

**DETERMINANTS OF LOSS TO FOLLOW UP HIV EXPOSED INFANTS IN LUSAKA,
ZAMBIA**

BY

RUTH CHEMBA- RN/RM/ BSc

A dissertation submitted in partial fulfilment of the requirements for the Degree of Master of
Science in Midwifery, and Women Health at the University of Zambia

MARCH 2022

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DECLARATION

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Certificate of Completion

I, **Dr Concepta Kwaleyela**, having supervised and read through this dissertation, am satisfied that this is the original work of the author under whose name it is presented. I confirm that the work has been completed satisfactorily and approve it for final submission.

Signed..... Date.....

(Supervisor)

Signed..... Date.....

(Candidate)

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The University of Zambia approves the dissertation on “Determinants of loss to follow up HIV exposed infants in Lusaka, Zambia” in partial fulfilment for the requirements for the award of Master of Science in Midwifery and Women Health Degree

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DEDICATION

This dissertation is dedicated to my beloved husband Elisha Chipandwe for always supporting and encouraging me during the course of my study. To our beloved children Kaluba, Chishimba, Manyowa and Konjela for the love and understanding. To the entire family members for the love, support and encouragement rendered to me.

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ABSTRACT

Introduction - Prevention of Mother-To-Child-Transmission (PMTCT) programmes aimed at preventing vertical transmission have been widely implemented in Zambia by the Ministry of Health (MoH). However, many infants are not benefitting from the programmes due to loss to follow up (LTFU) at different points of the PMTCT cascade, with the highest loss occurring at 18 months. This compromises the effectiveness of PMTCT services. The aim of this study was to establish determinants of LTFU infants born to HIV positive women in Lusaka district.

Methodology - A descriptive cross sectional study design using a quantitative approach was conducted in three Lusaka Urban District Clinics. The sample size comprised of 160 caretakers of LTFU infants and 25 health care providers. Data from caretakers were collected using a semi-structured questionnaire while that from healthcare workers were through a self-administered semi-structured questionnaire. Data were analysed using the Statistical Package for Social Sciences (SPSS) version 22.0 and presented using frequency tables, bar charts, and cross tabulations. Logistic regression was used to test associations between the dependent and independent variables. The cut off point for statistical significance was set at 5%. P-values of 0.05 or less were considered statistically significant.

Results - The finding showed that 42.4% caretakers were not aware that they needed to continue with follow up care, while 28.0% stated forgetting taking their infants for follow up care. The results further showed that the association between gender of caretaker [OR 0.252 (1.101-0.633) p-value 0.003], relationship between caretaker and infant [OR 0.592 (0.699-0.189) p-value 0.003], staff attitude [OR 10.012 (4.194-23.947) p-value 0.003], prophylaxis given at birth [OR 0.299 (0.131-0.684) p-value 0.004], and place of birth [OR 2.324 (1.050-5.143) p-value 0.037]

and LTFU were statistically significant. Binary logistic regression indicated that association between gender of caretaker [OR 0.4 (CI, 0.287-0.966) p-value-0.040], negative staff attitude [OR-2.7 (1.050-5.114) p-value-0.047] and waiting time [OR 0.7 (CI-0.314-5.665) p-value-0.003] and LTFU were also statistically significant.

Conclusion - The results suggest that change in staff attitude and improvement in waiting time can reduce chances of loss to follow up care. Therefore, the study recommends that clinics should come up with an easy appointment scheduling process to help reduce waiting time for follow up care clients; such as providing a specific appointment time.

Key Words: HIV-exposed infants, Lost to follow up, Prevention of mother to child transmission.

ABBREVIATIONS

AHRQ - Agency for Healthcare Research and Quality

ANC – Antenatal care

ART- Antiretroviral Therapy

CD4 - Cluster Differential Cells

CSO – Central Statistical Office

eMTCT - Elimination of Mother to Child Transmission

EID - Early Infant Diagnosis

HAART- Highly Active Antiretroviral Therapy

HIV- Human Immunodeficiency Virus

IOM - Institute of Medicine

ICRW - International Center for Research on Women

LTFU- Lost to follow up

MoH- Ministry of Health

MTCT- Mother-to-Child-Transmission

NAC - National AIDS Council

PMTCT- Prevention of Mother to Child Transmission

UNAIDS- Joint United Nations Program on HIV/AIDS

USAID - United States Agency for International Development

UNZA - University of Zambia

WHO- World Health Organisation

ZDHS - Zambia Demographic and Health Survey

CHAPTER ONE: INTRODUCTION

1.0 INTRODUCTION

An infant born from a Human Immune Virus (HIV) infected mother is referred to as an HIV exposed infant. Majority of HIV exposed infants acquire HIV infection through vertical transmission from their infected mothers (World Health Organisation [WHO], 2016). The WHO (2013) has, therefore, devised measures to prevent mother-to-child-transmission (MTCT) of HIV infection, and such measures include; initiating lifelong antiretroviral therapy (ART) to all HIV positive pregnant women and breastfeeding mothers and administering prophylactic ART to HIV exposed infants from birth to 6 weeks old. According to the Joint United Nations programme on HIV and acquired immunodeficiency syndrome (AIDS) (UNAIDS, 2014), an HIV exposed infant is less likely of dying from an AIDS related illness if given ART within the first 12 weeks of life. It is therefore, important that all infants born to mothers living with HIV get tested between four to six weeks of age and initiated on ART if HIV positive (UNAIDS, 2016). However, majority of these infants end up being LTFU at different points of the PMTCT cascade, with the highest loss occurring at age of 18 months (MoH, 2017).

1.1 BACKGROUND

HIV infection remains a challenge to the world and continues to be a major global public health problem, with increase in the number of HIV infections in children (UNAIDS 2014). The increase can be attributed to the rising number of HIV infected women of childbearing age, majority of which live in low- and middle-income countries (WHO, 2014). According to global HIV and AIDS statistics of 2014, an estimated 36.9 million people are living with HIV out of which 2.6 million are children (UNAIDS, 2018). About 90% of the infected infants acquired the virus through MTCT during pregnancy, delivery, or breast-feeding (United Nations International Children's Emergency Fund ([UNICEF], 2012). In the presence of effective interventions, the risk of MTCT is less than 2% (Bucagu, 2014). However, the uptake of PMTCT programmes is affected by various barriers that hinder pregnant women with HIV from accessing and engaging in the HIV care continuum (UNAIDS, 2017).

In Zambia, 1.2 million people are living with HIV; of which 94,000 are children under the age of 15 years (UNAIDS, 2016). In 2017, around 41,000 adults and 7,300 children became newly infected with HIV (UNAIDS, 2018). Since the start of the HIV pandemic, children have been severely affected, with an estimated 72,000 living with HIV as a result of vertical transmission, arising from a high antenatal HIV prevalence (UNAIDS, 2018). As a response to this burden, Zambia initiated the PMTCT within HIV programme in 1999 with support from various donors, including the United States Agency for international Development (USAID) and Zambia Prevention, Care and Treatment Partnership (ZPCT) (MoH, 2010). Integration of PMTCT into all Maternal, New-born and Child Health Services throughout the country was done with the goal of preventing new HIV infections in children, early diagnosis of infection in pregnant women, and commencement of ART (UNAIDS, 2016) to reduce morbidity and mortality rates (MoH, 2010). In 2013, the WHO released a new set of guidelines directed towards eMTCT of HIV (WHO, 2013). Many countries worldwide, including Zambia, adopted the guidelines. The guidelines recommend that all pregnant women diagnosed with HIV infection should be commenced on life-long ART regardless of their cluster differential cells (CD4) count, while HIV exposed infants receive daily Nevirapine or Azidothymidine from birth up to six weeks, regardless of infant feeding method (WHO, 2013).

In the past, there was poor health outcomes associated with early cessation of breastfeeding (Cournil et al., 2015). Women are therefore, currently advised to continue breastfeeding up to two years or more, as evidence proved that commencing ARV drugs to either an HIV-infected mother or HIV exposed infant can significantly reduce the risk of postnatal transmission of HIV through breastfeeding to less than 5% (WHO, 2018). The guidelines, further, recommend a scheduled series of HIV virologic tests for exposed infants to be done between four to six weeks, at nine months, and at eighteen months, to confirm or exclude perinatal HIV infection (WHO, 2013). Continued follow-up of exposed infants is hence, required to ensure success of these strategies. HIV-related follow-up care for infants have benefits that include continued counselling to the mother regarding eMTCT, administering neonatal ARV prophylaxis, early infant diagnosis (EID) to determine HIV status, and timely initiation of ART for positive results (WHO, 2013). However, many infants miss out on these benefits due to high rates of LTFU

(Lain et al., 2020). In Zambia the situation is not different. Despite effective eMTCT programmes, with about 92% of pregnant women living with HIV receiving ART yearly (UNAIDS 2014), retaining HIV exposed infants in the eMTCT programme is a problem. According to the Zambia National AIDS Council (NAC, 2013), around 70% of HIV exposed infants were tested in 2013, while in 2017, only 47% of exposed infants were retained in the care, and 53% were LTFU (MoH, 2018). Thus, non-retention of infants under HIV care is a problem in Zambia.

There are several factors that may contribute to LTFU of HIV exposed infants. The factors can be categorised into two; namely, socio-behavioural factors and service related factors. Disclosure of HIV status is an important factor in promoting ART adherence and patient retention in care (Umeokonkwo et al., 2019), and it is a crucial goal in HIV testing and counselling, as well as PMTCT (Alemayehu et al., 2015). This is because patients receive social support from family members, which is a key factor in fostering and maintaining adherence to ART. However, with all the benefits of status disclosure, the disclosure rates in developing countries are still low; they range between about 16.7% - 86% (Stockton et al., 2018).

There is strong evidence indicating that women's fears of stigma and involuntary HIV status disclosure to family members are barriers to EID and the continuation of HIV care for mothers and their children (Hampananda et al., 2017). Even though women do enrol in PMTCT programmes or HIV care; fears of accidental disclosure, stigma, and discrimination may make it difficult for them to adhere to ART prophylaxis or highly active antiretroviral therapy (HAART) if they need to hide HIV clinic visits and medications from others, or if permission has to be obtained from their partners to travel to access services (Colombini et al., 2018).

In many settings around the world, traditional gender roles and cultural beliefs give power to the males in decision making, which include women's use of HIV-related services, such as; follow up appointments, and uptake and adherence to ARV regimens (Central Statistical Office [CSO], 2017). It is therefore, important that men are fully incorporated in health issues of women and children for positive outcomes. Male involvement could enhance partner support for follow-up care for HIV-positive women and HIV exposed infants, including ARV adherence, improved

adherence to infant feeding methods, and early management of HIV exposed infant. The low proportions of HIV disclosure to the male partners by the HIV-positive female partners' highlights reported low male partner involvement (Kigen et al., 2018). Adane et al. (2018) in a study to explore Male involvement in prevention of mother to child transmission of human immunodeficiency virus and associated factors in Enebsiesarmider District, North West Ethiopia, highlighted the beneficial impact of male involvement in programmes to prevent MTCT of HIV to tackle new infections among infants. The practice could also eliminate harmful consequences faced by women who seek PMTCT services, such as, stigmatisation and gender-based violence (GBV). Moreover, male involvement in PMTCT services could address the healthcare needs and responsibilities of men, providing them with positive male norms, and linking them to other healthcare services.

In a multitude of settings, HIV positive people experience HIV-related stigma and discrimination in their daily lives (Dong et al., 2018). Stigma affects quality of life, healthcare service utilisation, and mental health (UNAIDS, 2017). In addition to the stigma of being HIV-positive, stigma associated with having a child while being HIV positive is also encountered (People Living with HIV [PLHIV], 2015). This causes women to struggle disclosing their HIV status to their partners for fear of negative consequences (Prudden et al., 2017). Stigma and discrimination negatively affect the PMTCT cascade at any stage, as well as the uptake and retention of PMTCT services, which may significantly impact rates of infant HIV infection (Prudden et al., 2017). According to the International Center for Research on Women (ICRW, 2014) over 50% of vertical HIV transmissions globally can be attributed to the cumulative effect of stigma. Similarly, Prudden et al (2017) state that while the effect of stigma on retention of women at any given stage along the PMTCT cascade can be relatively small; the cumulative effect can be large. Stigma influences a pregnant woman's decision to enrol in PMTCT programmes and adherence to treatment and retention in care for themselves and their infants (Nepua, 2016).

