

**KNOWLEDGE ON MOTHER-TO-CHILD TRANSMISSION OF HIV AND PRACTICES
OF INFANT FEEDING AMONG HIV-INFECTED MOTHERS ATTENDING
ANTIRETROVIRAL THERAPY CENTERS IN JUBA, SOUTH SUDAN**

LILY LEJENG LEWAI NAGIB

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DECLARATION OF ORIGINALITY

Name of student: LILY LEJENG LEWAI NAGIB

Registration Number: H57/76374/2014

College: HEALTH SCIENCES

Faculty: PUBLIC HEALTH

Department: PUBLIC HEALTH

Course: MASTER OF PUBLIC HEALTH

Title of Research work: KNOWLEDGE ON MOTHER-TO-CHILD TRANSMISSION OF HIV AND PRACTICES OF INFANT FEEDING AMONG HIV-INFECTED MOTHERS ATTENDING ANTIRETROVIRAL THERAPY CENTERS IN JUBA, SOUTH SUDAN

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Date _____

SUPERVISORS

This Research Dissertation has been submitted for examination with our full approval as university supervisors:

Dr. Rose Okoyo Opiyo (PhD, MSc, BEd)

School of Public Health,
College of Health Sciences,
University of Nairobi

Signed:

Date:

Prof. Joyce Olenja (PhD, MPhil, BEd)

School of Public Health,
College of Health Sciences,
University of Nairobi

Signed:

Date:

DIRECTOR

Prof. Mutuku A. Mwanthi (PhD, MSEH, BSc)

School of Public Health,
College of Health Sciences,
University of Nairobi

Signed:

Date:

DEDICATION

I dedicate this book to my role model, my mother, Hellen Ikuse Samuel, you are truly inspirational.

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ABSTRACT

Background

Exclusive breastfeeding for the first six months of infant's life is recommended for HIV-infected mothers. Formula feeding which is the best alternative to breastfeeding may not be practical in the Republic of South Sudan.

Objectives

This study sought to assess knowledge on mother-to-child transmission of HIV and practices of infant feeding 0-6 months among HIV-infected mothers attending the Antiretroviral Therapy Centers in Juba, South Sudan.

Methodology

This was a cross-sectional study in which 304 HIV-infected mothers with children aged 6-18 months were interviewed between October and December 2016 using structured questionnaires. Key informant interviews and focus group discussions were also conducted. Quantitative data was analyzed using Statistics Package for Social Sciences software and descriptive statistics were presented in frequency tables and graphs. Chi-square test was used to test the presence of significant association between the variables, and multiple logistic regression analysis was used to identify which predictor variables have major effect on the dependent variable. Qualitative data from key informant interviews and focus group discussions was analyzed manually and the information obtained was used to supplement and interpret the findings of the quantitative data.

Study findings

Of the 304 HIV-infected mothers, 42.4% of them were aged between 20 to 29 years and 39.5% were aged between 30 to 39 years with mean age of 29.7 years. Half of the mothers were married

and 52.3% had three or more children. The highest level of formal education attained by majority of the mothers (54.6%) was primary level. Most of the mothers (52.6%) were the breadwinners in their families, and 95.4% of them earned less than 50 US dollars per month.

Only 40% of the HIV-infected mothers had good knowledge on mother-to-child transmission of HIV. Majority of the mothers (70.1%) practiced mixed feeding, 23.0% of them practiced exclusive breastfeeding, while 6.6% of them practiced exclusive formula feeding.

The factors that were found to have significant effect on choice of infant feeding methods were: number of children (odds ratio = 0.303, 95% Confidence interval: 0.161-0.571, $p = 0.001$); religion (odds ratio = 5.488, 95% Confidence interval: 1.590-18.944, $p = 0.007$); and mothers' participation in prevention of mother-to-child transmission of HIV program (odds ratio = 2.260, 95% Confidence interval: 1.251-4.084, $p = 0.007$). There was no relationship between maternal level of knowledge on mother-to-child transmission of HIV and their infant feeding practices (chi-square at 3 degree of freedom = 6.995, $p = 0.072$).

Conclusions and Recommendations

Knowledge on mother-to-child transmission of HIV, its prevention and infant feeding options in the context of HIV is low. However, maternal level of knowledge does not affect their infant feeding practices. Mixed feeding before six months of age is predominant among the HIV-infected mothers attending the antiretroviral therapy centers in Juba.

It is therefore recommended that the HIV-infected mothers should receive adequate information from the counselors regarding mother-to-child transmission of HIV, and exclusive breastfeeding in the first six months of infant's life should be promoted among them with emphasis on continuation of breastfeeding for at least one year or beyond to increase child survival.

ABBREVIATIONS

AFASS - Affordable, Feasible, Acceptable, Sustainable, and Safe

AIDS - Acquired immune deficiency syndrome

ANC - Antenatal care

ARV - Antiretroviral drug

ART - Antiretroviral therapy

B - Regression coefficient

CI - Confidence interval

df - Degree of freedom

EBF - Exclusive breastfeeding

EFF - Exclusive formula feeding

Exp (B) - Exponentiation of the B coefficient

ERC - Ethics and Research Committee

FGD - Focus group discussion

HIV - Human immunodeficiency virus

JMH - Juba Military Hospital

JTH - Juba Teaching Hospital

KII - Key informant interview

MOH - Ministry of Health

MTCT - Mother-to-child transmission of HIV

OR - Odds ratio

P - Probability value

PMTCT - Prevention of mother-to-child transmission of HIV

ROSS - Republic of South Sudan

SE - Standard error

Sig - Significance level

SPSS - Statistics Package for Social Sciences

STI - Sexually transmitted infection

UNAIDS - United Nations Program on HIV and AIDS

UNFPA - United Nations Population Fund

UNICEF - United Nations Children's Fund

VCT - Voluntary Counselling and Testing

WHO - World Health Organization

χ^2 - Chi square

DEFINITIONS OF OPERATIONAL TERMS

Appropriate infant feeding options - According to WHO, UNICEF, UNAIDS, and UNFPA guidelines on HIV and infant feeding, appropriate infant feeding options are those that have no or low risk of HIV transmission from an infected mother to her infant. In this study, these refer to exclusive breastfeeding for the first six months of life, and commercial infant formula milk if it is acceptable, feasible, affordable, sustainable and safe (WHO, 2010).

Commercial infant formula milk - According to WHO and UNAIDS, this refers to a breast milk substitute formulated industrially in accordance with applicable Codex Alimentarius standards to satisfy nutritional requirements of infants up to six months of age (WHO and UNAIDS, 1998).

Exclusive breastfeeding - According to WHO and UNICEF, exclusive breastfeeding is defined as giving an infant no other food or drink (not even water) except breast milk (including milk expressed or from a wet nurse) for the first six months of life, but allows the infant to receive oral rehydration solution and drops or syrups of vitamins, mineral supplements and medicines (WHO and UNICEF, 2016).

Exclusive formula feeding/replacement feeding - According to WHO, this refers to feeding an infant during its first six months of life on commercial infant formula milk only if it is acceptable, feasible, affordable, sustainable and safe (AFASS) (WHO, 2010).

Inappropriate infant feeding options - According to WHO, UNICEF, UNAIDS, and UNFPA guidelines on HIV and infant feeding, inappropriate infant feeding options are those that have high risk of HIV transmission from an infected mother to her infant, and those that do not provide adequate nutrients to the infant. In this study, these refer to mixed feeding, and home-modified animal milk (WHO, 2010).

Infant - According to WHO and UNAIDS, it refers to a child from birth to 12 months of age (WHO and UNAIDS, 1998).

Level of Knowledge - In this study, this refers to a measure of how much the HIV-infected mothers know about mother-to-child transmission of HIV, risk factors associated with HIV transmission through breastfeeding, breast milk alternatives, and, prevention of mother-to-child transmission of HIV based on a scoring system adopted from the Stanford Institute for Research in the Social Sciences (Stanford University, 2007) as used in a related study conducted in Kiambu, Kenya (Mwangi, 2012).

Mixed feeding - According to WHO and UNICEF, mixed feeding refers to the practice of giving other liquids and/or foods together with breast milk to infants under six months of age (WHO and UNICEF, 2016).

CHAPTER 1.0 INTRODUCTION

1.1 Background

Mother-to-child transmission of human immunodeficiency virus (HIV) accounts for more than 90% of HIV infection in children around the world (UNAIDS, 2012). The transmission may occur during pregnancy, labor and delivery or after birth through breastfeeding. It has been observed that without treatment, around 15%-30% of children born to HIV- infected women will become infected with HIV during pregnancy and delivery. A further 5%-20% becomes infected through breastfeeding (De Cock *et al.*, 2000). The overall risk of mother-to-child transmission of HIV (MTCT) without breastfeeding is 15%-25%, and 30%-45% with extended breastfeeding up to two years (De Cock *et al.*, 2000). Several factors affect the risk of HIV transmission including high maternal viral load or amount of virus in the mother's blood and low CD4 count independent of viral load (Tindyebwa *et al.*, 2011). Untreated sexually transmitted infections during pregnancy, rupture of membranes for more than 4 hours during labor, episiotomy and instrumental delivery increase the risk of HIV transmission (Tindyebwa *et al.*, 2011). Risk factors associated with HIV transmission through breastfeeding include mixed feeding (Coovadia *et al.*, 2007), duration of breastfeeding (De Cock *et al.*, 2000), thrush or sores in baby's mouth and conditions of the breasts(mastitis, breast abscesses) and nipples fissures (Ngacha *et al.*, 2005; Rollins *et al.*, 2004; WHO, 2004).

In 2000, the World Health Organization (WHO) recommended avoidance of breastfeeding by HIV-infected mothers when replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS). Otherwise, exclusive breastfeeding is recommended during the first months of baby's life and discontinue as soon as AFASS replacement feeding becomes practical. Later, new

evidence revealed that exclusive breastfeeding carries a lower risk of HIV transmission compared to mixed feeding (WHO, 2006). In 2006, WHO revised the previous guidelines and recommended HIV-infected mothers to exclusively breastfeed for the first 6 months unless replacement feeding is AFASS. At 6 months, to continue breastfeeding with additional complementary food if replacement feeding is not met (WHO, 2006). Where breastfeeding is judged to be the best option, the 2010 WHO revised guidelines recommended HIV-infected mothers to exclusively breastfeed for the first 6 months and continue breastfeeding until 12 months of age while providing prophylactic antiretroviral (ARV) drugs to either mother or infant and wean gradually within 1 month after age one. When the infant is HIV-infected, mothers are strongly encouraged to exclusively breastfeed for the first six months of life and continue breastfeeding as per the recommendations for the general population, which is up to two years or beyond (WHO, 2010). In 2016, WHO and UNICEF revised the 2010 guidelines and recommended that mothers living with HIV should breastfeed for at least 12 months and can continue breastfeeding for up to 24 months or beyond as for general population while being fully supported for ART adherence (WHO and UNICEF, 2016).

