering HIV post exposure prophylaxis to their infants in Lusaka, Zambia.

Dear Ms Mildred Lusaka,

The **Response to Modifications - (New Application)** received on **06-Jun-2016**, was reviewed by members of **Health Research Ethics Committee 1** via Expedited review procedures on **24-Jun-2016** and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **24-Jun-2016 -23-Jun-2017**

Please remember to use your **protocol number** (S16/04/062) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics

approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 219389819.

Included Documents:

20160622 MOD Cover letter response from researcher

Checklist.pdf

Protocol.pdf

CV T Crowley.pdf

CV M Lusaka.pdf

20160622 HREC Modifications Required letter

Protocol Synopsis.pdf

20160622 MOD Protocol Synopsis

Declaration T Crowley.pdf

Application Form.pdf

Consent form.doc

Declaration M Lusaka.pdf

20160622 MOD Consent form

Sincerely,

Ashleen Fortuin
HREC Coordinator
Health Research Ethics Committee 1

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.
2. Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.
3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.
4. Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the HREC approval of the research expires, it is **your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur**. If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.
5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.
6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the HREC within five (5) days of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HRECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Health Research Ethics Committee Standard Operating Procedures www.sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.
7. Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC
8. Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.
9. Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.
10. Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.
11. On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

Appendix 2: Permission obtained from institutions

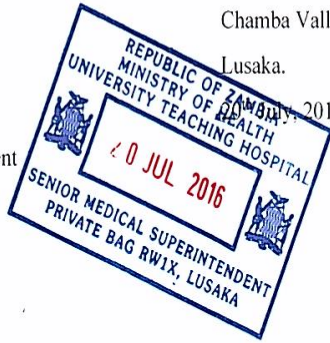
Plot No. 40

Chamba Valley

Lusaka.

2016

The Senior Medical Superintendent
University Teaching Hospital
P.O Box RW X1
Lusaka.
Dear Sir,



*A/HCC
MA
[Signature]*

REQUEST FOR AUTHORITY TO CONDUCT RESEARCH

I wish to draw your attention to the aforementioned subject matter.

I write to request for permission to conduct a research study at the University Teaching Hospital (UTH), focusing on the **“Experiences of mothers administering HIV post exposure prophylaxis to their infants in Lusaka, Zambia”**.

I am a student pursuing a master’s degree programme at the University of Stellenbosch in South Africa.

I herewith submit to you the research proposal that is undergoing consideration for ethical approval from the University of Zambia Biomedical Research Ethics Committee (UNZABREC). In response, the UNZABREC seeks your permission to this approach.

I am hopeful that the findings may help improve counselling support that could be provided to HIV infected women in the Zambian community.

Thanking you in advance.

Yours Sincerely,
M Lusaka
Mildred M. Lusaka.

+260966132792

Cc: The Head of Department- UTH (OBGY and Paediatrics).

The Director: Paediatric Centre of Excellence

*No objection
CHD - obgy &
paeds - FYA
[Signature]*

Appendix 3: Participant information leaflet and declaration of consent by participant and investigator

TITLE OF THE RESEARCH PROJECT: Experiences of mothers administering HIV post exposure prophylaxis to their infants in Lusaka, Zambia.

REFERENCE NUMBER: S16/04/062

PRINCIPAL INVESTIGATOR: M.M Lusaka

ADDRESS: Plot No. 40.

Chamba Valley

Lusaka.

Zambia.

CONTACT NUMBER: +260966132792

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The research study aims to explore the experiences of mothers on administering post exposure prophylaxis to their infants in Lusaka, Zambia. The study will be conducted at the University Teaching Hospital (UTH). The study intends to recruit a minimum of six participants. Participants will be selected from the Maternal Child Health Clinic (MCH) of the UTH. Participants will be subjected to an in-depth interview by the researcher for 30 to 45 minutes. Participants will not be exposed to any medicine in the study.

Why have you been invited to participate?

The study is selecting HIV-positive women that are administering post exposure prophylaxis to their infants. Participants that are willing to provide real life experience about the topic in search.

What will your responsibilities be?

Your responsibility is to provide a signed consent form before participating in the study. You are required to provide real life experiences and personal details for record keeping and all audio interview sessions.

Will you benefit from taking part in this research?

There will be no financial benefit to participating in the study. The study personnel may offer supportive counselling if need arises. There will be no immediate benefit to you, but it may be beneficial to others after the results of the study have been analysed.

Are there any risks involved in your taking part in this research?

There are no risks involved, in case you become emotionally distressed, the researcher will be in a position to refer you for counselling and support.

If you do not agree to take part, what alternatives do you have?

Participation in this study is entirely voluntary. If you decide not to participate, either now or at a later stage, you are free to do so and this will not in any way affect your current or future care or other benefits.