Access to health care is defined as having timely use of personal health services to achieve the best possible health outcome (Institute of Medicine [IOM], 1993). Access requires gaining entry into the health-care system, getting access to sites of care where patients can receive needed services, and finding providers who meet the needs of patients and with whom patients can

develop a relationship based on mutual communication and trust (Agency for Healthcare Research and Quality [AHRQ], 2017). Patients fail to access care if it does not exist in their geographic area. Such care includes PMTCT and other HIV related services. Even though patients are not charged for services, barriers such as walking long distances or unaffordable transportation costs incurred when travelling to ART centres, and sometimes in difficult terrain may contribute to non-retention in the care of patients on ART programmes (Mpinganjira et al., 2020)

Staff shortage influences retention in care of patients on ART as it leads to long queues at the clinic, resulting in long waiting times (Mukumbang et al., 2017). Because of this, patients get frustrated and tired of waiting to be seen. Long waiting times is perceived as a predictor of LTFU (Kweyamba, et al., 2018). Patient clinic waiting time is therefore, an important indicator of quality of services offered (Pandit et al., 2018). The amount of time a patient waits to be seen is one factor which affects utilisation of healthcare services and leads to LTFU (Opio et al., 2019).

The attitudes of health workers can affect health care utilisation in a positive or negative way. Evidence suggests that poor provider attitudes have a variety of adverse impacts on patient care and health outcomes (Dapaah, 2016). Just like a friendly, informative and reassuring manner can help to reduce the existing fears of a patient, an uncaring, judgmental or hostile attitude can exacerbate fears, and inhibit people from seeking reproductive and maternal health care services including PMTCT services (Kawale et al., 2015).

1.2 STATEMENT OF THE PROBLEM

PMTCT programmes provide many benefits such as providing virological testing to infants after birth and during the breastfeeding period, administering ART prophylaxis for prevention and effective treatment to HIV exposed infants. The programmes are widely implemented at various sites in Zambia. The Government and various stakeholders have made this possible by ensuring that all HIV services are free and accessible by increasing EID through health education. However, despite the efforts and interventions put in place, many infants do not benefit from the programmes mainly due to the LTFU problem, which compromises their effectiveness. MoH (2017) estimated that out of 38,128 HIV exposed children; only 43% (16,431) got tested at 18

months' country wide, indicating that 56% (21,697) were LTFU. The figures for Lusaka district are not different from the national ones. Table 1.1 shows levels of about 50% of infants in Lusaka being LTFU. The causes of LTFU are unclear, and hence, this was the motivation for conducting this study.

Table 1.1: Infants LTFU at 18 Months in Lusaka district

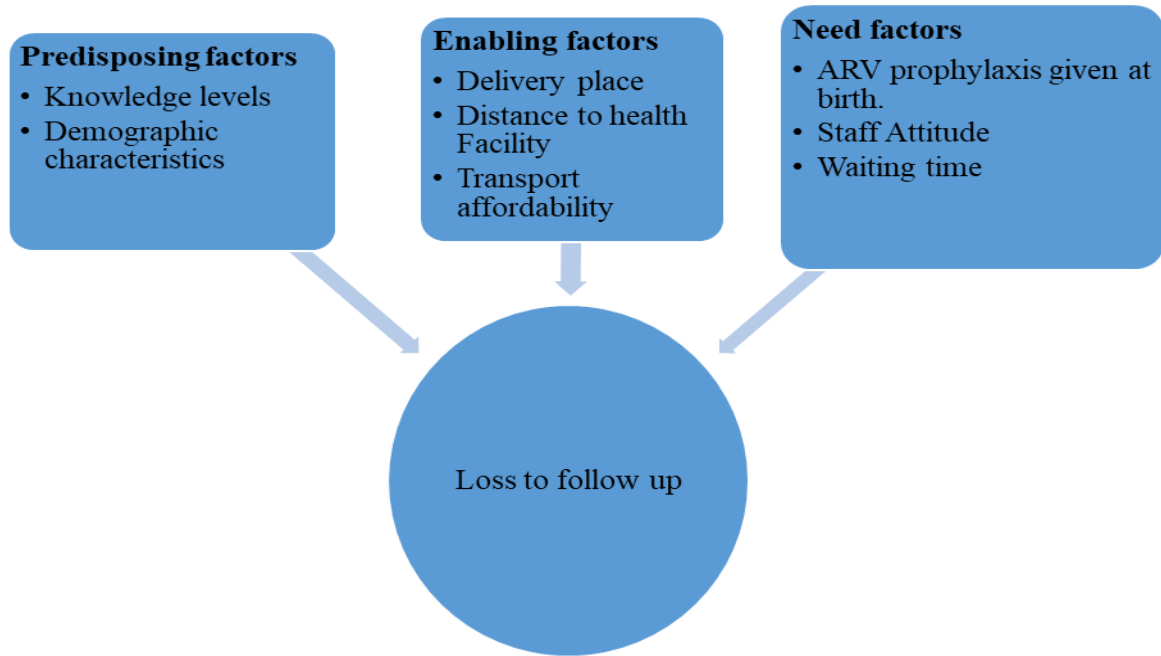
DURATION	INFANTS ENROLLED	INFANTS RETURNED AT 18 MONTHS %	INFANTS LTFU AT 18 MONTHS%
2016	9,681	40% (3,872)	60% (5,809)
2017	10,204	44% (4,490)	56% (5,714)
2018	9,088	39% (3,544)	61% (5,544)

Source: Lusaka DHO, HMIS (2016-2018).

1.3 CONCEPTUAL FRAMEWORK

This study was guided by Andersen's Health Care Utilisation Model, which was developed by Ronald M. Andersen in 1968. The model aims at demonstrating factors that lead to utilisation of health services (Andersen, 1968). According to the model, usage of health services is determined by three factors: predisposing factors, enabling factors, and need factors (Andersen, 1968). Some of the probable factors could be accessibility to health facilities, shortage of staff, stigma and, discrimination. These factors can influence utilisation of follow up care services independently or as a group, hence, affecting the outcome of the dependent variable, which in this study is LTFU. To suit the focus of the study the model was modified to enable answer the research question and address the research objectives.

Figure 1.1: Modified Andersen’s Health Care Model



1.3.1 APPLICATION OF THE FRAMEWORK TO THE STUDY

Predisposing factors include biological factors that may influence the likelihood of an individual needing a health service, social structure that may influence how an individual can cope with health problems and health beliefs that may influence an individual's perceptions of their need for health. In this study the factors comprised of knowledge levels and demographic characteristics because, these factors encouraged caretakers to adhere to the prescribed follow up visits. An individual who believes that follow up visits are beneficial will most likely utilise health services.

Enabling factors are factors that make it possible for individuals to change their behaviour or their environment, and they include resources, conditions of living, societal supports and skills (Andersen, 1968). In this study they comprised of place of birth, distance to health facility and transport affordability. Need factors represent both perceived and actual needs for health care services, and in this study they comprised of ARV prophylaxis given at birth, health status of

infant/caretaker and staff attitudes. According to Andersen (1968) an individual will feel the need for health services based on their experiences and current health status.

1.4 JUSTIFICATION OF THE STUDY

According to UNAIDS (2017) an estimated 180,000 children became newly infected with HIV and AIDS worldwide. Most of the cases live in sub-Saharan Africa (UNAIDS, 2017). Based on this information, many studies have been conducted in low to middle income countries, including Zambia. Despite the plethora of studies on HIV and AIDS, LTFU has remained a challenge in the implementation of programmes aimed at preventing vertical transmission. Most studies conducted on LTFU focused mainly on mother-infant pairs, such as; a cohort study by Obai et al. (2017) entitled rate and associated factors of non-retention of mother-baby pairs in HIV care in the elimination of mother-to-child transmission programme, Gulu-Uganda, and the other by Chipukuma et al. (2013) on factors contributing to low turn up of HIV exposed children for follow up care between 12 to 18 months in Chongwe, Livingstone and Ndola districts. Information obtained from only HIV positive mothers may miss out on other associated factors influencing LTFU, as other caretakers were not part of the study. In Zambia there is inadequate information and follow up studies to determine why infants in the country exposed to HIV still discontinue follow up care, hence this study was conducted. The results of this study have provided information on the factors in association with the LTFU and what factors influence LTFU. Consequently, the results can help in the implementation of strategies that will target the barriers to utilisation of eMTCT programmes, increase PMTCT service uptake and retention of HIV exposed infants in the PMTCT cascade.

1.5. RESEARCH QUESTION

What are the determinants of LTFU HIV exposed infants in Lusaka district?

1.6. RESEARCH OBJECTIVES

1.6.1 General Objective

The general objective of this study was to establish determinants of LTFU in infants born to HIV positive women in Lusaka District.

1.6.2 Specific Objectives

The specific objectives were to:

1. Determine the knowledge levels of caretakers of LTFU HIV exposed infants about the eMTCT programmes.
2. State environmental factors associated with LTFU of HIV exposed infants.
3. Identify health system factors that influence LTFU of HIV exposed infants.

1.7 CONCEPTUAL DEFINITION OF TERMS

eMTCT refers to interventions aimed at eliminating transmission of HIV from an HIV positive mother to her infant during pregnancy, labour, delivery, or breastfeeding (United States Agency for International Development [USAID], 2015).

Knowledge refers to understanding of information about a subject which has been obtained by experience of study and which is either in a person's mind or possessed by people generally (Burn and Groove, 2005)

PMTCT refers to interventions to prevent transmission of HIV from an HIV-positive mother to her infant during pregnancy, labour, delivery, or breastfeeding (USAID, 2015).

1.8 OPERATIONAL DEFINITION OF TERMS

LTFU refers to an infant that has failed to attend an HIV clinic 30 days after the date of their last appointment, and has not been documented as having been transferred to another clinic or died.

Determinant is a circumstance or fact that actively influences caretakers of HIV exposed infants from taking them for follow up care.

Follow up care refers to interventions put in place for HIV exposed infants to prevent vertical transmission, early detection of infection and commencement of ARVs upon identification at 6 weeks, 9 months and 18 months of age.

Caretakers refers to either a male or female family member aged 18 years and above, looking after an HIV exposed infant.

1.9 VARIABLES

1.9.1 DEPENDENT VARIABLE

The dependent variable of the study is Loss to Follow Up.

1.9.2 INDEPENDENT VARIABLES

The independent variables are:

- Caretakers' knowledge
- Place of delivery
- Prophylaxis given
- Distance to health facility
- Transport affordability
- Healthcare providers' attitudes
- Waiting time

1.9.3 VARIABLES, INDICATORS AND CUT-OFF POINTS

Table 1.2: Variables, Indicators and Cut off Points

VARIABLE	INDICATOR	CUT OFF POINT	QUESTION NO.
DEPENDENT VARIABLE			
Loss to follow up	Yes	Missed scheduled appointment for 30 days	22
	No	Up to date with scheduled appointment	
INDEPENDENT VARIABLES			
VARIABLE	INDICATORS	CUT OFF POINTS	QUESTION NO.
Knowledge	High	A score of 11-15 on knowledge questions	10-21
	Moderate	A score of 6-10 on knowledge questions	
	Low	A score below 0-5 on knowledge questions	
Place of delivery	Yes	If Place of delivery had influence on LTFU	29
	No	If Place of delivery had no influence on LTFU	
Prophylaxis given at birth	Yes	If prophylaxis given at birth had influence on LTFU	30
	No	If the prophylaxis given at birth did not have an influence on LTFU	
Distance to health facility	Yes	If distance to health facility had influence on LTFU	40-42
	No	If distance to health facility had no influence on LTFU	
Transport	Yes	If transport to health facility had an influence on LTFU	43-45
	No	If transport to health facility had no influence on LTFU	
Attitude of Health care Providers	Negative	If attitude of healthcare providers had an influence on LTFU	24-28
	Positive	If attitude of healthcare providers had no influence on LTFU	
Waiting time	Yes	If waiting time had an influence on LTFU	22
	No	If waiting time had an influence on LTFU	

CHAPTER TWO: LITERATURE REVIEW

2.0 INTRODUCTION

Chapter two provides information on the literature that was reviewed. The aim of the review was to establish what has been researched about the topic and to identify gaps in the existing literature. The literature review is presented according to the study variables which include; Overview of LTFU, Knowledge of caretakers and Health care providers about eMTCT, Distance to health facility, Place of Birth, Prophylaxis given, Attitude of health care providers, and Waiting time.

The sources of this literature include electronic search from PubMed, Science Direct, Directory of Open Access Journals (DOAJs), WHO, UNAIDS, Google, and Google Scholar websites.

2.1 OVERVIEW OF LTFU

PMTCT has undergone considerable evolution based on scientific evidence, resulting in vertical transmission rates of 1% or less in the developed countries; which demonstrates that eMTCT is possible (Phanuphak, 2016). Success in eMTCT can be achieved through effective strategies such as identifying women with HIV and initiating them on ARVs, providing ARV prophylaxis for the exposed infant and continuous post-test counselling (WHO, 2018). As a result, the 2013 WHO treatment guidelines recommend that infants exposed to HIV should be tested at the first postnatal visit, and that infants who test positive for HIV should start treatment immediately (WHO, 2013). However, even where treatment is available and accessed, retention in care is a problem in many countries (Ahoua et al., 2020). Chances of children becoming LTFU is higher than any age stage (Kranzer et al., 2017), this is because decisions to gain access to healthcare services is made by their caretakers.