In developed countries, rates of mother-to-child transmission of HIV (MTCT) has fallen to as low as 2% due to the introduction of routine HIV testing among antenatal mothers, the provision of antiretroviral drugs, elective caesarean delivery, and safe infant feeding practices (Lynne and James, 2000).

1.2 Statement of the research problem

According to the WHO and United Nations Program on HIV and AIDS (UNAIDS) estimates, there were 36.7 million people living with HIV worldwide in 2016. Of these, 2.1 million were

children (below 15 years of age). UNAIDS also estimated that as of 2016, 1.8 million individuals became newly infected with HIV worldwide. These included 160,000 children (under 15 years old). Most of the newly-infected children live in Sub-Saharan Africa and were infected by their HIV-infected mothers during pregnancy, childbirth or breastfeeding (UNAIDS, 2016). The vast majority of people living with HIV are in low and middle-income countries. According to UNAIDS, East and Southern Africa is the most affected region, with 19.4 million people living with HIV as of 2016, almost half of all people living with HIV in the world live in this region. 790,000 new infections occurred in East and Southern Africa in 2016 (UNAIDS, 2016). In 2016, HIV-related deaths were 1.0 million worldwide, these included 120,000 children. 420,000 deaths were from the East and Southern Africa region (UNAIDS, 2016).

According to South Sudan Antenatal Care Clinics Sentinel Surveillance Report, the Republic of South Sudan had an estimated national HIV prevalence of 2.66% in 2012 compared to 3.0% in 2009 (Jervase, 2011). As of 2016, an estimated 200,000 people in the Republic of South Sudan were living with HIV, new infections were 16,000 and HIV-related deaths were 13,000 (UNAIDS, 2016).

In 2010, the World Health Organization recommended HIV-infected mothers to exclusively breastfeed their infants in the first six months of life, or to avoid breastfeeding altogether when formula feeding is acceptable, feasible, affordable, sustainable, and safe (AFASS). Exclusive breastfeeding in the first six months of an infant's life was found to be associated with a 3-4 fold decreased risk of HIV transmission compared to infants who were breastfed and also received other milks or foods (Smith and Kuhn, 2000). Exclusive formula feeding has no risk of postnatal HIV transmission (WHO, 2004). Mixed feeding, which is the practice of giving other liquids and/or foods together with breast milk to infants under six months of age has been associated with

a higher risk of HIV infection for the infant than exclusive breastfeeding (Coovadia *et al.*, 2007; Coutsooudis *et al.*, 2001). Studies have found gap in knowledge of infant feeding options among HIV-infected mothers which was attributed to a gap in counseling in PMTCT programs (Laar and Govendor, 2012; Chopra and Rollins, 2008).

Safe infant feeding practices was found to be limited in Juba in 2014 (Ojuku *et al.*, 2014), and with the high level of poverty and health system challenges in the Republic of South Sudan, formula feeding, which is the best alternative to breastfeeding, may not be practical.

1.3 Justification

Republic of South Sudan is the newest country in Africa, and is currently recovering from over four decades of civil war. Given the long period of under-development, the country faces major challenges ranging from establishing peace and stability, developing infrastructure, management of massive population movements and displacement, ensuring food security, human resource development, establishing and building governance structures and systems, provision of education, delivery of health and HIV/AIDS services as well as water and sanitation services (SSNHSP, 2013). With the high level of poverty and health system challenges in the Republic of South Sudan, some measures like formula feeding which is the best alternative to breastfeeding may not be practical. Improved adherence to exclusive breastfeeding in the first six months of infant's life can be attained if factors influencing choice of infant feeding options among the HIV-infected mothers were identified and appropriate actions were taken to increase utilization of PMTCT services.

Although many studies were conducted on knowledge on MTCT and practices of infant feeding in Africa, little information is available in the Republic of South Sudan. This study therefore sought to assess knowledge on MTCT and practices of infant feeding 0-6 months among HIV-infected mothers attending the ART centers in Juba, and to identify the factors that influence choice of

infant feeding options among the HIV-infected mothers, while establishing the relationship between level of knowledge on MTCT and infant feeding practices of the HIV-infected mothers.

The findings of this study will provide information to the health authorities and health practitioners on the practice of exclusive breastfeeding in the PMTCT programs in Juba, South Sudan. It will also help in evaluation of adequacy of the current infant feeding counseling in the context of HIV.

1.4 Research questions

1. What is the level of knowledge on MTCT among the HIV-infected mothers?
2. What are the infant feeding practices 0-6 months among the HIV-infected mothers?
3. Which factors influence choice of infant feeding options among the HIV-infected mothers?
4. Is there relationship between level of knowledge on MTCT and infant feeding practices of the HIV-infected mothers?

1.5 Broad objective

To assess knowledge on MTCT and practices of infant feeding 0-6 months among HIV-infected mothers attending the ART centers in Juba.

1.6 Specific objectives

1. To assess the level of knowledge on MTCT among the HIV-infected mothers.
2. To determine the infant feeding practices 0-6 months among the HIV-infected mothers.
3. To identify the factors that influence choice of infant feeding options among the HIV-infected mothers.

4. To establish the relationship between level of knowledge on MTCT and infant feeding practices of the HIV-infected mothers.

1.7 Research hypothesis

The null hypothesis is that there is no relationship between maternal level of knowledge on MTCT and their infant feeding practices.

1.8 Conceptual framework

The WHO guidelines on HIV and infant feeding when followed to the later markedly reduce MTCT. However, the most appropriate infant feeding option for an HIV-infected mother depends on her individual circumstances, including her health status and the local situation, but should take into consideration the health services available and the counseling and support she is likely to receive (WHO, 2010). The conceptual framework outlines some of the factors that may influence knowledge on MTCT and practices of infant feeding and provides a framework that can be used to formulate preventive measures to address MTCT.

Independent variables

Intermediate variable

Dependent variable

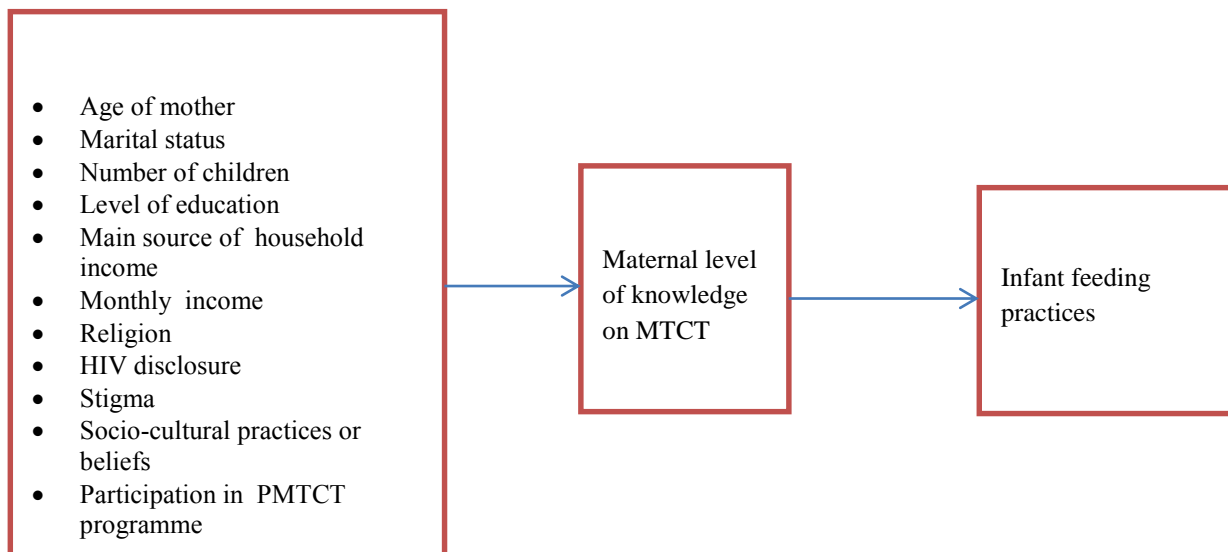


Figure 1: Conceptual framework (adopted from Mwangi, 2012)

CHAPTER 2.0 LITERATURE REVIEW

2.1 Introduction

The Human Immunodeficiency Virus (HIV) causes a devastating condition known as Acquired Immunodeficiency Syndrome (AIDS) with high morbidity and mortality worldwide.

HIV infection in children is mainly due to mother-to-child transmission of the virus. Without intervention up to 20% of children are at risk of acquiring the virus from their mothers during breastfeeding (De Cock *et al.*, 2000). Mixed feeding in the first six months of infant's life carries a higher risk of HIV transmission than exclusive breastfeeding.

Currently, WHO recommended that mothers living with HIV should exclusively breastfeed their infants for the first six months of life and should continue to breastfeed for at least 12 months or beyond while being fully supported for ART adherence (WHO and UNICEF, 2016). Mixed feeding before six months of age was found to be the predominant method of infant feeding in Sub-Saharan Africa (Nduati *et al.*, 2005).

This review provides information on MTCT and its prevention, various infant feeding options and breast milk alternatives in the context of HIV.

2.2 Overview of HIV infection

HIV is one of the world's most serious health and development challenges. According to UNAIDS, there were 36.7 million people living with HIV worldwide in 2016. Of these, 2.1 million were children (below 15 years of age). UNAIDS also estimated, that as of 2016, 1.8 million individuals became newly infected with HIV worldwide. This included 160,000 children (under 15 years old), down from 520,000 newly-infected children in 2000. Most of the newly-infected children live in

Sub-Saharan Africa and were infected by their HIV-infected mothers during pregnancy, childbirth or breastfeeding (UNAIDS, 2016).

Progress has been made in preventing mother-to-child transmission of HIV and keeping mothers alive. According to UNAIDS, 1,107,000 pregnant women globally received ARV for PMTCT in 2016, with 854,000 (85%) of these women living in East and Southern Africa. This is up from 47% in 2010. As a result of scaled-up HIV prevention services there was a 70% reduction globally in the number of new HIV infections among children between 2000 and 2015 (UNAIDS, 2016).