Who will have access to your medical records?

Medical records will not be accessed by anyone. Participant information obtained in this study will be confidential and any reports from this study will be kept confidential. The study supervisor will ensure that all ethical conditions have been applied. If any questions, do not hesitate to ask the researcher.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. An incentive shall be considered to compensate for the travel expenses in the case where you are inconvenienced in any manner.

Is there anything else that you should know or do?

- Contact Mrs. M.M. Lusaka at phone no. +260966132792 for further questions or problems encountered.
- Contact the study supervisor, Mrs. T. Crowley at phone no. +27219389239
- Health research ethics committee at telephone no. +27219389207 (SU)
- Biomedical research ethics committee at telephone no. +260211256067 (UNZA)
- You will receive a copy of the information sheet and consent form for your own records.
- You can contact the Health Research Ethics Committee at +27021-938 9207 if you have any concerns or complaints that have not been adequately addressed.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled experiences of mothers administering HIV post exposure prophylaxis to their infants in Lusaka, Zambia.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2016.

.....

.....

Signature of participant

Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged her to ask questions and took adequate time to answer them.
- I am satisfied that she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2016.

.....

Signature of investigator

.....

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*)
- using the language medium of
- Bemba/Nyanja.
- We encouraged her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all her question satisfactorily answered.

Signed at (*place*) on (*date*) 2016.

.....

Signature of interpreter

.....

Signature of witness

Appendix 4: Data collection tool.

Interview guide: questions to ask individual participants

Participant code

Date of interview

Section A

Demographic information

Age

Gravidity.....parity:

Marital status.....

Section B

You know from the informed consent form that I am interested to know more about your experiences on administering PEP to your infant.

1. Tell me more about your experiences of administering pep to your infant? (probes: What ARV drugs do you administer, times, disclosure in family/partner, support, appointments at the clinic etc.)
2. Can you tell me more about your views on administering PEP to your infant? (probes: beliefs about ARV drugs, side-effects, fears etc.)
3. Help me to understand the challenges you experience in administering PEP to your infant. (probes: how to administer, how much, remembering times, what to do if infant vomits/spits out, storage of solution, stigma, going back to work, attending clinic appointments, etc.).
4. Do you have any suggestions on how mothers administering PEP to their infants can be supported/counselled better?

Appendix 5: Extract of transcribed interview

Interview with participant 10

Interviewer: Good morning, I thank you so much for accepting my invitation that you could participate in this research. I am here to learn more about your experiences of giving Nevirapine to your baby. Please tell me about your experiences of giving the medication Nevirapine to your baby.

Respondent: Ok. What I know about Nevirapine is that we are given to help protect our children from getting the HIV virus. I was told that the medicines were safe. I want to understand that Nevirapine is safe and proven that it can protect the baby from getting the virus when you exclusively breastfeed. But I need to follow the rules and instructions. This helps to prevent transmitting the infection to the baby, even when the baby is breastfeeding. I was given Nevirapine to give my baby while I was breastfeeding. I gave the Nevirapine when the baby was born and I stopped giving when the baby was one week old. She was tested to check if she was okay at 6 weeks, I was told the results that the baby is HIV negative. I am so glad that she is negative. I lost my other child before he turned two years. It was a mere sickness, high temperature, I don't know what caused the fever. He died.

Interviewer: Okay thank you for the information. I am so sorry about the loss of your child; you are saying that you lost the baby because of a high temperature. You also mentioned that you were informed about the safety of the medications and that these you started giving whilst breastfeeding. Did they tell you what caused the high temperature and eventually death of the baby?

Respondent: No I did not bother to ask. You know the stress one goes through after losing a child. It happened so quickly. The God I serve knows why.

Interviewer: Okay. Can you share more with me the involvement of your family, your husband and friends during this time of administering Nevirapine to your infant?

Respondent: You know having the disease is one thing and giving medication to an innocent infant every day is another. It is so sad that the baby has to drink medications on a daily basis. Babies know nothing.

Within my family, others are encouraging and others are so discouraging. What I would say is that there is a lot of gossip within my family. But I told my sister immediately I knew

about my status in 2012 this is when I was diagnosed. I started taking the ARVs that time though I was not consistent.

My sister was the first person I informed. She has been supportive. And that she stayed nearby my place was an advantage for me. I informed her immediately I got back from antenatal clinic. I went straight to her home. My sister spoke to me and has been supporting me all the time. I have shared my status with my best friend as well because she shared with me that she was positive. I have shared my status with those that I trust, not everyone.

I stopped breastfeeding my baby at one week. I did not want to breastfeed at all from the beginning when the baby was born. I was scared that my baby would get the virus, my husband encouraged me to wean the baby for the same reasons. The other thing I was avoiding gossip, friends ask too many questions when they see something unusual. People and family ask a lot of questions, to avoid questions and suspicion we agreed that I breastfeed for a week only. At least after a week I thought I would tell them that the baby stopped by its self.