EID coverage globally still remains low; with only 43% of infants exposed to HIV in 2016 receiving an HIV test within the first recommended two months of life (UNAIDS, 2017). LTFU care has a negative influence on the effectiveness of strategies put in place as seen by continued occurrence of new HIV infections in children globally, and a challenge in timely diagnosis and treatment of infants and children living with HIV (WHO, 2018). A Cohort study by Kyaw et al.

(2017) on Low mother-to-child HIV transmission rate but high loss-to-follow-up among mothers and babies in Mandalay revealed that there is an unacceptable high rate of LTFU mothers and HIV exposed infants at several points in the PMTCT care cascade. The proportion of mothers who were LTFU after delivery was found to be five times higher than LTFU before delivery. HIV positive pregnant women in sub-Saharan Africa are lost between ANC registration and delivery, whereas about 24% of infants are LTFU by three months. More infants are lost after HIV testing (Ankunda et al., 2020). The results are concurrent with those of Kalembo and Zgambo (2012), with rates of LTFU mother-child pairs ranging from 19% to 89.4%. These percentages show that there is a great loss of mother-child pairs to follow-up in PMTCT in sub-Saharan Africa.

2.2 KNOWLEDGE OF CARETAKERS AND HEALTH CARE PROVIDERS ABOUT eMTCT

Lack of awareness and knowledge about HIV/AIDS, MTCT and PMTCT follow-up services have a negative impact on postnatal follow-up services. A number of studies have identified a connection between these factors with uptake of PMTCT services. Haile et al., (2016) concluded that adequate knowledge levels are associated with various factors such as experiencing at least one pregnancy, higher education levels, higher household wealth, living in an urban area, being exposed to HIV education, having taken an HIV test or knowing where to get tested for HIV. This information was from a study involving more than 10,000 women of which women living with HIV were more likely to have adequate knowledge of MTCT (56%) than women who were HIV negative (46%).

Coulibaly et al. (2016) investigated Prevention and care of paediatric HIV infection in Ouagadougou, Burkina Faso: knowledge, attitudes and practices of the caregivers. The results of the study revealed that, Overall, 97 % of caregivers knew that the main transmission route for HIV-infected infants was through their mothers. Fourteen (38 %) specified that mother-to-child transmission occurred during pregnancy or delivery. 87 % of the caregivers responded that testing mothers and providing ARVs to the HIV-infected ones can help prevent children's HIV infection. despite an overall knowledge of MTCT modes, a few misconceptions still existed

(Coulibaly et al., 2011). Knowledge levels therefore resulted in a 92% HIV testing uptake among participants (Tatagan et al., 2011). However, other studies have associated high levels of HIV, MTCT and PMTCT knowledge with lower acceptability and utilisation of PMTCT services.

According to CSO (2015) majority of respondents had high levels of knowledge about eMTCT. Results from the survey further revealed that around 89% of women and 82% of men knew that HIV can be transmitted through breastfeeding (CSO, 2015). Around 82% of women and 66% of men were aware that the risk of MTCT can be reduced during pregnancy by taking ART (CSO, 2015). Contrary to the results of the survey, a study done by Ramoshaba and Sithole (2017) discovered that majority of the participants lacked knowledge on how a mother can transmit HIV to her child after birth. Participants failed to mention breastfeeding as a mode of transmission (Ramoshaba and Sithole, 2017). Mothers who lack knowledge about MTCT may ignore follow-up care, and miss out on HIV treatment for both their health and that of their babies. It is important therefore to increase knowledge levels about HIV, MTCT and importance of ART, which is critical in reducing MTCT of HIV (CSO, 2015).

Kiyaga et al. (2018) who investigated the Retention outcomes and drivers of loss among HIV-exposed infected infants in Uganda concluded that frequent late entry and high drop out among infants enrolling for care and EID were due to lack of knowledge and understanding of EID by service providers and consequently, caregivers. Other studies are in agreement that mother infant pairs who have good knowledge about HIV and ARVs being able to reduce MTCT are more likely to have successful follow up outcomes (Bwana et al., 2018). However Kigen et al. (2018) concluded that parents' lack of knowledge that HIV exposed infants should receive follow-up care for 18 months despite initial HIV-negative PCR results could influence a caregiver's decisions on continuing appointments for HIV exposed infants who appear healthy.

Another study by Kweyamba et al. (2018) concluded that mothers' knowledge about the possibility of infecting their babies is a predictor for LTFU. This indicates that mothers are knowledgeable about the transmission of HIV to their babies. But, upon defaulting from the PMTCT care, mothers may perceive that their breastfed child is HIV positive and hence, fear returning to the clinic to avoid being blamed by the health workers if the child turns out to be

HIV positive on testing (Kweyamba et al., 2018). It is therefore important to improve health provider attitudes and provide training to help change the way patients perceive care and their choice on whether to continue receiving care or not.

2.3 DISTANCE TO HEALTH FACILITY AND TRANSPORT AFFORDABILITY

Geographical distance to health facilities influences utilisation of health services greatly, despite ART services being free. Travel distance and additional costs incurred on travelling to ART centres contribute to non-retention in the care of patients on ART programme (Mukumbang, 2017). A number of authors have documented the association between distance and health care utilisation; indicating patients who live closer to healthcare facilities having higher rates of utilisation of services than those who live far away. Escamilla et al. (2015) in a study to determine association between distance from household to a clinic and its association with the uptake of PMTCT regimens in rural Zambia concluded that uptake of any PMTCT regimen and ART for PMTCT decreased as the per kilometre (km) distance to the clinic increased. Results of the study revealed that distance between a woman's home and clinic affects the uptake of ART during pregnancy and breastfeeding. Adelekan et al. (2019) concluded that the high cost of transport is a major barrier in preventing access to HIV treatment. Inability to afford transport costs related to the long distances to hospitals has been cited as strongly associated with mother infant pairs being LTFU (Mpinganjira et al. 2020). Results from a study done by Akullian et al., (2016) also concluded that patients on ART encountered financial difficulties in attending follow-up visits.

2.4 PLACE OF DELIVERY

HIV positive women's choice of delivery location is influenced by various factors which include; cultural influences, poor socio-economic status, and fear of the stigma associated with an HIV positive status (Kifle et al. 2018). It is the care that women receive during labour and delivery that can facilitate successful PMTCT programmes. A study by Kebede et al. (2014) on delay in EID and high LTFU among infants born to HIV infected women in Ethiopia found that the dynamics between place of delivery and PMTCT interventions were major challenges to EID. Mothers who delivered at government health institutions had the highest rate of early HIV

DNA-PCR testing compared to deliveries which took place in homes. Most mothers who gave birth in homes did not receive ARV prophylaxis during labour and the infants were not given ARV prophylaxis immediately on delivery (Kebede et al., 2014). In addition, mothers who delivered at private health facilities were less likely to bring their infants for EID. Elang (2015) is in agreement with the results in a study on factors associated with LTFU of infant-caretaker pairs enrolled in the early EID clinic. The study concluded that mothers that delivered from the hospital were less likely to become LTFU (Elang, 2015). This is an indicator that accessing delivery services and care can facilitate successful PMTCT programme and retention in care. This may probably be due to timely counselling offered to the mother/caretaker on how to keep their HIV exposed infants negative and also ARVs given during postnatal periods which motivate caretakers to return for follow up care.

2.5 PROPHYLAXIS GIVEN

Initiation of ART to HIV positive pregnant women is important not only for maternal health and in reducing MTCT; but also improves follow-up of HIV exposed infants (Muyunda et al., 2019). A study by Feinstein et al. (2015) revealed that having a mother on ART was associated with a significant reduction in LTFU compared to not having a mother on ART; and thus efforts to ensure linkage of testing with treatment in the Option B+ programme are likely to reduce LTFU amongst HIV exposed infants. The findings of the study are in line with Lain et al. (2020), who concluded that mothers who take ARVS during labour and delivery with their infants given cotrimoxazole prophylaxis is a strong protective effect in preventing the infant from being LTFU, as mothers are more likely to remain in contact with the health facility. However, the results are different from those of Tukei et al. (2020) in a cohort study on 24-Month HIV-free survival among HIV-exposed Infants in Lesotho: the PEAWIL. Results from the study indicated that there was a high proportion of ARV prophylaxis uptake among HIV exposed infants, yet a great number of infants were found to be LTFU (Tukei et al., 2020). It is likely that perceptions of mothers regarding the advantages of continuing follow-up care after 6 weeks decrease when pharmacological intervention is terminated.

2.6 ATTITUDE OF HEALTHCARE PROVIDERS

The attitudes of health care providers can affect utilisation of health services positively or negatively. This is because it influences satisfaction of health services by patients and their families. Interactions between health care providers and their patients therefore, play an important role in improving the uptake of health services (Yelin, 2015). Effective interaction between care provider and patients brings about satisfaction with health services, acquisition of knowledge and adherence to care (Molina-Mula & Gallo-Estrada, 2020). Provider-patient interaction that consists of negative provider attitude is among the cited barriers to retention of patients on ART in sub-Saharan Africa (Layer et al., 2014). Stigma and discrimination in the community, self-stigma and stigma by care providers also contribute to discontinuation of treatment by patients (Helms et al., 2018). After an HIV positive pregnant woman gives birth, fears of stigma and discrimination again become a barrier to adherence to follow up care for the infant or the mother due to the need to hide visits and medications from others (Suryavanshi, et al. 2018).

2.7 WAITING TIME

Waiting time is very important in health care because it has an impact on patient satisfaction. Long waiting time has been considered frustrating to patients and thus appears to be a potential cause of patient dissatisfaction (Sun et al, 2017). It is therefore important that patients are seen within a reasonable time frame, for a better experience. Kweyamba et al. (2018) indicated that waiting at the health facility for more than an hour before being attended to by a health worker was a predictor of LTFU. Long waiting time could be as a result of low staffing levels compared to the volumes of patients. In another study by Ankunda et al. (2020) a health worker pointed out that waiting time was a hindrance to child follow up. This is because of long queue at the clinic especially for working class mothers. Time spent waiting for a health worker can act as a barrier to utilisation of health services, and it can determine the quality of services rendered to clients.

CONCLUSION

The reviewed literature indicated that globally, many studies have been conducted on factors influencing the uptake of PMTCT services by pregnant women. However, information on understanding infant retention to HIV care during the postpartum period and determinants of LTFU is limited. Therefore, it was essential to conduct this study.

CHAPTER THREE: RESEARCH METHODOLOGY

3.0 INTRODUCTION

This chapter presents how the study was conducted. This is done by providing the study design, setting, the population and how they were sampled, how data were collected, stored and managed, how validity and reliability were assured, and the ethical considerations.

3.1 STUDY DESIGN

A descriptive cross sectional quantitative study design was used. This design was chosen because the required data could be obtained at one specific point in time. The quantitative component enabled comparison and analysis of many different variables.

3.2 STUDY SETTING

The study was conducted in Lusaka district of Zambia, at three urban health centres namely; Kalingalinga, Mtendere and Kabwata. The facilities were randomly selected among other urban health centres in the district that offer both preventive and curative services with Maternal, Neonatal and Child Health (MNCH) services.

3.3 STUDY POPULATION

The study population comprised of caretakers whose children had been registered for eMTCT services as well as nurses, midwives and HIV counsellors offering eMTCT services. The target population comprised of caretakers whose children were registered for eMTCT services at the three study setting, as well as the nurses, midwives and HIV counsellors offering eMTCT services there.

3.4 ELIGIBILITY CRITERIA

3.4.1 Inclusion Criteria

In this study the inclusion criteria were:

- Parents and Caretakers aged 18 years and above. This is because participation was by consent. In line with the Helsinki Declaration Code of Ethics, participant aged below 18 require parents or guardians assent to participate in any study.
- Nurses, midwives and HIV Counsellors who had work experience of at least 6 months in eMTCT.

3.4.2 Exclusion Criteria

The exclusion criteria were:

- Caretakers whose HIV exposed infants were unwell.
- Nurses, midwives and HIV counsellors who were currently not working in eMTCT.
- Nurses, midwives and HIV counsellors who were on leave during the time of data collection.
- Caretakers, nurses, midwives and HIV counsellors who did not consent to participate in the study.

3.5 SAMPLING TECHNIQUE

Purposive sampling was used to select the caretakers. This was to allow diversity among respondents, such as; marital status, clients who are LTFU, gender, age, education level and work experience. Due to limited numbers, convenience sampling was used to select nurses, midwives and HIV counsellors.