2.3 Mother-to-child transmission of HIV

Mother-to-child transmission of HIV accounts for more than 90% of HIV infection in children around the world (UNAIDS, 2012). Transmission occurs during pregnancy, labor and delivery or after birth through breastfeeding. The absolute risk of transmission without intervention during pregnancy is 5% to 10%; during labor and delivery 10% to 20%; during breastfeeding 5% to 20%; overall with breastfeeding through 6 months 25% to 35%; overall with breastfeeding through 18-24 months 30% to 45%; and overall without breastfeeding is 15% to 25% (De Cock *et al.*, 2000). Several factors affect the risk of transmission, including high maternal viral load and low CD4 count independent of viral load (Tindybwa *et al.*, 2011). Increased rate of transmission occurs when maternal viral loads are at their peak (new infection or advanced AIDS) (Tindybwa *et al.*, 2011). Little or no HIV transmission occurs with viral loads of <1000 copies/ml, regardless of zidovudine use (Sperling *et al.*, 1996). Women with severe immunosuppression (CD4 350 cells/mm³) are at the highest risk of transmitting HIV to their infants (Tindybwa *et al.*, 2011).

Other risk factors that may increase HIV transmission during pregnancy include amniocentesis, chorionic villus sampling, and chorioamnionitis from untreated sexually transmitted infection

(STI) or other infections (Tindyebwa *et al.*, 2011). During labor, placental abruption and rupture of membranes for more than 4 hours may increase the risk of transmission (Tindyebwa *et al.*, 2011). Invasive delivery procedures including artificial rupture of membranes, forceps delivery and episiotomy increase the risk of HIV transmission during delivery because of the increased contact of the baby with the mother's infected blood or body fluids (Tindyebwa *et al.*, 2011; John *et al.*, 1997).

Other risk factors for HIV transmission during breastfeeding include mixed feeding, duration of breastfeeding, oral disease in the baby (thrush or sores), and conditions of the breasts and nipples (mastitis, breast abscesses, nipple fissures).

Mixed feeding, that is breastfeeding combined with giving the infant solid foods or other liquids such as formula milk, water, tea, or juice before six months of age carries a higher risk of HIV transmission than exclusive breast feeding. This is because the other liquids and foods damage the epithelial lining of the baby's stomach and intestines which allows the virus in the breast milk to infect the baby more easily (Doherty *et al.*, 2006). The risk of HIV transmission when mixing breast milk with formula or solids is higher than mixing breast milk with water or other non-food fluids (Coovadia *et al.*, 2007).

HIV can be transmitted through breast milk at any point during breastfeeding, and thus the rate of infection in breastfed infants increases with duration of breastfeeding (WHO, 2004). A study in South African women found that women in whom HIV was detectable in their breast milk at any time during the first six months after delivery are more likely to transmit the virus to their infants than those in whom it was undetectable (Pillay *et al.*, 2000). The anti-HIV antibodies in breast milk are not protective against postnatal transmission of HIV (Becquart *et al.*, 2000). Without

intervention, the risk of HIV transmission is as high as 45% with extended breastfeeding up to two years (De Cook et al., 2000).

Conditions that damage the mucus membrane of infants such as oral thrush/sores, maternal breast conditions such as mastitis and breast abscesses, and nipple lesions such as nipple fissures are all associated with increased risk of HIV transmission through breastfeeding (Ngacha *et al.*, 2005; Rollins *et al.*, 2004; WHO, 2004).

2.4 Prevention of mother-to-child transmission of HIV

With effective interventions during pregnancy, labor, delivery and breastfeeding the rate of MTCT can be reduced to below 5% (WHO website, accessed 19 April 2016). Interventions involve ARV prophylaxis for HIV-infected pregnant women starting as early as 14 weeks of gestation (or as soon as possible thereafter), or daily ART, starting as soon as possible irrespective of gestational age, and continued for life. This should be accompanied with ARV prophylaxis for infants born to HIV-infected mothers, starting from birth or as soon as feasible thereafter until 4 to 6 weeks of age, irrespective of the mode of infant feeding, and until 1 week after all exposure to breast milk has ended for breastfeeding infants (WHO, 2010 version). Interventions also include measures to prevent HIV acquisition in the pregnant woman and appropriate breastfeeding practices (WHO website, accessed 19 April 2016).

In developed countries, widespread use of antiretroviral therapy during pregnancy has been associated with a dramatically reduced incidence of mother-to-child transmission of HIV among HIV-infected mothers who do not breastfeed (below 2%). When combined with elective caesarean delivery, the rate of MTCT can fall below 1% in developed countries (Coovadia *et al.*, 2007).

Similar success was seen in under-resourced areas when prenatal care and access to antiretroviral is provided (De Cock *et al.*, 2000).

The risk of HIV transmission during breastfeeding is mainly due to mixed feeding. WHO and UNICEF recommended that HIV-infected mothers of HIV-uninfected (or unknown-status) infants should either breastfeed with accompanying prophylactic ART, or should avoid breastfeeding altogether if replacement feeding/formula feeding is acceptable, feasible, affordable, sustainable, and safe (WHO, 2010). If breastfeeding, the infant should be exclusively breastfed for the first six months, introducing appropriate complementary foods after that while continuing breastfeeding until 12 months of age or beyond. Breastfeeding should stop only once a nutritionally adequate and safe diet without breast milk can be provided (WHO, 2010).

Studies have shown that free and cell-associated HIV levels are reduced substantially if subjected to heat at 62.5°C for 30 minutes (Orloff *et al.*, 1993). However, heat treatment also reduces much of the immune and protective components of breast milk (WHO, 2004).

Exclusive formula feeding has no risk of postnatal HIV transmission but it carries increased risk of morbidity and mortality associated with malnutrition and infectious diseases such as pneumonia and diarrhoea (WHO, 2004).

2.5 Infant feeding options for HIV-infected mothers

The feeding of infants in the context of HIV is complicated because of the major influence that feeding practices and nutrition have on child survival.

In 2009 and 2010, several research studies reported evidence that ARVs interventions to either HIV-infected mother or the HIV-exposed infant can significantly reduce the risk of HIV

transmission through breastfeeding to 1–2% over a 12 month period (Kesho Bora Study Group, 2011; Chasela *et al.*, 2010; Shapiro *et al.*, 2010). ARVs can either be given to mothers or to their infants during the period of breastfeeding so that it is now possible for infants to breastfeed with little risk of acquiring HIV from their mothers, while also benefiting from the nutritional and protective properties of the breast milk. This evidence had led to the development of the WHO 2010 guidelines on HIV and infant feeding and it has major implications for how women living with HIV might feed their infants, and how health workers should counsel these mothers. In the previous guidelines, the health workers were expected to individually counsel all HIV-infected mothers about the various infant feeding options such as breastfeeding or formula feeding, and it was for the mothers to decide between the options and for health services to support them in their choices. The 2010 guidelines recommended that the national health authorities in each country should decide which infant feeding practice and interventions, i.e. breastfeeding with an ARV intervention (to either the mother or infant) or avoidance of all breastfeeding, should be promoted and supported as a single national public health recommendation by their maternal and child health services (WHO, 2010). Unfortunately, there were no national guidelines on infant feeding in the context of HIV in the Republic of South Sudan at the time of the study, the country uses the WHO guidelines.

According to WHO, UNICEF, UNFPA, and UNAIDS guidelines on HIV and infant feeding, appropriate infant feeding options are those that have no or low risk of HIV transmission from an infected mother to her infant, these include exclusive breastfeeding for the first six months of life, and exclusive formula feeding for the first six months of life if the commercial infant formula milk is acceptable, feasible, affordable, sustainable and safe (WHO, 2010).

Different studies showed consistent evidence that exclusive breastfeeding carries a lower risk of postnatal HIV transmission compared to mixed feeding (WHO website, 19/4/2016). Research had also shown that exclusive breastfeeding in the first six months of an infant's life was associated with a 3-4 fold decreased risk of HIV transmission compared to infants who were breastfed and also received other milks or foods (Smith and Kuhn, 2000). Formula feeding carries zero risk of postnatal HIV transmission (WHO, 2004).

If a mother decided to stop breastfeeding for any reason before six months, the recommended alternatives to breast milk are commercial infant formula milk and expressed, heat-treated breast milk.

Pretoria pasteurization and flash-heating are the only methods recommended by WHO for heat-treatment of expressed breast milk at home. These methods inactivate viral activity while retaining the nutritional and protective properties of the breast milk. Pretoria pasteurization uses the principle of heat transfer from 450 ml of water heated to boiling point in an aluminum pot to a smaller volume of milk in a glass jar placed into the water (Jeffery and Mercer, 2000). Flash-heating involves expressing breastmilk into a glass jar that is placed in a small pot of water and heated until the water boils (UC Davis Health, 2012). Flash-heating is a superior method to inactivate viral activity, compared to Pretoria pasteurization. HIV-infected mothers may consider expressing and heat-treating breast milk in special circumstances such as when the mother is unwell and temporary unable to breastfeed or when the infant is born with low birth weight or ill in the neonatal period and unable to breastfeed (WHO, 2010).

According to WHO, UNICEF, UNAIDS, and UNFPA guidelines on HIV and infant feeding, inappropriate infant feeding options are those that have high risk of HIV transmission from an

infected mother to her infant, and those that do not provide adequate nutrients to the infant, these include mixed feeding, and home-modified animal milk (WHO, 2010).

Mixed feeding in the first six months of life is not recommended by WHO because it carries a higher risk of HIV transmission than exclusive breastfeeding. Although exclusive breastfeeding is recommended, practicing mixed feeding is not a reason to stop breastfeeding in the presence of ARV drugs (WHO and UNICEF, 2016)

Pure animal milk does not provide all the nutrients that the infant needs in the first six months of life. Modification of the animal milk involves dilution of the milk with water and addition of micronutrients supplements. Earlier WHO guidelines recommended use of home-modified animal milk as main infant feeding option in the first six months of life. Currently home-modified animal milk is not recommended by WHO as main infant feeding option or replacement food in the first six months of life because the micronutrients supplements were not available and over/under dilution by the mothers/caregivers made the practice inappropriate. Boiled animal milk can be given to a child after six months of age.

In 2003, WHO suggested the use of a wet nurse as main infant feeding option for HIV-infected mothers who chose not to breastfeed their infants. Wet-nursing is breastfeeding of an infant by a woman other than the infant's mother who is tested HIV-negative. In 2006, wet-nursing was not removed as an option despite the concerns about HIV transmission from an infected infant to the wet nurse. There is evidence of infected infants transmitting the virus to their HIV-negative mothers during breastfeeding (Kristen *et al.*, 2012). Transmission likely occurs as a result of breastfeeding contact during a period of epithelial disruption such as maternal skin fissures and /or infant stomatitis (Kristen *et al.*, 2012). The WHO 2010 recommendations did not mention anything

regarding wet-nursing, so the practice may still be considered in communities where this option is accepted or practiced until clear recommendations regarding this practice are available.