Interviewer: Okay, I see you shared with your sister and your friend about your status.

You mentioned as well why you stopped your baby from breastfeeding early to avoid gossip, and the fear of the infant getting the disease. The decision you made together with your husband.

Respondent: Yes I told my husband in the evening when he got back from work and told him to have himself checked. The father of my baby never wanted to hear anything about HIV. Every time I spoke about HIV he would leave home and threatened to never come back. He left and stayed with another woman. He gets so aggressive.

I had to lie to him, otherwise he was not going to agree to be tested. I told him that there was something wrong with my pregnancy and that the midwives wanted to see him. We lost one of our babies like I said earlier on and this scared him. We were both excited to have another baby coming in the family, he eventually agreed to go to the clinic.

He was tested after so many times of forcing him. What I did I went back to the clinic and asked one of the sisters there to help me convince him and counsel him so that we know how to take care of ourselves and the baby. He eventually agreed to come along to the clinic. The

nurse was so calm, she managed to convince my husband to have himself tested and he agreed. He was found HIV-positive.

Interviewer: Alright that story you told him about your pregnancy made your husband agree. What you are saying is that you involved the sisters at the clinic to convince your husband to agree to be tested. Please share more about the gossip/stigma you have experienced.

Respondent: At the clinics, it is sometimes tough, you are told to sit in a waiting space before being given the results. When you are many, a counsellor would come out and call out names, giving the papers carrying the negative results first and after that she tells those that received their results to leave. An announcement would then be made for those remaining not to leave until results were given. And this routine continues with all other new groups every Wednesday. This arrangement becomes obvious, once you have been through the same, it indicates that those remaining were definitely HIV-positive.

In the compound/location where we stay people sometimes fight and in the course of fighting they start calling each other names relating to an HIV-infected person. Houses are so close together that one is able to pick up the arguments, it becomes worse when one is drunk, some couples shout across each other and once the neighbours hear, the names for the ones fighting change and they become identified with their status.

Interviewer: Okay, you are saying is that the counsellor from the clinic gives the negative results first to the mothers and they are sent home. She gives the results from outside, the waiting space and then let those with results leave for home; while the other mothers wait patiently for their turn to receive results; is that what you saying?

Respondent: Oh yah, now you start wondering the meaning of all this. It becomes so obvious that the remaining mothers were positive. You are given a section where to sit and given the HIV-positive results when everybody else has left.

Interviewer: The other mothers are given their results later. Are there any more experiences you encountered over giving the Nevirapine you would love to share?

Respondent: Yes. My baby was put on Septrim and Nevirapine. I was told to report any diarrhoea or body rash. Luckily enough she did not have any rash or diarrhoea.

Interviewer: I see that you were told to report any side effects/problems of the Septrim and the Nevirapine. When you look at what you have gone through, relating to the giving of the

medication, tell me more about your experiences on making appointments or fulfilling the scheduled appointments at the clinic.

Respondent: I have been able to get to the clinic without any problems. Just the transport money at times is a bit of a challenge. My sister would offer though. My husband would shout on top of his voice and call me all sorts of names when there was a misunderstanding, especially when he was drunk, it was difficult to ask for transport money or a lift for the clinic. I didn't experience anything alarming that I could not be able to handle and when the baby was sick, I would take the baby to the clinic.

Interviewer: Alright, what you are saying is that the baby did not have any problems with the medications that was being given. If the baby was unwell you would take the baby to the clinic. Have there been times when you thought that the baby hadn't taken all the medication for a particular dosage?

Respondent: not at all. I am glad that there was no vomiting or spitting like the other children.

Interviewer: Okay, there was no vomiting or spitting and you are happy that the baby received the right dosage. Can you tell me more about your views on administering Nevirapine and Septrim to your infant?

Respondent: I am less sickly and my baby is not sick at all, when I visited the clinic it was the fear that gripped me. She was restless and crying uncontrollably. I don't have any complaints. Taking these medications makes one more health except for the first two weeks when I used to have bad dreams. I have no worries with my baby. I have less worries as long as the baby doesn't get sick. I believe that the Nevirapine works well.

Interviewer: That is fine thank you, you are happy that the medications that you have been given for yourself and for your baby help to keep your health. What have you heard or what do you know about the beliefs of giving Nevirapine

Respondent: On the belief system, it is a mere hearsay, people have been testifying that when pastors pray for you, you get healed from the HIV virus, I have never been to one myself, but I am sure once you get prayed for, you have to go back to the clinic to get yourself checked. You know the way they lie in churches, the pastor would say, come to me all of you, even on radios they do advertise, they announce that they are able to cure HIV and they say all sorts of things, those are lies. What I believe is that these medications we receive, with His powers (Gods) powers and if we only believe we shall be healed and one day treatment will be found. These medications are just like Panadol. Just the way we take Panadol. Panadol is a tablet taken

for pain, we take all these medications because we are told that they make us feel better, we believe these medications can cure us, which is why we drink them. That is how I accept everything, if Panadol can make me feel better and so will the ARVs make me better.