3.6 SAMPLE SIZE

3.6.1 Sample size for caretakers

The sample size for caretakers was calculated using Krejcie and Morgan (1970) formula for calculating sample size of a finite population.

$$n = \frac{Z^2 NP (1-P)}{d^2 (N-1) + Z^2 P (1-P)}$$

$$d^2 (N-1) + Z^2 P (1-P)$$

Where: n = Required Sample size

P = the proportion/prevalence (0.5)

$Z = 1.96$ standard normal variate at 95% confidence level

$d = \pm 5\% = \pm 0.05$ is the degree of accuracy (5%), expressed as a proportion (0.05); It is margin of error

$N =$ Accessible study population Size (250)

$n = \frac{1.96^2 \times 250 \times 0.5 (1 - 0.5)}{0.05^2 (250 - 1) + 1.96^2 \times 0.5 (1 - 0.5)}$

$n = \frac{3.84 \times 250 \times 0.5 (0.5)}{0.0025 \times 249 + 3.84 \times 0.5 \times 0.5}$

$n = 160$ caretakers

3.6.2 Sample size for nurses, midwives and Psychosocial Counsellors

23 health care providers took part in the study of which; 6 were registered midwives, 6 Psychosocial Counsellors, 1 Enrolled midwife, 9 Registered nurses and 1 Social worker.

3.7 DATA COLLECTION

Data was collected by the researcher on 2nd September to 1st October 2020.

3.7.1 Data collection tool

A semi-structured questionnaire (Appendix 3) was used to collect data from caretakers (Also translated in Nyanja (Appendix.7). The tool was adapted from Kabir (2016). A semi-structured questionnaire was used because its advantage of being able to collect information from a big sample in a short period of time (Goyal, 2013). The questionnaire had both open and close-ended questions. Open ended questions allowed respondents to provide more information regarding their understanding and opinions about the problem. A self-administered semi-structured questionnaire (Appendix 4) was used to collect data from the health care workers because all of them were literate.

3.7.2 Data collection technique

After ethics approval and permission to carry out the study was granted by the relevant authorities, the researcher with assistance from the clerk checked registers so that residential addresses and mobile numbers for caretakers who are LTFU could be traced and data collection arrangements made. The researcher also provided information about the study to caretakers who had brought infants born from HIV+ patients for their various reviews. Each participant who was willing to participate was given a consent form (Appendix 2) to sign and more detailed information about the study provided through a Participant Information Sheet (Appendix 1).

On the day of data collection, each respondent was greeted. Respondents chose the place where the preferred data to be collected from. Whichever place was chosen, the researcher ensured that privacy was maintained at all times. Since the questionnaire was written in English, those that could read and write, were given to fill in, while respondents who could not had questions read and translated in their preferred language, and responses were written for them by the researcher. After data was collected, each respondent was given a drink, thanked and transport refund of K30.00 was provided.

3.8 DATA MANAGEMENT AND STORAGE

Unauthorised access to filled-in questionnaires was controlled by storing them in a lockable cupboard whose key was kept by the researcher. To maintain security, soft data was entered on a Password protected computer. To prevent loss of data, three copies were stored and an up-to-date anti-virus on the computer was maintained.

3.9 VALIDITY

Data was collected using a validated questionnaire adapted from Kabir (2016). Questions were expressed in simple term, they were brief and precise. The questionnaire was examined by research supervisors for content and item validation, and a pilot study was conducted before embarking on the main study. During data collection at the end of each day, the answered questionnaires were checked for completeness to ensure that the information was properly collected. External validity was ensured by maintaining the required number of participants.

3.10 RELIABILITY

Reliability was ensured by the use of a pretested semi-structured questionnaire. The questionnaire had both open and closed ended questions. The use of open ended questions provided clarity to close ended questions, and each respondent was given enough time to complete the questionnaire; nobody was rushed through.

3.11 ETHICAL CONSIDERATION

Ethics approval (Appendix 10) was obtained from the University of Zambia Biomedical Research Ethics Committee (UNZABREC) and National Health Research Authority (Appendix 11). Permission to carry out the study was obtained from the Lusaka District Health Medical Directorate (LDHMD) (Appendix 12), as well as the in-charges of the health facilities where the study was conducted. Written consent was obtained by either a signature or thumb print from all participants after fully informing them about the study and that they were free to withdraw their participation at any point without facing any negative repercussions. No respondent withdrew. A Participant Information Sheet was utilised to provide detailed information about the study to each respondent. Due to the sensitive nature of the study, confidentiality and anonymity was assured and maintained. No names were used; instead codes were assigned for identification. Records were reviewed only by the researcher and/or Supervisor.

CHAPTER FOUR: DATA ANALYSIS AND PRESENTATION OF FINDINGS

4.0 INTRODUCTION

This chapter provides information on how data was processed and analysed, and then analysed data from the study through frequency tables, bar graphs and cross tabulations were presented.

4.1 DATA PROCESSING AND ANALYSIS

The collected data was screened for completeness, followed by categorisation of open ended questions, and numerical codes were assigned to each category. Closed ended questions were also assigned numerical codes. Data were then entered in the computer and double-checked before analysis using SPSS version 22.0. Frequencies were obtained, cross tabulations and lastly logistic regression was used to test associations between dependent variable and the independent variables. The cut off point for statistical significance was set at 5%, p-values of 0.05 or less were considered statistically significant.

4.2 DATA PRESENTATION

The findings have been presented in form of frequency tables, bar graphs and cross tabulations in four sections which are: socio-demographic characteristics of the respondents, caretakers' knowledge about eMTCT, environmental and service-related factors.

4.2.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF CARETAKERS

This section presents the socio-demographic characteristics of caretakers, which included age of HIV exposed infants, gender and age of caretaker, relationship between caretaker and infant, marital status, level of education, occupation and religion. It also comprises of gender of health care providers, work experience and trainings done.

Table 4.1: Socio-demographic characteristics of caretakers (n=160)

Demographic characteristics	Frequency	Percentage (%)
Gender of caretaker		
Male	17	11.0
Female	143	89.0
Total	160	100
Age of caretaker		
18-29 Years	30	18.8
30-39 Years	82	51.3

40-49 Years	33	20.6
50-59 Years	15	9.3
Total	160	100
Relationship between caretaker and infant		
Mother	110	68.8
Father	19	11.9
Grandmother	27	16.8
Aunt	4	2.5
Total	160	100
Marital status		
Single	34	21.3
Married	100	62.5
Widowed	7	4.3
Divorced/Separated	19	11.9
Total	160	100
Level of Education		
No formal education	3	1.9
Primary	52	32.5
Secondary	85	53.1
Tertiary	20	12.5
Total	160	100
Occupation of Caretakers		
Employed	11	6.9
Housewife	28	17.5
Self employed	101	63.1
Unemployed	20	12.5
Total	160	100
Religion for Caretakers		
Christian	160	100.0

Table 4.1 shows that 89.0 % (143) of the caretakers were female. Half 51.3% (82) were aged between 30 to 49 years, 62.5% (100) were married, and 68.8% (110) were biological mothers to the infants.

Table 4.2: Socio-demographic characteristics of health care providers (n=25)

Socio demographic characteristics	Frequency	Percentage
Gender		
Female	22	88.0
Male	3	12.0
Total	25	100
Professional qualification		
Enrolled Midwife	1	4.0
Psychosocial counsellor	6	24.0
Registered midwife	6	24.0
Registered nurse	9	36
Social Worker	1	4.0
Total	25	100
Work experience		
6-11 months	9	37.5
1-5 years	10	41.7
6-10 years	2	8.3
11-15 years	2	8.3
Total	25	100
Trainings		
VCT	25	100
PMTCT	24	96
Breastfeeding	23	52
Young infant feeding	6	24
Comprehensive ART	4	16
DBS Collection	2	8.0
Couple counselling in HIV and TB	1	4.0

Table 4.2 shows that 88.0% (20) of the health care providers were female and 12% (3) were registered nurses (RNs). All the health workers 100% (25) had been trained in VCT at least once and less than half 41.7% (10) had work experience of 1 to 5 years.

4.2.2 CARETAKERS' KNOWLEDGE ABOUT eMTCT

Table 4.3: Caretakers' knowledge about eMTCT (n=160)

Knowledge about eMTCT	Frequency	Percentage
Are you aware of the existence of MTCT of HIV		
Yes	160	100
No	0	0
Total	160	100
Are you aware of PMTCT HIV		
Yes	160	100
No	0	0
Total	160	100
Source of information		
Health workers	110	68.8
Mass media	26	16.2
Friends and relatives	24	15
Total	160	100
How to prevent MTCT after birth		
Modified infant feeding	11	6.9
Stop breastfeeding before teething	13	8.1
ARV drugs given to mother and baby	136	85
Total	160	100
Which services provided during follow up care		
Counselling	21	13
Vaccination	2	1.3
HIV Testing	129	80.6
Collection of ARVs	4	2.5
Growth monitoring	4	2.5
Total	160	100
How MTCT can be prevented after birth		
Modified infant feeding	11	6.9
Stop breastfeeding before teething	13	8.1
ARV drugs given to mother and baby	136	85
Total	160	100
When follow up care begins		
At 6 weeks	142	88.7
do not know	18	11.3
Total	160	100
When follow up care stops		
When first HIV test is negative	11	6.9
When infant stops breastfeeding at 2 years old	109	68.1

Do not know	40	25.0
Total	160	100

Table 4.3 shows that all 100% (160) caretakers were aware about the existence of MTCT and PMTCT of HIV. Half of them, 68.8% (110) obtained information about MTCT and eMTCT from health care providers; more than half caretakers 85% (136) mentioned ARV drugs to mother and baby as a way of preventing MTCT of HIV after birth; more than three quarters of the caretakers 88.7% (142) mentioned 6 weeks as a time when follow up care begins; and more than three quarters 109 (68.1) said that follow up care stops when an infant stop breastfeeding at 2 years old.

Overall knowledge levels of caretakers

The study findings revealed that more than half, 67.5% (108) of the caretakers had high knowledge levels, and 32.5% (52) displayed moderate knowledge, with none exhibiting low knowledge.

Overall knowledge levels of health care providers about eMTCT

More than half 69.6% (16) health care providers had high knowledge levels on eMTCT, while less than half 30.4% (7) had moderate knowledge levels.

4.2.3 SECTION C: ENVIRONMENTAL AND SERVICE-RELATED FACTORS

This section comprises of caretaker's data on environmental and service related factors. Caretakers were asked questions on place of birth, prophylaxis at birth, distance to the health facility, transport affordability, and reasons for discontinuing follow up. Health care providers were also asked questions on availability of logistics and factors likely to influence LTFU HIV exposed infants.

Table 4.4: Environmental related factors (n=160)

Independent variables	Frequency	Percentage
Place of birth		
Yes	149	93.1
No	11	6.9
Total	160	100
Prophylaxis at Birth		
Yes	160	100
No	0	0
Total	160	100
Distance to health facility		
Yes	135	84.4
No	25	15.6
Total	160	100
Transport affordability		
Yes	134	83.7
No	26	16.3
Total	160	100

Table 4.4 shows that, 6.9% (11) were home births, all 100% (160) HIV exposed infants received prophylaxis from birth up to 6 weeks, more than half caretakers 135 (84.4%) of the caretakers lived within 5kms to the health facility, and 16.3% (26) could not afford transport cost to health facility.

4.2.4: SERVICE-RELATED FACTORS FROM CARETAKERS' PERSPECTIVE

Table 4.5: Service-related factors

Factor	Frequency	Percentage
Attitude of health providers		
Reception by health providers		
Very good	114	71.3
Good	33	20.6
Poor	13	8.1
Total	160	100
Supportive health providers		
Yes	147	91.9
No	13	8.1
Total	160	100
Enough time spent with health workers		
Sometimes	46	28.7

Always	114	71.3
Total	160	100
Health providers explain in a way that is easy to understand		
Sometimes	24	15
Always	136	35.1
Total	160	100
Health providers show respect		
No	24	15
Yes	136	85
Total	160	100
Waiting time		
5-10 minutes	48	30
11-20 minute	11	6.8
21-30 minutes	44	27.5
More than 30 minutes	57	35.6
Total	160	100

Table 4.5 shows that, more than half caretakers 71.3% (114) said health care providers Reception give a very good reception, half 71.3 % (114) of the caretakers mentioned that Sometimes health care providers spent enough time with them, more than Half 85% (136) caretakers said health care providers always explain in a way that is easy to understand, more than three quarters 85% (136) said that health care providers showed them no respect whenever they went for follow up care, and 32.0% (47) caretakers stated that they waited for more than 30 minutes before being attended to.

Overall Attitude of health care providers from caretakers' perspective

Half 52.5% (84) caretakers said that health care providers had negative attitude, while 47.5% (76) caretakers said health care providers had positive attitude.