2.6 Gap in knowledge of infant feeding options among HIV-infected mothers

According to WHO 2010 guidelines, appropriate infant feeding options in the first six months of life are exclusive breastfeeding and exclusive formula feeding. Breast milk alternatives in the first six months of life are commercial infant formula milk, expressed heat-treated breast milk, and breast milk from a wet nurse.

The level of counseling in the health facilities on PMTCT is found to be linked with knowledge and practices related to infant feeding (Leshabari *et al.*, 2007). Studies have shown that poor quality of counseling in PMTCT programs have created confusion for HIV-infected mothers regarding feeding their infants (Woldensenbet and Jackson, 2009; Chopra *et al.*, 2005).

Studies have also found that while mothers were knowledgeable of infant formula as a replacement option, their awareness of breast milk alternatives such as expressed heat-treated breast milk and wet nursing was limited and this was attributed to a gap in counseling in PMTCT programs (Laar and Govender, 2011; Chopra and Rollins, 2008).

CHAPTER 3.0 METHODOLOGY

3.1 Study design

The study employed a cross-sectional study design in which both quantitative and qualitative data were collected.

3.2 Variables

Dependent variable: Infant feeding practices of the HIV-infected mothers was used as the dependent variable for the study.

Intermediate variable: level of knowledge on MTCT among the HIV-infected mothers was used as an intermediate variable.

Independent variables: The independent variables for the study include age of mother, marital status, number of children, level of education, main source of household income, monthly income, religion, HIV disclosure, stigma, socio-cultural practices or beliefs, and participation in PMTCT program.

3.3 Study area

Republic of South Sudan, where this study was conducted, is a landlocked country in East-Central Africa, it borders territories of Sudan to the north, Ethiopia to the East, Kenya, Uganda and the Democratic Republic of the Congo to the South and the Central African Republic to the West. The country has a land mass area of about 644,329 square kilometers and is administratively divided into 10 states and 79 counties (South Sudan Statistical Yearbook, 2011).

Juba is the capital of the Republic of South Sudan as well as the state capital of Central Equatoria

State, and is also the largest city in the country. There are only two ART centers in Juba: one in Juba Teaching Hospital, which is the only national referral hospital in the Republic of South Sudan; and the second one in Juba Military Hospital, which is accessed by the military and their families as well as the people residing nearby.

The country's population was estimated at 11.88 Million in 2015, of which 83% lives in rural areas (5th Sudan Population and Housing Census, 2008; MOH HMIS Report 2015 Projections). Health outcomes in South Sudan are generally poor. In 2006, the maternal mortality rate was 2,054 per 100,000 live births, rated the highest in the world (South Sudan Household Health Survey, 2006).

In 2010, infant mortality rate was 75 per 1,000 live births, child mortality rate was 105 per 1,000 live births, children under 2 years fully immunized was 6.3%, and births attended by skilled personnel were 19.4% (South Sudan Household Health Survey, 2010). These health outcomes reflect a health system that is not effective and of concern is that the HIV epidemic is happening within this context of multiple challenges and needs. Due to the long period of instability in the country the national exclusive breastfeeding rate was not known till 2010, and according to UNICEF exclusive breastfeeding rate in South Sudan has improved from 45% in 2010 to 74% in 2018 (UNICEF, 2019).

3.4 Study population

The study population comprised HIV-infected mothers who were attending the ART centers in Juba Teaching Hospital (JTH) and Juba Military Hospital (JMH).

3.4.1 Inclusion criteria

HIV- infected mothers who:

- Were aged between 15-49 years
- Had children aged 6-18 months
- Were willing to participate in the study.

3.4.2 Exclusion criteria

HIV- infected mothers who:

- Had children younger than 6 months and older than 18 months of age
- Did not agree to participate in the study.

3.5 Sampling

3.5.1 Sample size determination

The sample size was determined using the following formula with finite population correction (Daniel,1999) and was worked out as below:-

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

Where:

n' ; is the sample size with finite population correction

N ; is the population size = 1440 (number of HIV-infected patients who were diagnosed and on treatment according to the JTH ART registry from January 2015 to December 2015, JMH ART registry was not available)

Z ; is the Z statistic corresponding to 95% confidence level (1.96)

P ; is the estimated proportion of mothers who practiced the appropriate infant feeding options (estimated at 50%)

d ; is the precision or margin of random error, set at 0.05

Therefore,

$$n' = \frac{1440 (1.96)^2 (0.50) (1-0.50)}{(0.05)^2 (1440 - 1) + (1.96)^2 0.50 (1 - 0.50)}$$

$n' = 304$ patients

3.5.2 Sampling technique

The JTH and JMH were purposively sampled because they are the only hospitals with Voluntary Counseling and Testing (VCT), PMTCT and ART services in Juba, South Sudan.

The study participants were purposively sampled with focus on particular characteristic such as having children 6 months and above which will best help in answering the research question on infant feeding practices. Recruitment of the study participants was done by the principal investigator and the research assistants at the ART centers. The participants who met the initial inclusion criteria (age of mother and child) were referred to the research team by the health workers as they came for services at the ART centers, those who agreed to take part in the study after being explained to about the study were then interviewed until the desired sample size was achieved.

The key informants were purposively sampled and the participants of the focus group discussions (FGDs) were systematically sampled.

3.6 Data collection

The study used both quantitative and qualitative research techniques of data collection.

For quantitative data, one-to-one interviews with the HIV-infected mothers were conducted using structured questionnaires with closed-ended questions. The questionnaires were administered by the principal investigator and two research assistants to collect data on socio-demographic characteristics, knowledge on MTCT and infant feeding practices of the HIV-infected mothers. Interviews were conducted in Juba Arabic (local language) and respondents' choices were ticked accordingly. Interviews were conducted in two offices within the ART centers.

For qualitative data, key informant interviews and focus group discussions were conducted using interview guides. Two key informant interviews (KIIs) were conducted with the nurses-in-charge of the ART centers to collect qualitative data on the HIV services offered by the facility, the PMTCT services, presence of any socio-cultural practices or misconceptions that could affect uptake of the PMTCT services and challenges facing implementation of the program. The interviews were facilitated by the principal investigator after the participants were fully informed of the study and had agreed to participate. The KIIs were conducted in English and there was no voice capture and recording of the interviews because the informants said that they were not comfortable with that. The interviews were privately conducted in the offices of the nurses-in-charge of the centers.

Two focus group discussions were also conducted with 10 HIV-infected mothers per group to collect qualitative data regarding knowledge on mother-to-child transmission of HIV and its prevention, infant feeding in the context of HIV, and breast milk alternatives. The FGDs were conducted to verify the information collected from the quantitative data and to explore more on

the issues under study. Other caregivers were not chosen for the FGDs because the objective was to assess maternal knowledge on MTCT and their feeding practices which will best be answered by the mothers themselves. These FGDs were facilitated by the principal investigator who acted as the moderator while two research assistants took the notes during the discussions. The FGDs were conducted in Juba Arabic. Responses from the FGDs were transcribed in English and summarized according to the key themes, using simple words as close as possible to the mothers' words. There was no voice capture and recording of the discussions because the mothers did not agree to that. The discussions took place in a hall within the hospitals.

3.7 Data management and analysis

Completed questionnaires were checked by the principal investigator. Quantitative data was coded and entered into the computer and was analyzed using SPSS software version 22. Descriptive statistics were determined and presented in frequency tables and graphs. Chi-square test was used to test the presence of significant association between the variables and the association is statistically significant when the p-value is < 0.05 . Multiple logistics regression analysis was used to identify which predictor variables had major effect on the dependent variable.

The qualitative data was analyzed manually and summarized in relation to the topics of discussion. Information obtained from the KIIs and FGDs was used to supplement and interpret the findings of the quantitative data in discussion of the results.

3.8 Scoring of level of knowledge

The level of knowledge was measured using a scoring system adopted from the Stanford Institute for Research in the Social Sciences (Stanford University, 2007) as used in a related study conducted in Kiambu, Kenya (Mwangi, 2012) as follows:

Six questions with 15 correct responses were asked. A score of 1 was awarded for each correct response and 0 for incorrect response. A summary indicator for knowledge was calculated as follows: 0 correct response = No knowledge, 1-5 correct responses = Poor knowledge, 6-10 correct responses = Average knowledge, 11-15 correct responses = Good knowledge.

3.9 Assessment of infant feeding practices

The infant feeding practices were assessed using a close-ended question with answers for both appropriate and inappropriate practices. The mothers' answers were classified as appropriate and inappropriate according to the WHO definitions of infant feeding options. Appropriate infant feeding practices include exclusive breastfeeding and exclusive formula feeding, while inappropriate infant feeding practices include mixed feeding and home-modified animal milk (WHO, 2010).

3.10 Ethical consideration

Approval to conduct the study was sought from Kenyatta National Hospital - University of Nairobi Ethics and Research Committee. Further permission to carry out the study was sought from the Ministry of Health, Republic of South Sudan, as well as from hospital administrators. A signed informed consent was obtained from each participant after being explained what the study entailed. The research assistants were trained on how to ensure privacy of the participants and confidentiality of the information obtained, while interviews were conducted in offices within the ART centers. Mothers who chose not to participate in the study were respected and assured that they will continue to get the services they were entitled to, from JTH & JMH, despite of non-participation. No names were mentioned in this document and all the information obtained from

the participants was treated with strict confidentiality. The filled questionnaires were securely kept under lock and key at all times with restricted access to the principal investigator only.

3.12 Minimization of errors and biases

The questionnaire was pre-tested before the actual data collection. Pre-testing was done using a purposive sample of 20 HIV-infected mothers with children aged 6-18 months from the two ART centers. Questions that were not clear to the mothers during the pre-testing were rephrased to convey the same meaning to all participants.

The questionnaires were administered by the principal investigator and two research assistants who were certified nurses. The research assistants were familiarized with the objectives of the study and the terms used in the questionnaire, and were thoroughly trained before and after the pre-testing on the data collection procedure and how to ask the questions and tick the responses accordingly. The questionnaires were administered individually to ensure confidentiality, while interviews were conducted in offices within the ART centers. Filled questionnaires were checked daily by the principal investigator for completeness.

3.11 Significance of the study

The findings of the study provided information to the health authorities and health practitioners in the Republic of South Sudan on the practice of exclusive breastfeeding in the PMTCT programs. The findings also helped in evaluation of adequacy of the current infant feeding counseling in the context of HIV. The findings of the study will also be used as baseline information for future researches in the Republic of South Sudan.