Interviewer: Okay, the pastors tell people that they can be healed, but you also say that you take the medications given to you since you believe that they keep your health. Can we talk about the storage of the medication, how do you store the baby's medication?

Respondent: Ah I don't have specific rules, I just keep it anywhere. I was told to keep in a cool place. The house is cooler inside.

Interviewer: okay, you are saying that as long as the medication is in a cool place, then that is fine. Tell me about the fears that you encounter when giving medications to the baby.

Respondent: The fears are there, this is not treatment, it is just prevention sometimes I wonder! Any way it is scary. That is why I weaned my baby early.

Interviewer: You are saying that it is scary and the fear made you decide to wean the baby early. Help me to understand the challenges you experienced in administering PEP to your infant with remembering of times. Did you have any challenges when remembering the times for giving the medication?

Respondent: Time is not a problem, I was giving the medication on time, if you are told to give 07:00 hours this has to be followed for medication to work. I do understand that medications work well once given on the right time and not giving anytime that suits you.

Interviewer: Okay that is great to know that you always give the baby the medications at 07:00 in the morning, is there a system to remind you?

Respondent: I have set an alarm on the phone, this is when I take my medications as well. As I said earlier on, there is a lot of stigma, I used to give the medication to the baby in front of a friend of mine and she would be so nosy wanting to know what medication I was giving as early as 07:00 in the morning, she is already at my house at 07:00, hours. "What type of medication are you giving the baby" she would ask me, I don't like their behaviour, one just has to be careful who one tells. I would tell her that the hospital knows better why they gave me this medication to give it to my baby. This is a very good friend of mine who is always by the door step immediately her husband goes for work. This is the type of life we lead in the location/compound. I suspect she knew about my status before we shared our status. That is how we leave in our compounds/locations. Gossip groups and updates start as early as husbands

leave the homes. I stay with my stepchild as well. I had challenges telling her the truth. There are times when I would want my stepchild to give the medication to the baby. And I would just instruct her and not tell her what it was. She is a grown up girl. One day I told her that it was medicine for diarrhoea, please give the baby when she wakes up. I was the only one who could give the medication.

Interviewer: Okay, I see you are saying that you're reminded to give the baby the medicines as you drink yours. You have sent up an alarm as well to remind you. You have not told your step child about the Nevirapine. Do you have any suggestions on how mothers giving Nevirapine to their infants can be supported or counselled better?

Respondent: The advice from the hospital is always the best; prevention of HIV to the baby as for me, I started a long time ago, when I was told a long time ago that I had to take the ARVs to protect the unborn baby. Okay I have something to say from the experiences of nursing my children. I think I know almost everything but I am willing to learn more, the counsellors should continue reminding the women about the safety measures. Women should be informed about the modes of transmission, the sisters told us about the dangers involved in injuring oneself whilst the baby is in utero. That is why I had to force my husband to come over with me to the clinic because I wanted him to know what I am going through.

It is good to have someone to chat with, I have my sister who reassures me when I am down
Keep reminding the mothers about the benefits of Nevirapine.

Interviewer: Thank you for all the suggestions, unless there is anything else to say.

Respondent: No thank you.

Interviewer: Thank you so much.

Appendix 6: Declaration by language and technical editors

Division for Postgraduate Studies
University of the Western Cape
Private Bag X17
Bellville, 7535
South Africa

4 August 2017

To Whom It May Concern,

EDITING CONFIRMATION LETTER

This is to confirm that the research report of Mildred Mwewa Lusaka titled, *EXPERIENCES OF MOTHERS ADMINISTERING HIV POST EXPOSURE PROPHYLAXIS TO THEIR INFANTS IN LUSAKA, ZAMBIA*, was edited by me. It was the product of research towards the candidate's Master of Nursing Science degree in the Faculty of Medicine and Health Sciences, Stellenbosch University.

The work of editing involved the language usage and technical layout of the research report to ensure compliance with the required standards. Kindly address any related concerns to me.

Sincerely,



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15 November 2017

Ms Mildred Mwewa Lusaka
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The above-named student' thesis titled ***“EXPERIENCES OF MOTHERS ADMINISTERING HIV POST EXPOSURE PROPHYLAXIS TO THEIR INFANTS IN LUSAKA, ZAMBIA,”*** was edited for grammar, spelling, syntax and referencing.