Waiting time from caretakers' perspective

The study revealed that some caretakers 36.9% (59) said waiting time did not influence decision to stop follow up care while 101% (63.1) said waiting time influenced decision to discontinue follow-up care.

Table 4.6: Waiting time from health care providers' perspective (n=25)

Waiting time	Frequency	Percentage
1 hour 30 minutes to 2 hours	9	36.0
30 minutes to 1 hour	7	28.0
Less than 30 minutes	7	28.0
Total	23	100

Table 4.6 shows that 36.0% (9) of the health care providers said caretakers wait for 1 hour 30 minutes to 2 hours at the health facility before being attended to.

Table 4.7: Reasons caretakers gave for discontinuing follow up care (n=131)

Reasons	Frequency	Percentage
Busy with work	6	4.5
Caretaker unwell	6	4.5
Forgot	37	28.0
Not aware	56	42.4
Out of town	26	19.7
Total	131	100

Table 4.7 shows that most 42.4% (56) of caretakers were not aware they needed to continue with follow up care, while 28.0% (37) forgot to take the infant for follow up care.

General Availability of logistics for eMTCT

Health workers were asked about availability of logistics. More than half of health care providers 72.0% (18) said that logistics for eMTCT were adequately available, while 28.0 % (7) said that they were not adequately available.

Some 39.1% (9) of health care providers said that all specific logistics were available, 21.7% (5) said test kits and medicine were out of stock sometimes, 30.4% (7) mentioned that airtime to call clients was not available, and while 8.7% (2) mentioned that there was no transport to use in the follow up of clients. 8% (2) Mentioned non-disclosure of results, 8% (2) mentioned long distance

to the health facility while 8% (2) of health workers mentioned two negative PCR results influence of LTFU.

4.3 ASSOCIATIONS BETWEEN VARIABLES

LTFU was correlated with each independent variable, to establish statistical significance

Table 4.8: Association between respondents' demographical characteristics and LTFU (n=160)

Independent variable	LTFU		Total	P-value <0.05
	Yes	No		
Gender of caretaker				0.038
Female	80	17	97	
Male	51	12	63	
Total	131	29	160	
Age of caretaker				0.477
18-29 Years	23	7	30	
30-39 Years	66	16	82	
40-49 Years	28	5	33	
50-59 Years	14	1	15	
Total	131	29	160	
Relationship between caretaker and infant				0.052
Mother	89	24	110	
Father	16	3	19	
Grandmother	24	3	27	
Aunt	2	2	4	
Total	131	29	160	
Marital status				0.036
Single	26	8	34	
Married	81	19	100	
Widowed	7	0	7	
Divorced/Separated	17	2	19	
Total	131	29	160	
Level of Education				0.184
No formal education	3	0	3	
Primary	45	7	52	

Secondary	67	18	85	
Tertiary	16	4	20	
Total	131	29	160	
Occupation of Caretakers				0.130
Employed	9	2	11	
Housewife	22	6	28	
Self employed	24	17	41	
Unemployed	16	4	20	
Total	131	29	160	

Table 4.8 shows that the association between gender (p-value 0.038) and marital status of caretaker (p-value 0.036) and LTFU were statistically significant. The association between age of caretaker (p-value 0.477), relationship between caretaker and infant (p-value 0.052), level of education (p-value 0.184), occupation (p-value 0.130) and LTFU were not statistically significant.

Table 4.9: Association between knowledge of caretakers and LTFU (n=160)

Independent variable	LTFU		Total	P-value <0.05
	Yes	No		
Knowledge Levels				0.160
High	89	19	108	
Moderate	42	10	52	
Low	0	0	0	
Total	131	29	160	

Table 4.9 shows that the association between knowledge and LTFU was not statistically significant (p-value 0.160)

Table 4.10: Association between environmental factors and LTFU (n=160)

Independent variable	LTFU		Total	P-value <0.05
	Yes	No		
Place of Birth				0.001
Yes	120	11	131	
No	29	0	29	
Total	131	29	160	
Prophylaxis given at birth				0.102
Yes	131	29	160	
No	0	0	0	
Total	131	29	160	
Distance to health facility				0.001
Yes	106	29	135	
No	25	0	25	
Total	131	29	160	
Transport Affordability				0.000
Yes	105	29	134	
No	26	0	26	
Total	131	29	160	

Table 4.10 shows that the association between LTFU and place of birth (p-value 0.001), distance to health facility (p-value 0.001) and transport affordability (p-value 0.000) was statistically significant, whereas as that between LTFU and prophylaxis given at birth was not (p-value 0.102).

Table 4.11: Association between service related factors and LTFU (n=160)

Independent variable	LTFU		Total	P-value <0.05
	Yes	No		
Staff attitude				0.016
Negative	68	16	84	
Positive	63	13	76	
Total	131	29	160	
Waiting time				0.008
No	86	15	101	
Yes	45	14	59	
Total	131	29	160	

Table 4.11 shows that the association between LTFU and staff attitude (p-value 0.016) and waiting time (p-value 0.008) were statistically significant.

4.14 BINARY LOGISTIC REGRESSION OF FACTORS ASSOCIATED WITH LTFU

Binary logistic regression analysis was used to determine the true predictors of LTFU as well as to control for confounding factors. All the variables that were statistically significant were analysed.

Table 4.12: Binary Logistic Regression Analysis

Independent variable	Odds Ratio	P-value	CI-95%
Gender of caretaker			
Male	3.794	0.999	0.0432,2.2246
Female	0.440	0.040	0.287,0.966
Age of caretaker			
18-29 Years	2.157	0.718	0.33,139.645
30-39 Years	0.944	0.976	0.22,39.739
40-49 Years	2.063	0.630	0.108,39.423
50-59 Years	0.694	0.505	0.237,2.032
Relationship between caretaker and infant			
Mother	3.063	0.450	1.082,12.068
Father	6.169	0.094	0.318,119.725
Grandmother	2.453	0.778	0.125,48.286
Aunt	0.482	0.299	0-033,6.988
Marital status			
Single	1.368	0.390	0.339-5.833
Married	0.177	0.357	0.019,1.617
Widowed	0.559	0.203	0.099-3.178
Divorced/Separated	1.347	0.360	0.135,13.410
Level of Education			
No formal education	2.565	0.503	0.311,8.366
Primary	11.444	0.724	0.115,3.982
Secondary	1.908	0.411	0.305,12.724
Tertiary	2.098	0.225	1,050,5.143
Occupation of Caretakers			
Employed	0.870	0.301	0.058,6.736
Housewife	0.048	0,098	0.001,1.743
Self employed	0.078	0.117	0.003,1.887

Unemployed	0.092	0.064	0.007,1.151
Knowledge			
High	1.360	0.629	0.391,4.733
Moderate	1.444	0.569	0.408,5.115
Low	1.080	0.722	0.058,6.736
Place of Birth			
Institutional	0.646	0.999	0.182,5.594
Non- Institutional	9.758	0.990	0.128,3.724
Prophylaxis given at birth			
Yes	9.731	0.030	0.248-76.769
No	1.296	0.789	0.193,8.682
Distance to health facility			
Yes	5.483	0.308	0.208,14.178
No	0.985	0.998	0.432,3.633
Transport Affordability			
Yes	9.449	0.998	0.012,12567
No	0.854	0.713	0.370,1.975
Staff attitude			
Negative	2.723	0.047	1.050,5.114
Positive	0.738	0.590	0.253,2.073
Waiting time			
Yes	0.671	0.010	0.050,5.1430
No	0.913	0.940	0.314,5.1430

Table 4.12 shows that the association between LTFU and female caretaker (p-value 0.040), negative staff attitude (p-value 0.047) and waiting time (p-value 0.010) were statistically significant; meaning that the chances of LTFU were higher in female caretakers than males.

Healthcare providers were asked what they thought were the factors that led to LTFU care. Table 4.15 shows the reasons that were mentioned.

Table 4.13: Factors likely to influence LTFU HIV exposed infant (n=25)

Factors	Frequency	Percentage
Stigma	8	32.0
Wrong addresses	8	32.0
Relocating	10	40.0
Non-disclosure of results	2	8.0
Long distance to health facility	2	8.0
Two negative PCR results	2	8.0

Table 4.13 shows that 10 (40.0%) of health care providers mentioned that LTFU cases could be due to caretakers relocating, 32% (8) said clients giving wrong addresses, 32% (8) said stigma, 8% (2) mentioned non-disclosure of results, 8% (2) mentioned long distance to the health facility while 8% (2) of health workers mentioned two negative PCR results influence of LTFU.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.0 INTRODUCTION

Follow-up care of PMTCT is one of the important factors in achieving the goal of eMTCT. To meet this goal, there is need for retention and adherence to PMTCT interventions. However, in Lusaka district it has been noted that the effectiveness of these interventions is being negatively influenced by high rates of LTFU HIV exposed infants. Hence, the general objective of this study was to establish the determinants of LTFU HIV exposed infants in the district. This chapter discusses the findings of the study in relation to findings from other study, as well as the implications of the findings on practice. The discussion is based on data collected from 160 caretakers and 23 health care providers randomly sampled from three health centres in Lusaka district. The dependent variable for the study was LTFU, while the independent ones were: knowledge, attitude of health care workers, place of birth, prophylaxis given at birth, and distance and transport to health facilities.

5.1 SOCIO DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

The socio demographic characteristics of the caretakers which were relevant to this study were gender, age, relationship between caretaker and infant, marital status, level of education and occupation (Table 4.1). A total of 160 HIV exposed infants who were LTFU were traced and followed up. More than three quarters (87.8 %) of caretakers who participated in the study were females. Almost half (50.4%) of the caretakers who participated in this study were aged between 30 to 49 years; the results are different from a study conducted by Sidze et al (2015), which indicated that infants born to mothers aged less than 25 years were likely to be LTFU. Another study by Elang, 2015 revealed that younger caretaker and mothers within the maternal ages of 15-24 years were more likely to be LTFU as compared to older maternal ages. In this current study, the 67.9% of the infants' primary caregivers were biological mothers (Table 4.1) and the association between the female gender and LTFU was statistically significant (p-value 0.040). The explanation for this could be that the mothers stopped going for follow up services due to fear and guilt of knowing the status of their children's final test. Another explanation could be on the fact that the Zambian culture is patriarchal (CSO, 2014), therefore mothers may find it hard

to disclose the HIV status of their children to spouses and/or family members. This could be due to fear of consequences such as stigma, discrimination, and gender based violence (GBV) (Paudel and baral, 2015). Kigen et al., (2018) found that, 94% of caretakers in their study were mothers to the HIV exposed infants. This was because they were in denial or ill to honour clinic appointments (Kigen et al., 2018). The finding is in contrast with a study conducted by Saumu (2019) in which grandmothers were the primary caretakers.

Caretakers in this study who were married consisted of 61.8% (Table 4.1). These findings are similar with a study on evaluation of non-adherence to anti-retroviral therapy, the associated factors and infant outcomes among HIV-positive pregnant women: a prospective cohort study in Lesotho (Kadima et al., 2018), which had almost all the participants married or living with a partner. Overall, 51.1% of the caregivers had attained secondary education (Table 4.1). This could be because the study was done in the urban area, where schools are many and located within communities. The information correlated with that of the ZDHS, which stated that secondary attendance level in Zambia for the urban population is at 60% (CSO, 2015). A study entitled the magnitude and factors associated with LTFU among children attending the HIV clinic at Kangundo level four hospital is in agreement, indicating that caretakers with low levels of education were associated with LTFU. In this study 64.1% of the caretakers were employed (Table 4.1). This could be attributed to the fact that most caretakers had attained secondary education; hence they were more likely to be employed. This could imply that caretakers would not have enough time to visit the clinic during working hours. This is in line with the study done by Saumu (2019), which found that children whose caregivers were in informal employment were found to be more likely to be LTFU due to the financial constraints of paying for transport from home. A study by Kadima et al (2018) also found out that employed clients were more likely not to adhere to PMTCT interventions.