CHAPTER 4.0 STUDY FINDINGS

4.1 Introduction

This study sought to assess knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending the ART centers in Juba, and to identify the factors that influence choice of infant feeding options among the HIV-infected mothers, while establishing the relationship between level of knowledge on MTCT and infant feeding practices of the HIV-infected mothers. A total of 304 HIV-infected mothers of reproductive age with children 6-18 months were interviewed between October and December 2016. Two focus group discussions with the HIV-infected mothers and two key informant interviews with the nurses-in-charge of the ART centers were also conducted.

The findings are presented under six main sections, namely, demographic profile of the HIV-infected mothers, social characteristics of the HIV-infected mothers, level of knowledge on MTCT among the HIV-infected mothers, infant feeding practices 0-6 months among the HIV-infected mothers, bivariate analysis of factors influencing choice of infant feeding options among the HIV-infected mothers, and multiple logistic regression analysis.

4.2 Demographic profile of the HIV-infected mothers

The demographic profile revealed that 129 (42.4%) of the HIV-infected mothers were aged between 20 to 29 years and 120 (39.5%) were aged between 30 to 39 years (Table 1). The mean age of the mothers was 29.7 years.

Half of the mothers, 154 (50.7%) were married, 12.5% were cohabiting and the rest were; single, separated, widowed or divorced.

More than half of the mothers, 159 (52.3%) had three or more children. Only 22.7% had two children and 25.0% had one child.

The highest level of formal education attained by most of the mothers was at primary level, 166 (54.6%) and 47 mothers (15.5%) had no formal education.

The main source of income for the household was provided for by the mothers, 160 (52.6%) female headed household, with 144 (47.4%) of them claiming that their main source of income was their spouses/partners.

Majority of the mothers, 290 (95.4%) had a monthly earning of less than 50 US dollars, 12 mothers (3.9%) earned between 50-150 US dollars, and only 2 (0.7%) earned more than 300 US dollars.

Majority of the respondents, 291 (95.7%) were Christians, while the rest, 13 (4.3%) were Muslims.

Table 1: Demographic characteristics of the HIV-infected mothers

Characteristics	Frequency n	Percentage %
Age		
15-19	26	8.6
20-29	129	42.4
30-39	120	39.5
40-49	29	9.5
Marital status		
Married	154	50.7
Cohabiting	38	12.5
Divorced	14	4.6
Separated	34	11.2
Widowed	30	9.8
Single	34	11.2
Number of children		
One	76	25.0
Two	69	22.7
Three or more	159	52.3
Level of education		
None	47	15.5
Primary	166	54.6
Secondary	83	27.3
Tertiary	8	2.6
Main source of income		
Self	160	52.6
Spouse/partner	144	47.4
Monthly household income		
<50 USD	290	95.4
50-100 USD	8	2.6
101-150 USD	4	1.3
>300 USD	2	0.7
Religion		
Christian	291	95.7
Muslim	13	4.3

4.3 Social characteristics of the HIV-infected mothers

The study found that 265 mothers (87.2%) had disclosed their HIV status to their spouses/partners, family, relatives, and friends, while 39 mothers (12.8%) had not disclosed their status to anyone (Table 2).

Although a majority of mothers, 198 (65.1%) did not experience stigma/discrimination from spouse, family, relatives, friends or the community because of their HIV status, 106 mothers (34.9%) reported that they experienced such discrimination.

Majority of the mothers, 290 (95.4%) reported that there were no socio-cultural practices or beliefs associated with the way they fed their children in the first six months of their lives.

Most of the mothers, 191 (62.8%) reported that they participated in the PMTCT program, while 113 mothers (37.2%) had not taken part in the program.

Table 2: Social characteristics of the HIV-infected mothers

Characteristics	Frequency n (%)	
	Yes	No
Disclosure of HIV status to partner, family and relatives	265 (87.2)	39 (12.8)
Experienced stigma from spouse or relatives	106 (34.9)	198 (65.1)
Socio-cultural practices or beliefs associated with infant feeding	14 (4.6)	290 (95.4)
Participation in prevention of mother to child transmission program	191 (62.8)	113 (37.2)

4.4 Level of knowledge on MTCT among the HIV-infected mothers

Most of the HIV-infected mothers, 268 (88.2%) were aware that HIV can be transmitted from an infected mother to her baby (Table 3).

Most of the mothers, 254 (83.6%), also knew that transmission of the virus can occur during breastfeeding. This was closely followed by those who also knew that it occurred during labor and delivery, 227 (74.7%). Transmission of HIV infection during pregnancy was known by only 89 mothers (29.3%), and 36 mothers (11.8%) did not know when HIV can be transmitted from mother to child.

From the FGDs, almost all the mothers agreed that an infected mother can transmit the virus to her baby. They reported that a baby can get HIV from his/her infected mother during delivery if the scissor used for cutting the mother also used to cut the umbilical cord of the baby because the scissor will be contaminated with the mother's infected blood. Some of them also reported that a child can get the infection when breastfeeding if the mother had wound on her breast because of the contaminated blood coming from the wound. None of them mentioned anything about HIV transmission during pregnancy.

Regarding HIV transmission during breastfeeding, 254 mothers (83.6%) knew that the virus can gain entry into the baby through broken skin on mother's breast. 172 mothers (56.6%) knew that the virus can gain entry into the baby through sores in the baby's mouth. Only 59 mothers (19.4%) knew that the baby can get HIV from the breastmilk that is contaminated with the virus, and 50 mothers (16.4%) did not know how HIV gains entry into the baby during breastfeeding (Table 3).

During the FGDs, most of the mothers reported a wound on mother's breast as source of HIV infection during breastfeeding, some of them reported wounds inside the baby's mouth but they

do not understand how the virus can infect the baby if the breast is intact. None of them mentioned breast milk as source of HIV infection during breastfeeding.

Regarding breast milk alternatives in the first six months of infant's life, infant formula milk was reported by 263 (86.5%) of the HIV-infected mothers as an alternative to breast milk in the first six months of the infant's life. None of the mothers knew about expressed heat-treated breast milk or breast milk from a wet nurse. More than half of the mothers, 180 (59.2%) also considered water and/or porridge, tea, juice, food as alternatives to breast milk in the first six months of live. Only 96 mothers (31.6%) considered animal milk (cow/goat) as an alternative to breast milk in the first six months of infant's life (Table 3).

From the FGDs, most of the mothers reported infant formula milk as the best alternative to breast milk in the first six months of infant's life, but they could not afford it. Others reported that cow and goat milk are the only milk given to babies in their communities. There was no mention of expressed heat treated breast milk or breast milk from a wet nurse. When these were brought up, according to them expressing breast milk and then boiling it is not possible because they do not have enough milk, and breastfeeding the baby by another woman is risky because of transmission of diseases including HIV.

When mothers were asked about prevention of mother-to-child transmission of HIV, 263 mothers (86.5%) reported that giving the baby HIV medicines can prevent the transmission, and 189 (62.2%) of them reported that taking HIV medicines by the mother can prevent the transmission. Another 92 mothers (30.3%) reported that not breastfeeding the baby at all can help, and 43 of them (14.1%) reported caesarean section as a prevention method. Only 35 (11.5%) mothers did not know how mother-to-child transmission of HIV can be prevented (Table 3).

From the FGDs, majority of the mothers were convinced that giving the baby medicine for HIV is the only way that can prevent him from getting the virus. Some mothers did not agree with giving the baby medicine for HIV when you do not even know whether the baby has the virus or not, but they do not mind giving their babies these medicines when they were known to be HIV infected. One mother reported that taking HIV medicines by the mother during breastfeeding can also help the baby. None of the mothers mentioned cesarean section and not breastfeeding the baby at all as modes of prevention of mother-to-child transmission of HIV.

Table 3: Knowledge on MTCT, risk factors associated with HIV transmission through breastfeeding, breast milk alternatives, and PMTCT

	Frequency of responses (n)	Percentage of cases (N=304)
Mother-to-child transmission of HIV		
Yes	268	88.2
No	1	0.3
Do not know	35	11.5
Timing of mother-to-child transmission of HIV		
During pregnancy	89	29.3
During labor and delivery	227	74.7
During breastfeeding	254	83.6
When carrying the baby	1	0.3
Do not know	36	11.8
Mother-to-child transmission during breastfeeding		
Yes	254	83.6
No	0	0.0
Do not know	50	16.4
HIV entry from mother to child during breastfeeding		
Breast milk contaminated with HIV	59	19.4
Broken skin on the breast	254	83.6
Sores in the baby's mouth	172	56.6
Do not know	50	16.4
Other milk/food for baby in the first six months of life		
Infant formula milk	263	86.5
Animal milk (cow/goat)	96	31.6
Water and/or porridge, tea, juice, food	180	59.2
Expressed heat-treated breast milk	0	0.0
Breast milk from a wet nurse/another woman	0	0.0
Do not know	5	1.6
Prevention of mother-to-child transmission of HIV		
Caesarean section	43	14.1
Not breastfeeding the baby at all	92	30.3
Taking medicines for HIV by mother	189	62.2
Giving the baby medicine for HIV	263	86.5
Do not know	35	11.5

After scoring of maternal level of knowledge on MTCT, it was found that 141 (46.4%) of the HIV-infected mothers had average knowledge on MTCT, 120 (39.5%) of them had good knowledge, 36 (11.8%) of them had poor knowledge, while 7 (2.3%) of them had no knowledge on MTCT (Figure 2).

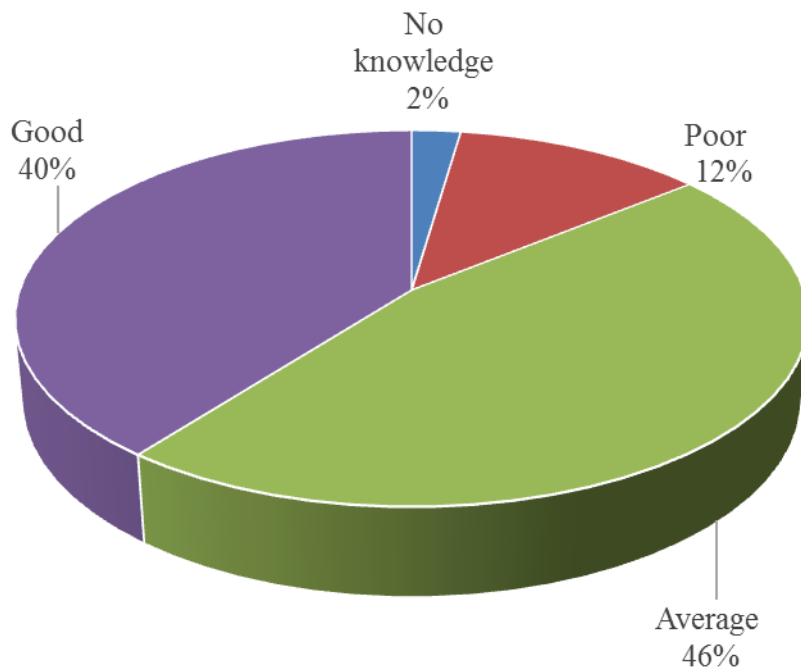


Figure 2: Maternal level of knowledge on MTCT score

4.5 Infant feeding practices 0-6 months among the HIV-infected mothers

Majority of the HIV-infected mothers, 213 (70.1%) practiced mixed feeding methods during the first six months of their infants' lives. The infants were fed on breast milk, water and/or infant formula milk, porridge, juice, food. Only 70 (23.0%) mothers practiced exclusive breastfeeding, while 20 (6.6%) of them practiced exclusive formula feeding (Table 4).