5.2 CARETAKERS KNOWLEDGE ABOUT eMTCT

Knowledge levels of caretakers about eMTCT and MTCT is a predisposing factor that may retain infants in the PMTCT follow up care and prevent LTFU. Knowledge affects how clients utilise PMTCT services and changes how they perceive the importance of the interventions put

in place. The association between knowledge levels and LTFU was not statistically significant with a p-value of 0.160. The study showed that 67.9% of caretakers had high knowledge levels (Figure 4.3). This could be because 67.9% of the infants had their biological mothers as primary caretakers (Table 4.1); hence, they could have obtained information about eMTCT from health care providers during their antenatal visits. The finding also suggests that health care providers had the opportunity to interact and emphasise the importance of follow up care. This can help identify clients likely to be LTFU and hence individualise the counselling sessions to retain clients. This finding is consistent with the findings by Dlamini (2015) who revealed that 77.8% of the respondents in their study showed high levels of knowledge on PMTCT. In contrast, the findings of Samson et al., (2018) showed that less of the mothers and caretakers of HIV exposed children had adequate knowledge on PMTCT. Some caretakers (42.2%) had incorrect knowledge about when follow up care stops (Table 4.3). This inadequacy in knowledge maybe attributed to the insufficient counselling sessions by healthcare providers, who were cited to be the main source of information (Table 4.3). Health care providers did not mention counselling as one of the services provided during follow up care. This may not have been an oversight, but an indication that health care providers did not know that counselling was an ongoing process. Health care providers therefore, need continuous mentoring and training to acquire more knowledge and skills.

5.3 PLACE OF BIRTH

In this study the association between place of birth and LTFU was not statistically significant (p-value 0.646). The explanation could be because maternal and child health services in Zambia are free; therefore, women are encouraged to give birth at health facilities. Most of the times women prefer institutional deliveries to home deliveries because of the benefits explained to them during antenatal care. This is in line with a study by Elang, (2015) who reported that the association between place of birth and LTFU was not statistically significant. The conclusion for the study was that mothers who delivered from health facilities were less likely to become LTFU.

5.4 PROPHYLAXIS GIVEN AT BIRTH

In relation to prophylaxis given at birth, 93.1% of infants received prophylaxis for PMTCT. Prophylaxis given at birth was found not to be statistically significantly associated with LTFU (p-value 0.102) (Table 4.11). At the setting where the study was conducted, timely prophylaxis is given to infants during the postnatal period, and thus, caretakers would be motivated to continue with follow up care. This could mean even though caretakers may have perceived their infants safe after receiving prophylaxis, other factors actually influenced LTFU instead. These results are in contrast with the study by Sidze et al (2015) that indicated that infants who did not receive ART prophylaxis for PMTCT were likely to be LTFU.

5.5 DISTANCE TO HEALTH FACILITY

Distance to the health facility can be a barrier in accessing PMTCT services. In this study 80.9% of the caretakers lived within 0-5km from the nearest health facility. However, distance to the health facility was not statistically significant to LTFU (p-value 5.483). Some caretakers did not continue with follow up care even when they stayed within 5kms to the health facility. This would suggest other factors involved in poor health seeking behaviours. A study by Escamilla et al., (2015) found a reduction in the uptake of PMTCT services as the distance between home and clinic increased. Uptake of PMTCT was highest among participants who lived within 1.9 km of a clinic and steadily declined as distance increased (Escamilla et al., 2015). This was consistent with a study done by Tsegaye et al (2016) in which the results revealed that uptake of PMTCT services was affected by travelling long distances because women were getting tired. Another study by Mpinganjira (2020) found that long distance to the health facility was a contributing factor to LTFU.

5.6 TRANSPORT AFFORDABILITY

Transport affordability is an enabling factor that could influence the uptake of PMTCT follow up services. In this study most caretakers (80.9%) could afford transport cost and only 19.7% could not afford transport costs to the health facility. The explanation could be because clinics in the urban district are within 5km distance from places of residence, therefore caretakers mostly walk

to the point of care. A study by Kiirya et al. (2021) indicated that inability to afford transport costs due to the long distances to health facilities was associated with LTFU. Similar findings were found by Nkhonjera et al. (2021) whose findings showed that LTFU was caused by transport costs, mothers found it difficult to afford.

5.7 ATTITUDES OF HEALTH CARE PROVIDERS

The finding in Figure 4 revealed that 51.9% of caregivers mentioned that health care providers showed negative attitude towards them. Attitudes of health care providers can affect utilisation of health services. Negative attitudes by health care providers could be attributed to work overload as evidenced by long queues at the clinics, which demotivated clients. Clinics usually have understaffed health care providers against a large number of patients to attend to. This is in agreement with the study by Saumu (2019) that showed that poor attitude of healthcare workers at the HIV clinic contributed to LTFU. Findings by Nkwabong et al (2018) are also in agreement; 60.7% of health practitioners were found to have negative attitude in the PMTCT of HIV. In addition, Mpinganjira et al (2020) indicated that poor staff attitudes were associated with LTFU. In contrast, the finding is contrary to Dapaah (2016), who found that most health workers had good perceptions of clients and showed positive attitudes and behaviours towards caretakers of infants on PMTCT follow up programmes during interactions. Himaubi (2017) found similar findings; (94.7%) of the respondents felt that health providers at the ART centers were welcoming.

5.8 WAITING TIME

The study revealed that the association between LTFU and waiting time (p-value 0.040) were statistically significant (Table 4.11). The reason could be because the clinic does not start on time as expected; therefore, clients and patients are made to wait longer before being attended to. Another explanation could be that there were too many patients to be attended to by a few health workers. These results are in line with Merga et al. (2016) who revealed that time spent for waiting for the service was high; other clients were actually told to go back the next day after waiting for a long period of time. In another study, mothers pointed out that waiting time was

one of the reasons why they did not return their babies to the facility for follow-up (Ankunda et al., 2020).

5.9 LIMITATIONS OF THE STUDY

The study was conducted in Lusaka Urban Clinics therefore; generalisation of results will have to be done with caution due to contextual difference such as, social and cultural characteristics.

5.10 IMPLICATIONS TO NURSING

5.10.1 Implication to Nursing Administration

The study found that 21.7% of health care providers mentioned that test kits and ART medicines were sometimes out of stock. Despite the percentage of health care providers who said this being small, it is a very important determinant that has negative consequences on HIV positive clients and patients' adherence to treatment. Some health care providers, 30.4% mentioned non availability of airtime to call clients and 8.7% mentioned that there was no transport for use in the follow up of clients. These two determinants are also critical in the running of PMTCT programmes and none availability can lead to negative implications. There was a small percentage (28%) of caretakers who mentioned that they did not take their infants for follow up services because they had forgotten. Thus, availability of airtime and transport would have abated this determinant.

5.10.2 Implication to Nursing Practice

The study showed that 42.2% of caretakers were not aware that they needed to continue with follow up care. Information is an important factor in PMTCT programmes; hence, if this is not done well the results that are expected after implementation of interventions would not be achieved. Health care providers directly involved in implementation of PMTCT services should take it upon themselves to, remind caretakers about review dates. This can be done by sending reminders on time rather than doing so when infants are already LTFU.

5.10.3 Implication to Nursing Research

The results of this study have shown the determinant to LTFU in Lusaka district, which cannot be generalised to other settings. However, due to contextual differences determinants may differ, and these can only be known by conducting similar researches on a bigger scale and in different locations, so that cross-cutting evidence based and sustainable interventions can be implemented to solve the problem.

5.11 CONCLUSION

Change in the attitudes of members of staff from negative to positive and improvement in waiting time can reduce chances of LTFU. Thus, improving the relationship between healthcare providers and caretakers of infants on PMTCT programmes reducing the waiting time for health care services are critical in the averting the LTFU phenomenon. Healthcare providers should come up with an easy appointment scheduling process, such as providing specific appointment times to help reduce waiting time for follow up care clients.

5.12 RECOMMENDATIONS

5.12.1 Recommendation to the Health Care Providers

Support and counselling of caretakers about eMTCT should be an ongoing process and not only on the first visit. Counselling helps identify caretakers at high risk of missing follow-up visits. Identification of such clients would allow targeted counselling and education about the importance of follow-up care and thus, emphasise when to come back for review.

Clinics should come up with easy appointment scheduling processes to help reduce waiting time for follow up care. Each patient should be given a specific time to come for follow up care to avoid long waiting time. This will also help in booking manageable number of clients for a particular day to avoid work overload.

Health care providers should remind caretakers via messages or phones at least two weeks before review date. Facilities should also ensure that community health workers remind and follow up

clients in the community to ensure they do not miss out on their follow up care. This would be very helpful especially to clients without mobile phones.

5.12.2 Recommendations to the DHOs

The study has revealed that majority of health care providers directly involved in implementation of PMTCT services, have only done one training in VCT 25 (100%), PMTCT 24 (96%), and/or breastfeeding 23 (52%). Therefore, there is need for continuous staff development through workshops, staff orientations on PMTCT and Option B+, staff trainings, to impart more knowledge ensuring quality services in PMTCT programmes.

5.12.3 Recommendations to the MoH

There is need for the MoH to continuously impart healthcare providers, with information regarding new recommendations and guidelines. This can be done through training and seminars. By so doing there will be uniformity in the provision of PMTCT services, and health care providers will have adequate information regarding care that they give to patients. Without adequate resources, provision of care is compromised; therefore, it is recommended that the MoH should ensure that all the resources for PMTCT programmes are always adequately available. The MoH should consider strengthening partnership with stakeholders such as NGOs to ensure clients are reminded about review dates via SMS or voice calls at least two days prior the review date.

5.13 PLAN FOR DISSEMINATION OF DATA

Bound copies will be submitted to the UNZA, School of Nursing Sciences, UNZA Medical library, LDHMO and MoH. Results will be disseminated through presentations during meetings as well as national and international conferences, and journal publications.

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APPENDIX 1: PARTICIPANT INFORMATION SHEET

TITLE OF STUDY: DETERMINANTS OF LOSS TO FOLLOW UP HIV EXPOSED INFANTS IN LUSAKA, ZAMBIA

1. SELF INTRODUCTION

My name is Ruth Chemba, a second year student pursuing a Master of Science in Midwifery and Women's Health at the University of Zambia.

2. PURPOSE OF THE STUDY

The purpose of this study is to assess the determinants of loss to follow up HIV exposed infants in Lusaka. The information obtained from the study will help the policy makers and stakeholders to develop strategies that will help in service delivery hence eliminate vertical transmission.

3. STUDY PROCEDURES

The study will use a questionnaire to obtain information. After signing the consent form, a questionnaire will be given to you, and you will be required to write answers to the questions on the questionnaire. If you are unable to do so, the researcher will ask you the questions and your responses will be recorded on the questionnaire on your behalf. The session will take approximately 25-30 minutes.

5. VOLUNTARINESS

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to take part in this study, you will be asked to sign a consent form. After you sign the consent form, you are still free to withdraw at any time and without giving a reason. Withdrawing from this study will not affect your right to utilise health services, nothing will change.

6. CONFIDENTIALITY

Your responses to this study will be anonymous. Every effort will be made by the researcher to preserve your confidentiality by assigning codes instead of indicating the names. The participant

information will be kept confidential and locked at all times, except in cases where the researcher is legally obligated to report specific incidents, but this will be done with confidentiality.

7. BENEFITS

There is no direct benefit for participants, but your participation will ensure exchange of information regarding follow up care. The information that will be obtained is likely to help us find the answer to the research question and enable development of measures that will benefit the future generation.

If you have any questions you may ask them now or later. If you wish to ask questions later, you may contact the following:

PRINCIPAL INVESTIGATOR

Ruth Chemba

The University of Zambia

School of Nursing Sciences

P.O. Box 50110

Lusaka

Mobile No: +26 0977 866898/+26 0966 576905

Email: ruthchemba@gmail.com

CONTACT DETAILS OF ETHICS COMMITTEE

The Chairperson

UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Ridgeway Campus,

P.O. Box 50110

Lusaka, Zambia.

Telephone: 260-1-256067

E-mail: unzarec@unza.zm

APPENDIX 2: INFORMED CONSENT FORM

I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost.

I _____ (Names) agree to take part in this study.

Signed: _____ (Participant’s signature or thumb print)

Date: _____

Signed: _____ (Researcher)

Date: _____

APPENDIX 3: QUESTIONNAIRE FOR CARETAKERS

THE UNIVERSITY OF ZAMBIA

SCHOOL OF NURSING SCIENCES

DATE OF DATA COLLECTION: _____

PLACE OF DATA COLLECTION: _____

NAME OF RESEARCHER: _____

SERIAL NUMBER: _____

INSTRUCTIONS FOR THE RESEACHER

1. Introduce yourself to the participant.
2. Explain the reason for the questionnaire.
3. Assure the participant of confidentiality and anonymity
4. Get written consent from the participant
5. Do not write the name or addresses of the participant on the questionnaire.
6. Ensure that all questions are answered and fill in the most appropriate response to each question in the space provided.
7. Provide time for the participant to ask questions.
8. Thank the participant after collecting data.

INSTRUCTIONS: Please Tick the most appropriate response in the space provider.

SECTION A: SOCIO-DEMOGRAPHIC DATA

HIV-EXPOSED INFANT INFORMATION

1. Sex of HIV-exposed infant

a. Male

b. Female

2. Age

CARETAKER INFORMATION

3. Gender

a. Male

b. Female

4. How old are you (Years)?

a. 18-29

b. 30-39

c. 40-49

d. 50-59

e. 60 and above

5. What is your relationship to the infant?

Specify.....

6. What is your current marital status?

a. Single

b. Cohabiting

c. Married

d. Widowed

e. Divorced/ Separated

7. What is your level of education?

- a. No formal education
- b. Primary
- c. Secondary
- d. Tertiary

8. What is your occupation?

(Specify).....

9. What is your religion?

- a. Christian
- b. Muslim
- c. Other (Specify).....

SECTION B: KNOWLEDGE

10. Are you aware of the existence of mother to child transmission of HIV?

- a. Yes
- b. No

11. Are you aware of prevention of mother to child transmission of HIV?

- a. Yes
- b. No

12. If YES to question 11, where did you get information about prevention of mother to child transmission of HIV?

- a. Health workers
- b. Mass media
- c. School
- d. Social gatherings
- e. Friend/relatives

13. When does mother to child transmission of HIV occur?

- a. During labour and delivery
- b. During breastfeeding
- c. During pregnancy
- e. I do not know

14. How can mother to child transmission of HIV be prevented after birth?

- a. Modified infant feeding
- b. Antiretroviral drugs given to the mother and infant
- d. I do not know

15. Where can one access eMTCT services?

- a. At a health facility
- b. Health workers follow clients to their homes
- c. I do not know

16. Mention two interventions involved in eMTCT care

.....
.....

17. What services are provided during follow up care of HIV exposed infants?

- a. Counselling
- b. Vaccination
- c. HIV testing
- d. Collection of ARVs
- e. Growth monitoring
- f. I don't know

18. When does follow up care begin?

- a. At 6 weeks
- b. When child is sick
- c. When infant stops breastfeeding
- d. I don't know

19. Mention one importance of follow up care for HIV exposed infants?

.....
.....

20. When does an infant exposed to HIV stop going for follow up care?

- a. When first HIV test is negative
- b. When infant stops taking prophylaxis given
- c. When infant stops breastfeeding
- d. I don't know

21. Did any health care provider tell you the importance of follow up care?

- a. Yes
- b. No

22. Give two reasons why the infant discontinued follow up care?

.....
.....

SECTION C: SERVICE RELATED FACTORS

23. How long do you wait before you are attended to by a health care provider on each visit?

- a. 5-10 minutes
- b. 11-20 minutes
- c. 21-30 minutes
- d. More than 30 minutes

24. How do you perceive the reception you receive from health care providers during follow up visits?

- a. Very good
- b. Good
- c. Poor

25. Are health care providers supportive every time you visit?

- a. Yes
- b. No

26. Do health care providers spend enough time with you to explain things on each visit?

- a. Never
- b. Sometimes
- c. Always

27. Do healthcare providers explain things in a way that is easy to understand?

- a. Never
- b. Sometimes
- c. Always

28. Do Health care providers show respect for what you have to say and listen carefully?

- a. Yes
- b. No

SECTION D: PLACE OF BIRTH

29. Where was the infant born?

- a. Government facility
- b. Private facility
- c. Home

SECTION E: PROPHYLAXIS GIVEN

30. Was the child given Nevirapine after birth?

a. Yes

b. No

31. For how long has the infant taken Nevirapine?

a. Adhered to prophylaxis as per schedule

b. Defaulted or never started prophylaxis

SECTION F: HEALTH STATUS OF INFANT/CARETAKER

32. What was the weight of your infant at birth?

a. < 2500g

b. ≥ 2500g

c. I do not know

33. What is the current weight of your infant?

Specify.....

34. Has your infant been hospitalised since birth?

a. Yes

b. No

35. If YES to question 34, state the number of times your infant has been hospitalized.

Specify.....

36. Has the infant received immunisations as recommended?

a. Missed at least one appointment

b. Immunisation as per schedule

37. In general, how would you rate your health?

- a. Very good
- b. Good
- c. Moderate
- d. Bad
- e. Very bad

38. Overall in the last 30 days, have you had difficulties carrying out work or household activities due to physical or emotional conditions?

- a. Yes
- b. No

39. If YES to question 40, how would you rate the difficulty?

- a. Mild
- b. Moderate
- c. Severe
- d. Extreme/cannot do

SECTION G: DISTANCE TO HEALTH FACILITY

40. How far is the health facility from your home?

- a. Less than 5kms
- b. More than 5kms

41. If you live more than 5km, what mode of transport do you use to travel to the health facility?

- a. By foot
- b. Bicycle
- c. Public transport
- d. Other, Specify.....

42. If you go by foot to the health facility, how long does it take you to reach?

- a. Less than 30 minutes
- b. 30 minutes to 1 hour
- c. 1 hour 30 minutes to 2 hours
- d. More than 2 hours

SECTION H: TRANSPORT AFFORDABILITY

43. If it is by public transport, what is the cost of travelling to the health facility per visit?

Specify K.....

44. Are you able to afford transport cost to health facility on each visit?

- a. Yes
- b. No

45. Who provides this money?

- a. Self
- b. others, specify.....

APPENDIX 4: SELF ADMINISTERED QUESTIONNAIRE FOR HEALTH WORKERS

THE UNIVERSITY OF ZAMBIA

SCHOOL OF NURSING SCIENCES

DATE OF DATA COLLECTION: _____

PLACE OF DATA COLLECTION: _____

PROFESSION: _____

SERIAL NUMBER: _____

INSTRUCTIONS TO THE RESEARCHER

1. Introduce yourself to the participant.
2. Explain the reason for the questionnaire.
3. Assure the participant of confidentiality and anonymity
4. Get written consent from the participant
5. Tell not to write their name or address on the questionnaire.
6. Ensure that all questions are answered or filled in
7. Provide time for the participant to ask questions.
8. Thank the participant after collecting data.

Please tick the most appropriate response/s in the space provided.

1. Gender

a. Male

b. Female

2. Professional Qualification.....

3. How long have you worked in this Department?

4. Which of the following HIV related trainings have you done? (Please tick)

a. VCT

b. PMTCT

c. BREASTFEEDING

d. NONE OF THE ABOVE

5. Any other training not mentioned above?

Specify.....

6. When does follow up care of HIV exposed infants begin?

a. Immediately after birth

b. when infant tests HIV positive

c. At 6 weeks

d. At 6 months

Any other (specify).....

7. Mention two services offered during follow up care of HIV exposed infants?

.....
.....

8. On average, how much time do caretakers spend at the health facility during follow up visits?

- a. less than 30 minutes
- b. 30 minutes – 1 hour
- c. 1 hour 30 minutes – 2 hours
- d. More than 2 hours

9. From your experience, does the Department have all the logistics in place for follow up care?

- a. Yes
- b. No

10. If the answer to question nine (9) above is NO, mention two things not readily available for smooth running of follow up visits?

.....
.....

11. In your opinion list two factors /reasons that lead to HIV exposed infants being lost to follow up?

.....
.....

APPENDIX 5: NYANJA PARTICIPANT INFORMATION SHEET

ZA MUNTHU OCHITA KAFUKU-FUKU

MUTU WA PHUNZIRO LIMENELI

ZIZINDIKIRO ZOMWE ZILIPO PA KULEPHERA KULONDOLA ANA OMWE ALI NDI KALOMBO KA HIV MU MZINDA WA LUSAKA, ZAMBIA

1. ZA INU

Dzina langa ndine Ruth Chemba, mphunzi yemwe ali mchaka chachiwiri kuchita maphunziro ya ukachenjede mu unamwino pa sukulu la University of Zambia.

2. CHOLINGA CHA PHUNZIRO LIMENERI

Cholinga cha phunziroli ndi kuunguza pa zizindikiro zomwe zimalondola pa ana omwe ali ndi kalombo ka HIV mu mzinda wa Lusaka. Uthenga umeneu omwe udzatengedwa udzathandiza anthu opanga malamulo ndi ena onse okhudzidwa kupanga ndondomeko zoyenera zomwe zidzathandiza kaperekedwe ka zinchito za umoyo zomwe zidzachepetsa kufalikira kwa matenda.

3. NDONDOMEKO YA PHUNZIRO

Phunziroli lidzagwiritsa nchito pepala la mafunso kutenga uthenga ofunikira. Pambuyo posaina pepala lobvomera kutengako mbali, pepala la mafunso lidzapatsidwa kwa inu, mudzafunika kuti mulembe mayankho ya mafunso yomwe yali mu pepala la mafunso. Ngati simungakwanitse kuchita tero, munthu ochita kafuku-fuku adzakufunsani mafunso ndipo mayankho yanu yadzalembedwa pa pepala la mafunso m'malo mwanu. Chigawo chimenechi chidzatenga nthawi yokwanira mphindi 25 kapena 30.

5. KUDZIPEREKA

Kutengako mbali kwanu mu phunziroli ndi kodzipereka. Chili kuli inu kuganiza kuti mutengeko mbali kapena ai. Ngati mwaganiza kuti mutengeko mbali, mudzapemphedwa kuti musaine pepala loonetsa kuti mwabvomera kutengako mbali. Pambuyo posaina pepalalo, ndinu omasuka kuleka kutengako mbali pa phunziroli popanda kupereka zifukwa zina zilizonse. Kuleka kwanu kutengako mbali sikudzakhudza danga lanu lolandira zinchito za umoyo, palibe chomwe chidzasintha.

6. CHISINSI

Mayankho yanu yomwe mudzapereka mu phunziroli yadzakhala yachisinsi. Ochita kafuku-fuku adzayesetsa kusunga chisinsi chanu maka pogwiritsa nchito njira ina yapadela osati dzina lanu yai. Zilizonse zokhudza inu otengako mbali zidzasungidwa mwachisinsi komanso

zokhomeledwa nthawi zonse, pokhapo ngati munthu ochita kafuku-fuku ndi oloedwa kufotokoza pa zinthu zina zapadera, komanso zimenezi zidzachitidwa mwachisinsi.

7. PHINDU

Palibe phindu lomwe lidzaperekedwa kwa munthu otengako mbali, koma kugwapo kwanu kudzathandiza maka pa chisamaliro cholondolapo. Uthenga omwe udzatengedwa ungathandize kupeza yankho pa funso la phunziroli ndipo chidzathandiza kupeza njira zatsopano zomwe zidzathandizanso mbadwo wakutsogolo.

Ngati muli ndi mafunso ena alionse mungafunse tsopano kapena mtsogolomu. Ngati mufuna kufunsa funso kutsogolo, mungalembere kapena kutuma lamya kwa anthu awa:

PRINCIPAL INVESTIGATOR

Ruth Chemba

The University of Zambia

School of Nursing Sciences

P.O. Box 50110

Lusaka Mobile No: +26 0977 866898/ +26 0966 576905

Email: ruthchemba@gmail.com

CONTACT DETAILS OF ETHICS COMMITTEE

The Chairperson

University of Zambia

Biomedical research ethics committee

Ridgeway Campus

P.O. Box 50110

Lusaka, Zambia

Telephone: 260-1-256067

E-mail: unzarec@unza.zm

APPENDIX 6: NYANJA CONSENT FORM

PEPALA LA KUBVOMERA

Ndawerenga ndipo namvetsa uthenga omwe waperekedwa ndipo ndinapatsidwa umwai ofunsa mafunso. Ndamvetsa kuti kugwapo kwanga pa phunziro limeneli ndi kwaulele ndiponso kodzipereka komanso ndine omasuka kuleka kutengako mbali pa nthawi ina iliyonse, popanda kupereka zifukwa zina zilizonse kapena kulipira ndalama iliyonse.

Ine _____ (Maina) nabvomera kutengako mbali mu phunziro limeneli.

Signed: _____ (Siginecha ya otengako mbali kapena kufwatika)

Tsiku: _____

Signed: _____ (Ochita kafuku-fuku)

Tsiku: _____

APPENDIX 7: NYANJA QUESTIONNAIRE

CHIDA CHOTENGERA UTHENGA

THE UNIVERSITY OF ZAMBIA

SCHOOL OF NURSING SCIENCES

PEPALA LA MAFUNSO OPANGIDWA KALE

TSIKU LOFUNSIRA MAFUNSO: _____

MALO OFUNSIRAKO MAFUNSO: _____

DZINA LA OFUNSA MAFUNSO: _____

SERIAL NUMBER: _____

MALAMULO KWA OFUNSA MAFUNSO

1. Muuzeni otengako mbali kuti ndinu yani.
2. Masulirani chifukwa chomwe mugwiritsira nchito pepala la mafunso.
3. Muwatsimikizire kuti mudzawasungira chisinsi komanso dzina lao silidzachulidwa
4. Tengani pepala lobvomera kuti ndi okonzeka kutengako mbali lolembedwa
5. Osalemba dzina kapena malo yomwe achokera pa pepala la mafunso.
6. Onetsetsani kuti mafunso onse ayankhidwa ndipo lembani mayankho oyenera pa malo omwe aperekedwa mkati mwa pepala la mafunso.
7. Perekani mpata kwa otengako mbali kuti afunse mafunso.
8. Muwayamikire otengako mbali.