Table 4: Infant feeding practices of the HIV-infected mothers

Appropriate	Frequency n (%)	Inappropriate	Frequency n (%)
Exclusive breastfeeding	70 (23.0)	Mixed feeding	213 (70.1)
Exclusive formula feeding	20 (6.6)	Home-modified animal milk	1 (0.3)
Total	90 (29.6)	Total	214 (70.4)

The study found that the main reasons for choice of the appropriate infant feeding methods were that they have less risk of transmitting HIV, and that breast milk is cheap and readily available and is also nutritious for the baby. While the main reasons for choice of the inappropriate methods were that, the baby was left in other people's care while mother was at work, the mother was too ill or weak to breastfeed, and mother did not have enough milk (Table 5).

Table 5: Main reasons for choice of infant feeding methods

	Frequency of responses n (%)		Percentage of cases (n=304)
	Appropriate	Inappropriate	
Nutritious for baby	40 (42.6)	54 (57.4)	94 (30.9)
Less risk of transmitting HIV	29 (74.4)	10 (25.6)	39 (12.8)
Cheap and readily available	31 (54.4)	26 (45.6)	57 (18.8)
Mother did not have enough milk	2 (2.2)	90 (97.8)	92 (30.3)
Mother too ill or weak to breastfeed	0 (0.0)	10 (100.0)	10 (3.3)
It's the traditional feeding practice	1 (25.0)	3 (75.0)	4 (1.3)
Baby was left in other people's care while mother was at work	0 (0.0)	70 (100.0)	70 (23.0)
Total	90	214	304

Mothers from the FGDs reported that they were told at the clinic to exclusively breastfeed their babies for six months and stopped completely by the end of six months. So they started giving other liquids and foods from as early as 2 to 3 months for their babies to get used to them. Some mothers reported that they were not able to exclusively breastfeed because they did not have enough milk and others said because they had to go to work to be able to provide food for the older siblings. Their babies were fed on infant formula and/or porridge, juice, soups and mashed foods.

Some mothers reported that they were told that they can give their babies formula milk only and not breastfeed at all to avoid HIV infection during breastfeeding but they never used the formula at all, and those who tried could not use it exclusively because of its high cost, so they gave porridge, juice, soups and mashed food together with the formula milk.

Other mothers reported that they normally gave their babies water in the first days of life, even from 3 days, porridge from 3 to 4 months, juice and food from 4 to 5 months.

4.6 Bivariate analysis of factors influencing choice of infant feeding options among the HIV-infected mothers

The result of the bivariate analysis of the demographic characteristics of the HIV-infected mothers and their infant feeding practices indicated that there was statistically significant difference between infant feeding practices with respect to number of children ($\chi^2 (2) = 16.013, p = 0.0003$), level of education ($\chi^2 (3) = 8.608, p = 0.035$) and religion ($\chi^2 (1) = 6.645, p = 0.010$) (Table 6).

The bivariate analysis of the social factors and the infant feeding practices indicated that there was a statistically significant difference between infant feeding practices with respect to mothers' participation in the PMTCT program ($\chi^2 (1) = 10.483, p = 0.001$) (Table 7).

There was no statistically significant difference between infant feeding practices with respect to maternal level of knowledge on MTCT ($\chi^2 (3) = 6.995, p = 0.072$), the null hypothesis was thus accepted concluding that there was no relationship between maternal level of knowledge on MTCT and their infant feeding practices (Table 7).

Table 6: Association between demographic characteristics and infant feeding practices

	Frequency n (%)		Total n (%)	P value
	Appropriate	Inappropriate		
Age of mother				
15-19	9 (10.0)	17 (7.9)	26 (8.6)	p = 0.59
20-29	45 (50.0)	84 (39.3)	129 (42.4)	
30-39	33 (36.7)	87 (40.7)	120 (39.5)	
40-49	3 (3.3)	26 (12.1)	29 (9.5)	
Marital status				
Married	47 (52.2)	107 (50.0)	154 (50.7)	p = 0.713
Cohabiting	13 (14.4)	25 (11.7)	38 (12.5)	
Divorced	3 (3.3)	11 (5.1)	14 (4.6)	
Separated	9 (10.0)	25 (11.7)	34 (11.2)	
Widowed	6 (6.7)	24 (11.2)	30 (9.9)	
Single	12 (13.3)	22 (10.3)	34 (11.2)	
Number of children				
One	35 (38.9)	41 (19.2)	76 (25.0)	p = 0.0003
Two	22 (24.4)	47 (22.0)	69 (22.7)	
Three or more	33 (36.7)	126 (58.9)	159 (52.3)	
Level of education				
None	9 (10.0)	38 (17.8)	47 (15.5)	p = 0.035
Primary	44 (48.9)	122 (57.0)	166 (54.6)	
Secondary	34 (37.8)	49 (22.9)	83 (27.3)	
Tertiary	3 (3.3)	5 (2.3)	8 (2.6)	
Main source of household income				
Self	41 (45.6)	119 (55.6)	160 (52.6)	p = 0.109
Spouse/partner	49 (54.4)	95 (44.4)	144 (47.4)	
Monthly income				
Less than 50 USD	84 (93.3)	206 (96.3)	290 (95.4)	p = 0.684
50-100 USD	3 (3.3)	5 (2.3)	8 (2.6)	
101-150 USD	2 (2.2)	2 (0.9)	4 (1.3)	
More than 300 USD	1 (1.1)	1 (0.5)	2 (0.7)	
Religion				
Christian	82 (91.1)	209 (97.7)	291 (95.7)	p = 0.010
Muslim	8 (8.9)	5 (2.3)	13 (4.3)	

Table 7: Association between social characteristics and infant feeding practices

	Frequency n (%)		Total n (%)	P value
	Appropriate	Inappropriate		
Disclosure of HIV status				
Yes	77 (85.6)	188 (87.9)	265 (87.2)	p = 0.585
No	13 (14.4)	26 (12.1)	39 (12.8)	
Experienced stigma				
Yes	27 (30.0)	79 (36.9)	106 (34.9)	p = 0.248
No	63 (70.0)	135 (63.1)	198 (65.1)	
Socio-cultural practices or beliefs				
Yes	1 (1.1)	13 (6.1)	14 (4.6)	p = 0.059
No	89 (98.9)	201 (93.9)	290 (95.4)	
Participation in PMTCT program				
Yes	69 (76.7)	122 (57.0)	191 (62.8)	p = 0.001
No	21 (23.3)	92 (43.0)	113 (37.2)	
Level of knowledge				
No knowledge	0 (0.0)	7 (3.3)	7 (2.3)	p = 0.072
Poor knowledge	10 (11.1)	26 (12.1)	36 (11.8)	
Average knowledge	36 (40.0)	105 (49.1)	141 (46.4)	
Good knowledge	44 (48.9)	76 (35.5)	120 (39.5)	

4.7 Multiple logistic regression analysis

Multiple logistic regression analysis was performed to ascertain the effects of selected significant predictor variables on the likelihood that respondents would practice appropriate infant feeding practices. The predictor variables were respondents' number of children ($p = 0.0003$), level of education ($p = 0.035$), religion ($p = 0.010$), and participation in PMTCT program ($p = 0.001$).

A test of the full model versus the intercept-only (i.e., with no variables added) model was statistically significant ($\chi^2 (7) = 36.394$, $p = 0.0005$), meaning that the full model statistically significantly predicts the dependent variable better than the intercept-only model alone.

Table 8 shows the logistic regression coefficient (B), standard error of the regression coefficient, Wald chi-square test, degree of freedom for the Wald chi-square test, significance level/p value, exponentiation of the B coefficient/odds ratio for the predictor, and 95% confidence interval for odds ratio respectively.

Table 8: Multiple logistic regression analysis

	B	S.E.	Wald	df	Sig.	Exp (B)	95% CI for Exp (B)	
							Lower	Upper
Children			13.697	2	0.001			
Two	-0.666	0.362	3.381	1	0.066	0.514	0.252	1.045
Three or more	-1.192	0.322	13.696	1	0.000	0.303	0.161	0.571
Education			3.420	3	0.331			
Primary	0.036	0.445	0.006	1	0.936	1.036	0.433	2.478
Secondary	0.558	0.472	1.396	1	0.237	1.748	0.692	4.412
Tertiary	0.498	0.884	0.317	1	0.573	1.646	0.291	9.312
Religion	1.703	0.632	7.256	1	0.007	5.488	1.590	18.944
PMTCT	0.816	0.302	7.300	1	0.007	2.260	1.251	4.084
Constant	-0.972	0.477	4.150	1	0.042	0.378		

Based on the 0.05 criterion of statistical significance, the level of education was overall found not to be statistically significant ($P = 0.331$), and none of its dummy coded variables had significant effect on the infant feeding practices. One dummy coding for number of children that is three or more children ($P = 0.000$), religion ($P = 0.007$), and participation in PMTCT program ($P = 0.007$) had significant effects on infant feeding practices.

The number of children variable was dummy coded using one child as the reference group and all the other groups were compared with this group. Only three or more children had statistical significant effect on infant feeding practices. The odds of observing appropriate infant feeding

practices were 0.303 less likely for mothers with one child as compared to those with three or more children. .

Religion variable was dummy coded using Muslims as the reference group. The odds of observing appropriate infant feeding practices were 5.488 times more likely for Muslims as compared to Christians.

Participation in PMTCT program variable was dummy coded using mothers who participated in the program as the reference group. The odds of observing appropriate infant feeding practices were 2.260 times more likely for the mothers who participated in the PMTCT program as compared to those who did not participate in the program.