CHIGAWO A: UTHENGA WA CHIKHALIDWE

UTHENGA WA MWANA YEMWE ALI NDI KALOMBO KA HIV

1. Chibadwidwe cha mwana ali ndi kalombo

a. Mwamuna

b. Mkazi

2. Zaka

Tchulani

UTHENGA WA MAKOLO/ OMUSAMALIRA

3. Chibadwidwe

a. Mwamuna

b. Mkazi

4. Muli ndi zaka zingati?

a. 20-29

b. 30-39

c. 40-49

d. 50-59

e. Zopitirira pa 60

5. Ubale wanu ndi otani kuli mwana?

Tchulani.....

6. Kodi muli ndi banja kapena ai?

a. Osakwatira

b. Ndili ndi chibwenzi

c. Okwatira

d. Ofedwa

e. Olekedwa/opatukana

7. Kodi muyeso wanu wa maphunziro ndi otani?
- a. Ndine osaphunzira
 - b. Primary
 - c. Secondary
 - d. Maphunziro a pamwamba
8. Mugwira nchito yanji?
- a. Ogwira nchito m'boma
 - b. Ndigwira nchito yanga/zamalonda
 - c. Opuma pa nchito
 - d. Lova
 - e. Ndili pa sukulu palipano
9. Ndinu a chipembedzo chanji?
- a. Mkhristu
 - b. Msilamu
 - c. Zina (Tchulani).....

CHIGAWO B: CHIDZIWITSO PA EMTCT

10. Kodi mudziwa kuti kuyambukira kwa kalombo ka HIV kuchoka kwa amai kupita kwa mwana kumachitika?
- a. Inde
 - b. Ai
11. Kodi mudziwa kuti kuteteza kuyambukira kwa kalombo ka HIV kuchoka kwa amai kupita ku mwana kumachitika?
- a.Inde
 - b. Ai

12. Kodi mutenga kuti uthenga wa kuyambukira kwa kalombo ka HIV kuchoka kwa amai kupita ku mwana?

- a. Kwa ogwira nchito kuchipatala
- b. Ku manyumba ofalitsa nkhani
- c. Kusukulu
- d. M'misonkhano
- e. Abwenzi ndi abale

13. Kodi kuyambukira kwa kalombo ka HIV kuchoka kwa amai kupita ku mwana kumachitika nthawi yanji?

- a. Pa nthawi yobeleva
- b. Poyamwitsa
- c. Pa nthawi ya pathupi
- d. Zitsulo zakuthwa
- e. Sinidziwa

14. Kodi kuyambukira kwa kalombo ka HIV kungatetezedwe motani pambuyo pobeleva mwana?

- a. Kupeza njira zina zodyetseramo mwana
- b. Mankhwala ya ARV kuperekedwa kwa mwana ndi amake
- c. Kusagawana zida kapena zitsulo zakuthwa
- d. Sinidziwa

15. Kodi munthu angafikire pati mutumiki a eMTCT

- a. kuchipatala
- b. Ogwira ntchito yazaumoyo amatsatira odwala kupita kunyumba zawo
- c. Sinidziwa

16. Tchulani njira ziwiri zomwe zikuthandizira chisamaliro cha eMTCT

.....
.....

17. Ndi zinchito zotani zomwe zimaperekedwa pa chisamaliro chotsatira cha kalombo ka HIV?

- a. Uphungu
- b. Katemela
- c. Kuyeza za kalombo ka HIV
- d. Kutenga mankhwala ya ma ARVs
- e. Kuona pa kakulidwe ka mwana
- f. Sinidziwa

18. Kodi chisamaliro chotsatira chiyamba liti?

- a. Pakapita masabata 6
- b. Ngati mwana wadwala
- c. Ngati mwana waleka kuyamwa
- d. Sinidziwa

19. Kodi ubwino wa chisamaliro chotsatira ku mwana yemwe ali ndi kalombo ka HIV ndi otani?

.....

20. Kodi ndi pa nthawi yotani yomwe mwana ayenera kuleka kupita ku chisamaliro chotsatira?

- a. Ngati wapezeka kuti alibe kalombo ka HIV koyamba
- b. Ngati mwana waleka kulandira mankhwala omuteteza omwe anapatsidwa
- c. Ngati mwana waleka kuyamwa
- d. Sinidziwa

21. Wopereka chithandizo chaumoyo wina aliyense adakuwuzani kufunikira kotsatira chisamaliro

- a. Inde
- b. ayi

22. Kodi ndi zifukwa zotani zomwe zinapangitsa kuti mwana asapitirize ndi chisamaliro chotsatira?

.....
.....

CHIGAWO C: MAGANIZO

23. Mukudikirira nthawi yayitali musanachitike kwa oyamanira azaumoyo paulendo uliwonse

- a. 5-10mphindi
- b. 11-20mphindi
- c. 21-30mphindi
- d. Kupitirira mphindi 30

24. Mumaona bwanji kabuomeledwe ka anchito amuchipatala kulimwe anthu amatenda yanu

- a. Zabwino kambiri
- b. zabwino
- c. osauka

25. Kodi othandizira azaumoyo amathandizira nthawi iliyonse mukapita

- a. Inde
- b. ayi

26. Othandizira azaumoyo amafotokozera zinthu m'njira yosavuta kumva

- a. ayi
- b. Nthawi zina
- c. Nthawi zones

27. othandizira azaumoyo amakhala ndi nthawi yokwanira yologosolera zinthu pakamchezera kalikonse

a. ayi

b. Nthawi zina

c. Nthawi zones

28. Othandizira azaumoyo amalemekeza zomwe mukununa komanso mverani mosamala

a. Inde

b. ayi

CHIGAWO D: KOMWE MWANA ANABADWIRA

29. Kodi mwana anabadwira kuti?

a. Chipatala cha boma

b. Chipatala cha munthu wamba

c. Kunyumba

CHIGAWO E: MANKHWALA OTETEZA OMWE ANAPATSIDWA

30. Kodi mwana anapatsidwa Neverapine atabadwa?

a. Inde

b. Ai

31. Kodi mwanayu wakhala alikumwa Neverapine kwa nthawi yotani?

a. Kodi mwakhala mukulondola nthawi yomupatsiramo mankhwala mwana

b. Kodi munaleka kapena simunayambe kumupatsa mankhwala

CHIGAWO F: THANZI LA MWANA/OMUSUNGA

32. Kodi pobadwa mwana wanu analemela motani?

a. < 2500g

b. ≥ 2500g

c. Sinidziwa

33. Nanga palipano alemela motani?

Tchulani.....

34. Kodi mwana wanu anakhalako mchipatala ngakhale kamodzi kokha momwe anabadwira?

a. Inde

b. Ai

35. Ngati mwayankha funso 26, nenani kuchuluka kwa yombwe mwana wanu wagonekedwa m'chipatala

Tchulani.....

36. Kodi mwana wanu analandira katemela onse monga mwa lamulo?

a. Anaphonyako kamodzi

b. Analandira molondola ndondomeko yonse

37. Mwa zonse, munganene kuti thanzi lanu ndi lotani?

a. Ili bwino kwambiri

b. Ili bwino

c. Ili pakati-kati

d. Sili bwino

e. Ndiloipa kwambiri

38. Pa masiku 30 (miyezi imozi) yapita, mwakhala obvutika motani kugwira nchito kapena zinchito za panyumba chifukwa cha kufoka kwa thanzi lanu?

a.Inde

b.ayi

39. Ngati mungafunse 40 mungadziwe bwanji zovuta

a. Pang'ono

b. Pakati-kati

c. Kubvutika kwambiri

d. Kubvutika kwambiri/ sinikwanitsa

CHIGAWO G: MTUNDA OFIKA KU CHIPATALA

40. Kodi chipatala chili kutali motani kuchoka ku nyumba yanu?

a. Mtunda ochepekera pa 5kms

b. Mtunda opitirira pa 5kms

41. Ngati mukhala pa mtunda opyola pa 5km, mumayenda motani kufika ku chipatala?

a. Ndi mendo

b. Pa njinga

c. Magalimoto ya matola

d. Ena, Tchulani.....

42. Ngati mwayenda ndi mendo, mumatenga nthawi yotani kuti mufike ku chipatala?

a. Mphindi 30 kapena ola limodzi

b. Ola limodzi ndi mphindi 30 kapena maola awiri

c. Maola opitilira awiri

d. Zopitilira maola awiri

CHIGAWO H: MAYENDEDEWE

43. Ngati mugwiritsa nchito magalimoto yamatola, mumalipira ndalama zingati kufika ku chipatala?

Tchulani K.....

44. Kodi mumatha kulipira ndalama zoyendera kupita ku chipatala mukamachezera chilichonse

a. Inde

b. ayi

45. Ndani amakupatsani ndalama zimenezi?

a. Ndimazipezera ndekha

b. Ena (Tchulani).....

APPENDIX 8: BUDGET

BUDGET CATEGORY	UNIT COST(ZMK)	QUANTITY	TOTAL
1. REQUIREMENTS			
a) Bond paper	30.00	10	300.00
b) Pens	2.50	10	25
c) Pencils	2.50	4	10
d) Rubbers	5.00	2	10
e) Note book	8.00	2	16
f) Tippex	12.00	2	24
g) Bag for questionnaires	150.00	1	150
h) Stapler	25.00	1	25
i) Staples	15.00	1 Box	15
j) Plastic folder for field work	15	5	75
SUBTOTAL			650
2. PERSONNEL			
a) Lunch allowance Principal researcher	25.00	1 x 60 days	1,500.00
b) Refreshment	10	10 x 160	1,600.00
c)Transport for caretakers	30	30 x 131	3,930.00
			1,030.00
SUBTOTAL			7,030.00
3. SERVICES			
a) Ethics committee	1, 000.00	1	1,000.00
b) Data entry	500.00	1	500.00
c) Data analysis	1, 000.00	1	1,000.00
d) Photocopying proposal	1	100	100.00
e) Photocopying questionnaire	1	160 x 15 pages	1,200.00
f) Photocopying report	1	100x4	200.00
g) Binding	50.00	4 copies	200.00
SUBTOTAL			4,200.00
TOTAL			11,880.00
CONTIGENCY FUND10%			1,188.00
GRAND TOTAL			13,068.00

JUSTIFICATION OF THE BUDGET

STATIONERY

1. Reams of bond paper were required for the following activities:

- writing the research proposal
- Making extra copies of the research proposal for submission to the Research Ethics Committee and the Board of Graduate Studies
- Photocopying questionnaires
- Writing and printing the final report

2. The bag was required for carrying and keeping the questionnaires to ensure that they are kept safe.

3. Other accessories such as pens, pencils, rubbers stapler and staples and notes were required for the routine collection of research data.

PERSONNEL

Lunch allowances were needed because the researcher was collecting data throughout the day.

SECRETARIAL SERVICES

Funds were needed for photocopying, and binding the proposal and the report. One copy was printed and thereafter, several photocopies were be made.

CONTIGENCY

Contingency fund which was 10% of the budget, for any extra costs due to inflation and for any eventualities.

APPENDIX 9: GHANT CHART

	ACTIVITY	APR 2020	MAY 2020	JUN 2020	JULY 2020	AUG 2020	SEP 2020	OCT 2020	AUG 2020	SEP 2020	OCT 2020	NOV 2020	DEC 2020
1	Development of research proposal												
2	Presentation of research proposal to the school of nursing sciences.												
3	Submission to Research Ethics committee for approval												
4	Obtaining consent from Research Ethics Committee.												
5	Briefing Lusaka DHMT and District Development Coordinating committee												
6	Pre-test and reviewing data collection tools												
7	Data collection												
8	Data analysis												
9	Report writing												
10	Submission of final report												
11	Dissemination of final report												

NATIONAL HEALTH RESEARCH AUTHORITY



Paediatric Centre of Excellence, University Teaching Hospital, P.O. Box 30075, LUSAKA

Tell: +260211 250309 | Email: znhrasec@gmail.com | www.nhra.org.zm

Ref No.....

Date: 26th August, 2019

The Principal Investigator
Ms. Ruth Chemba University of Zambia
School of Nursing Sciences PO Box 50110,
LUSAKA

Dear Ms. Chemba,

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **“Determinants of Loss to Follow up HIV Exposed Infants in Lusaka, Zambia.”** I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,

**Dr. Godfrey Biemba Director/CEO
National Health Research Authority**

All correspondences should be addressed to the Director/CEO National Health Research Authority

APPENDIX 11: ETHICS CLEARANCE