CHAPTER 5.0 DISCUSSION OF RESULTS

Discussion of the results is presented in this chapter under four main sections, namely, knowledge on MTCT among the HIV-infected mothers, infant feeding practices 0-6 months among the HIV-infected mothers, factors influencing choice of infant feeding options among the HIV-infected mothers, and relationship between level of knowledge on MTCT and infant feeding practices of the HIV-infected mothers.

5.1 Knowledge on MTCT among the HIV-infected mothers

This study found that only 39.5% of the HIV-infected mothers had good knowledge on MTCT. Maternal knowledge on MTCT is an important pillar in prevention of mother-to-child transmission of HIV. When mothers know when MTCT happens and how to prevent it from happening, they will seek the services available for PMTCT and adhere to the program to protect their unborn babies and infants from HIV infection. Poor knowledge of MTCT might be due to the fact that majority of the mothers were less educated and had less access to health services and health information. It might also be due to poor counseling on the subject by the health workers and the counselors. Poor knowledge of MTCT and its prevention among the mothers may lead to underutilization of the PMTCT services and increased risk of HIV transmission from mothers to children. Similar facility based cross-sectional studies from Nigeria, Kenya and Southwest Ethiopia showed higher proportion of mothers 86.9%, 66.7% and 65.9% respectively with good level of knowledge on MTCT (Hailu *et al.*, 2017; Wapang'ana, 2013; Wangwe *et al.*, 2013). However, community based cross-sectional studies in Ethiopia and Kenya showed a far less level of knowledge on MTCT, 34.9% and 8.9% respectively (Luba *et al.*, 2017 and Omwega *et al.*, 2006). The difference between those facility based studies and the community based studies

showed that community based studies with more representation from the population give clearer picture of the real situation in the population.

Although most of the HIV-infected mothers (88.2%) were aware that HIV can be transmitted from an infected mother to her baby, there is gap in knowledge of timing of transmission and how MTCT occurs. The proportion of mothers who knew that MTCT can also occur in this study was high compared to a study from Southwest Ethiopia where 75.3% of the mothers were reported (Hailu *et al.*, 2017), and low compared to a similar facility based study from Nigeria where 91% of the mothers were found to be aware of MTCT (Adeleke *et al.*, 2009).

This study found that only 29.3% of the HIV-infected mothers knew that MTCT can occur during pregnancy. This might be due to poor counseling on the subject in the ANC clinics and PMTCT programs. All mothers need to know that their babies are not safe from HIV during pregnancy, and that ARVs are available to protect their babies during pregnancy. They also need to understand the importance of HIV testing through ANC clinics and VCT centers as well as ART adherence during pregnancy. Knowledge gap may make the mothers reluctant to take the ARVs during pregnancy because of the side effects of the drugs and the exacerbation of pregnancy symptoms and this will put their babies at risk of HIV during pregnancy. The proportion of mothers in this study was very low compared to the cross-sectional studies from Tanzania, Uganda and Southern Ethiopia where 91.2%, 60% and 48.8% respectively of the pregnant HIV-positive women had knowledge that HIV could be transmitted from an infected pregnant woman to her unborn child (Nakuzelwa and Kayombo, 2016; Asefa and Beyene, 2013; Robert *et al.*, 2010). In Nigeria, transplacental route (41%) was also the commonest route of MTCT identified by most of the HIV-infected mothers (Adeleke *et al.*, 2009).

This study found that 74.7% of the HIV-infected mothers knew about MTCT during labor and delivery, which is still not fulfilling because all mothers need to have this information so that they opt for hospital delivery or cesarean section to minimize risk of HIV transmission during this period. However, this proportion was higher than the study conducted in Southern Ethiopia where 58.6% of the pregnant women knew that MTCT can also occur during labor and delivery (Asefa and Beyene, 2013).

Although most of the HIV-infected mothers (83.6%) were aware about HIV transmission through breastfeeding, their knowledge about risk factors associated with HIV transmission through breastfeeding was limited. Most of the mothers were able to identify breast conditions as risk factors but only 19.5% of the mothers were able to identify mother's breast milk as a risk factor for HIV transmission to her baby because of contamination with the virus. Comprehensive knowledge of risk factors associated with HIV transmission during breastfeeding is crucial as well as ART adherence during the entire period of breastfeeding. In Southern Ethiopia, only 40.7% of the respondents were found to be knowledgeable of transmission through breastfeeding (Asefa and Beyene, 2013).

From the FGDs it was evident that the mothers lack knowledge and understanding of when and how MTCT occurs. None of the mothers mentioned HIV transmission from mother to child during pregnancy, they all think that the baby is safe during pregnancy and transmission can only occur during delivery when the mother's infected blood come into contact with the baby when cutting the umbilical cord and during breastfeeding if the mother had a wound on her breast. None of the mothers mentioned mother's breast milk as a source of HIV transmission from mother to child during breastfeeding.

One of the mothers had this to say *“I heard that the baby can get HIV even if the mother’s breast is ok, but I don’t understand how the bad blood from the mother will reach the baby if the mother’s breast is ok, it is confusing.”*

According to the WHO, UNICEF, UNAIDS, and UNFPA guidelines on HIV and infant feeding, recommended breast milk alternatives in the first six months of infant’s life include commercial infant formula milk, expressed, heat-treated breast milk, and breast milk from a wet nurse. Most of the HIV-infected mothers correctly identified infant formula milk as an alternative to breast milk in the first six months of infant’s life. None of the mothers knew about expressed, heat-treated breast milk or breast milk from a wet nurse as alternatives to breast milk in the first six months of infant’s life. This gap was also captured from the FGDs where most of the mothers agreed on infant formula milk as the best alternative to breast milk, expressed, heat-treated breast milk and breast milk from a wet nurse were not mentioned. More than half of the mothers also agreed with giving baby water and/or porridge, tea, juice, food in the first six months of life. . Animal milk was mentioned by some of the mothers because of its availability and is perceived to be more nutritious for the baby than the breast milk in some communities, this is an evidence for a gap in counseling because animal milk is no longer recommended by WHO as main infant feeding option or breast milk alternative in the first six months of infant’s life.

The knowledge gap of breast milk alternatives in the first six months of life could be attributed to a gap in counseling on them in the PMTCT programs. This gap in counseling was also found in Southern Ghana, Kenya, Uganda, Botswana and Malawi (Laar and Govender, 2011; Chopra and Rollins, 2008).

Regarding PMTCT, most of the HIV-infected mothers think that giving babies medicines for HIV is the only way of preventing them from getting the virus from their mothers, and 62.2% of them agreed that taking medicines for HIV by the mothers can also help their babies. Delivery by caesarean section was identified as a method of prevention of MTCT by only 14.1% of the mothers while 11.5% of the mothers did not know any method of prevention of MTCT. Poor knowledge of PMTCT can lead to unsafe infant feeding practices and poor adherence to ART during pregnancy and breastfeeding with disastrous consequences on children.

These findings were similar to a study conducted in a teaching hospital in Nigeria, where delivery by caesarean section as a method of prevention of MTCT was identified by only 15.5% of the respondents and as many as 29.8% of the respondents did not know any method of prevention of MTCT (Adelaja, 2012).

From the FGDs, almost all the mothers were convinced that giving the baby medicines for HIV is a way of preventing the baby from getting the infection, which was just a logical way of thinking. However, some mothers did not agree with giving the baby medicine for HIV when they did not even know whether the baby has the virus or not, but they do not mind giving their babies these medicines when they were known to be HIV infected.

Only one mother reported that taking HIV medicines by the mother can also help the baby, this is what she had to say *“Everything that the mother eats or drinks come in the breast milk including medicines, so the baby can benefit from these medicines coming from the mother during breastfeeding”*.

The mothers failed to mention avoidance of breastfeeding and caesarean section as methods of prevention of MTCT, which could also all be attributed to a gap in counseling in the PMTCT programs.

From the key informant interviews, the gap in counseling in the PMTCT programs could be attributed to:

- i. Lack of professionals such as doctors and pharmacists – the ART centers were managed by clinical officers and nurses. They have 2 counsellors at the VCT, 2 at the PMTCT, and 2 at the ART center, two laboratory technicians, two nurses who were trained on dispensing the ARVs, and 3 clinical officers who were responsible for management of the patients, including assessing the patients, ordering the laboratory tests and prescribing the ARVs.
- ii. Shortage in number of counselors and support staff – led to multitasking, and the increased workload among the counselors and lack of time to counsel effectively even for those who might have adequate knowledge
- iii. Lack of training opportunities for the staff in general and the counselors in particular to keep them up-to-date with the new guidelines and recommendations on HIV and infant feeding. Lack of trainings might have led to lack of confidence among the counselors to deliver the information to the HIV-infected mothers.

5.2 Infant feeding practices 0-6 months among the HIV-infected mothers

According to the WHO, UNICEF, UNAIDS, and UNFPA guidelines on HIV and infant feeding, recommended infant feeding options for HIV-infected mothers in the first six months of life include exclusive breastfeeding and exclusive formula feeding. Mixed feeding and home-modified animal milk are not recommended.

In this study, mixed feeding was the predominant method of infant feeding among the HIV-infected mothers. Majority of the mothers mix fed their infants in the first six months of their lives, they mainly mixed breast milk with water and/or infant formula milk, porridge, juice, food. This is consistent with findings from Kenya and Southern Ghana (Wapang'ana, 2013; Laar and

Govender, 2011). The fact that majority of the mothers mix fed their babies despite their knowledge of mother-to-child transmission of HIV through breastfeeding and knowledge of commercial infant formula milk as the ideal replacement feeding could be explained by the social norms, financial challenges facing the mothers as 95.4% of them earn less than 50 US dollars per month, alongside poor feeding, hence low milk production, and most of them are the breadwinners in the family, so they had to go to work and leave the baby in other people's care.

From the FGDs, mixed feeding is a normal practice in the community; water is given from the first days of life as a normal practice, and porridge mainly from three to four months because it was perceived to be more nutritious to the baby at that age. This mixed feeding could also be attributed to a gap in counseling in PMTCT programs because most of the mothers reported that they were told by the counselors to stop breastfeeding at six months, but they were not told about the risk of mixed feeding before six months and correct timing of weaning, so they started giving porridge, juice and food earlier for their babies to get used to other liquids and foods other than the breast milk to make weaning easier at six months.

One of the mothers had this to say, *“We were told at the clinic to breastfeed for six months only and stop completely by the end of six month, as for me, I started giving my baby powder milk from three months old, and porridge and soup from three and half so that he can get used to them early enough.”*

The mothers also reported that they could not afford to buy the infant formula milk because of its high cost and they also had other children to feed.

This is what one of them had to say *“A tin of the baby's milk is very expensive, some of us even don't earn that money in a whole month, leave alone other children in the house who also need to be fed, I don't think I will buy that milk if I ever get pregnant again.”*

In this study the proportion of HIV-infected mothers who practiced exclusive breastfeeding (EBF) was comparatively lower (23.0%) than the findings reported from Ethiopia (89.5%), Lesotho (89%), Nigeria (61.0%), Kenya (40.6%), and Uganda (24%) (Olorunfemi and Dudley, 2018; Usman *et al.*, 2015; Muluye *et al.*, 2012; Wapang'ana, 2011; Fadnes *et al.*, 2009).

In this study and all the above mentioned studies the proportion of mothers who practiced exclusive formula feeding (EFF) was far less compared to those who practiced EBF.

Mothers who practiced exclusive breastfeeding did so because of its nutritious benefits and availability, while those who practiced EFF was mainly to avoid the risk of transmitting HIV to their babies. In Ethiopia EBF was practiced as social norms and in Nigeria it was mainly practiced because of fear of stigmatization if they chose not to breastfeed their babies, and in all the above studies EFF was practiced due to the desire to reduce risk of MTCT.

One mother said her baby was fed on cow's milk only because she was too ill to breastfeed and the cow's milk was available.

Due to the economic crisis that the Republic of South Sudan has been facing since 2013, exclusive breastfeeding is almost impossible because of hunger due to famine, and subsequent insufficient breast milk in lactating mothers, as well as continuous absence of mothers from homes trying to earn a living or supplement household incomes. Exclusive formula feeding is impractical because of the financial constraints in the economy and high cost of the formula. Hence, mixed feeding is generally a widespread practice arising from the circumstances, which unfortunately put many children born to HIV-infected mothers at higher risk of infection from their mothers.

5.3 Factors influencing choice of infant feeding options among the HIV-infected mothers

5.3.1 Number of children

This study found that mothers with one child were less likely to practice appropriate infant feeding methods as compared to those with three or more children, most probably due to the fact that new mothers lack experience in infant feeding and can easily be influenced by advice and pressure from family members, relatives and friends. This is consistent with findings of Usman in Nigeria, where mothers with two or less children were more likely to practice mixed feeding (Usman *et al.*, 2015).

5.3.2 Religion

Majority of the mothers (95.7%) were Christians, while the rest were Muslims. This is consistent with Republic of South Sudan population where majority are Christians. This study found that Muslims were more likely to practice appropriate infant feeding methods as opposed to Christians, most probably because breastfeeding is the most common infant feeding method in Islamic communities. This finding is different from studies in Kenya and Ethiopia where there was no statistically significantly difference between Muslims and Christians with regard to infant feeding practices of the mothers (Mwangi, 2012; Muluye *et al.*, 2012).

5.3.3 Stigma

Although majority of the mothers did not experience stigma/discrimination from spouse, family, relatives, friends or the community because of their HIV status, 34.9% of them did experience stigma. Stigma was found not be statistically significantly associated with the mothers' infant feeding practices. This contradicts findings of Usman *et al.* and Muluye *et al.* in Nigeria and Ethiopia respectively, where high proportion of mothers practiced exclusive breastfeeding due to

fear of stigmatization (Usman et al, 2015; Muluye et al, 2012). From the FGDs it was also evident that fear of stigmatization can influence infant feeding decision making.

This is what one of the mothers had to say *“Some people suspect that you have HIV when you do not breastfeed your baby, I personally did not stop breastfeeding at six months to avoid questions from relatives and neighbors.”*

“That is true, and when they know that you were actually HIV-positive, they stopped talking to you and calling you names among themselves or even on your face” another mother added.

5.3.4 Participation in PMTCT program

This study found that mothers who participated in the PMTCT programs were more likely to practice appropriate infant feeding methods as compared to those who did not participate; this highlighted the importance of participation in PMTCT program which should be encouraged. This finding is consistent with that of Olorunfemi and Dudley in Lesotho and Usman et al. in Nigeria where knowledge received in the PMTCT programs was found to be statistically significantly associated with the mothers decision to exclusively breastfeed their infants, and earlier infant feeding counseling was found to be associated with more exclusively breastfeeding as compared to late infant feeding counseling (Olorunfemi and Dudley, 2018; Usman et al., 2015).

5.4 Relationship between level of knowledge on MTCT and infant feeding practices of the HIV-infected mothers

Maternal level of knowledge on MTCT was found not to be statistically significantly associated with their infant feeding practices. This was also found by Wapang'ana in Kenya (Wapang'ana, 2013), but the study conducted by Mwangi in Kenya found significant association between level of knowledge and infant feeding practices of the HIV-infected, those who had average and good knowledge made appropriate infant feeding choices, which was attributed to the accurate information they received from their participation in PMTCT programs (Mwangi, 2012).

Weaknesses of the study

1. There was selection bias due to language barrier, as some of the mothers who met the inclusion criteria did not speak English or Juba Arabic which led to their exclusion
2. There was recall bias, since mothers of children below six months of age were excluded from the study, yet participants were expected to recall infant feeding practices for children below six months of age
3. This was a hospital based study which involved only mothers who were able to access health facilities, hence it may not be a representative of the general population who do not attend health facilities.

CHAPTER 6.0 CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

Knowledge and understanding of when and how MTCT occurs and its prevention is low. Knowledge on infant feeding options in the context of HIV and breast milk alternatives in the first six months of infant's life is also low. Maternal level of knowledge on mother-to-child transmission of HIV does not however affect the feeding practices of the HIV-infected mothers.

Mixed feeding before six months of age is the predominant method of infant feeding among the HIV-infected mothers attending the antiretroviral therapy centers in Juba.

Number of children, maternal religion and participation in the PMTCT program may affect a woman's choice of infant feeding options among HIV-infected mothers.

6.2 Recommendations

Based on the study findings, discussion and conclusions, the followings are recommended:

1. The HIV-infected mothers should receive adequate information from the counselors regarding mother-to-child transmission of HIV, its prevention and various infant feeding options in the context of HIV to help them make decisions that are best for their children.
2. Exclusive breastfeeding in the first six months of infant's life should be promoted at the PMTCT and ART centers with emphasis on continuation of breastfeeding for at least one year or beyond for HIV-infected mothers to increase child survival.
3. HIV-infected mothers should be encouraged to actively participate in PMTCT program activities.

4. Study on infant feeding practices among HIV-infected mothers with children 0-6 months is recommended.
5. Community based study on knowledge on mother-to-child transmission of HIV and practices of infant feeding is recommended for more representation of Juba population.

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APPENDICES

Appendix 1: Structured questionnaire

HIV-infected mothers with children aged 6-18 months attending ART centers at JTH (1) and JMH (2)

Instructions

The questionnaire is set up in four parts. Please put/tick the exact response by the respondent in the box provided.

Questionnaire No _____

Date of interview _____

Name of interviewer _____

Respondent's location _____

PART A

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

1) How old were you at your last birthday?

(1=15-19, 2=20-29, 3=30-39, 4=40-49)

2) What is your marital status?

(1=Married; 2=Cohabiting; 3=Divorced; 4=Separated; 5=Widowed; 6=Single)

3) How many children do you have?

(1= One; 2=Two; 3=Three or more)

4) How old is your last child?

(1=6-12 months; 2=13-18 months)

5) What was the highest level of school you have completed?

(1=None; 2=Primary; 3=Secondary; 4=Tertiary)

6) Who is the main source of income in the family?

(1=Self; 2=Spouse/partner)

7) How much do you earn per month?

*(1=Less than 50 USD; 2=50-100 USD; 3=101-150 USD; 4=151-200 USD; 5=201-250 USD;
6=251-300 USD; 7=more than 300 USD)*

8) What is your religious background?

(1=Christian; 2=Muslim; 3=Others)

PART B

QUESTIONS ON HIV DISCLOSURE, STIGMA, SOCIO-CULTURAL PRACTICES OR BELIEFS, AND PARTICIPATION IN THE PMTCT PROGRAMME

9) Have you disclosed your HIV status to your spouse/partner, family, relatives, and friends?

(1= Yes, 2= No)

10) Have you ever experienced stigma /discrimination from your spouse, family, relatives, friends or the community because of your HIV status?

(1= Yes; 2= No)

11) Are there any socio-cultural practices or beliefs associated with the way you feed your children in the first six months of their lives?

(1= Yes; 2= No)

12) Have you been part of prevention of mother-to-child transmission program?

(1= Yes; 2= No)

PART C

LEVEL OF KNOWLEDGE ON MTCT, ITS PREVENTION, RISK FACTORS ASSOCIATED WITH HIV TRANSMISSION THROUGH BREASTFEEDING AND BREAST MILK ALTERNATIVES

13) If a mother is HIV-positive can she transmit HIV to her baby?

a) Yes b) No c) Do not know

14) When can HIV be transmitted from mother to her baby?

a) During pregnancy b) During labor and delivery

c) During breastfeeding d) When carrying the baby e) Do not know

15) Can HIV be transmitted from mother to child during breastfeeding?

a) Yes b) No c) Do not know

16) Through which of the following does HIV gain entry into the child during breastfeeding?

a) Breast milk contaminated with HIV b) Broken skin on the breast

c) Sores in the baby's mouth d) Do not know

17) When mother is HIV infected, what other milk/food can be given to the baby instead of the mother's breast milk in the first six months of live?

a) Infant formula milk b) Animal milk (goat or cow)

c) Water and/or porridge, tea, juice, food d) Expressed heat-treated breast milk

e) Breast milk from a wet nurse/another woman f) Do not know

18) How can HIV transmission from mother to baby be prevented?

a) Cesarean section b) Not breastfeeding the baby at all

c) Taking medicine for HIV d) Giving baby medicine for HIV

e) Do not know

PART D

INFANT FEEDING PRACTICES OF THE HIV-INFECTED MOTHERS

19) What did you use to feed your last baby/babies in their first six months of life?

a) *Breast milk only*

b) *Breast milk and/or water, formula milk, animal milk (cow/goat), porridge, tea, juice, food*

e) *Infant formula milk only*

f) *Formula milk and/or water, animal milk (cow/goat), porridge, tea, juice, food*

g) *Home-modified animal milk (cow/goat) only*

20) What could be the main reason/reasons for choice of the infant feeding method you practiced?

a) *Nutritious for the baby* b) *Less risk of transmitting HIV*

c) *Cheap and readily available* d) *Mother did not have enough milk*

e) *Mother too ill or too weak to breastfeed* f) *It's the traditional feeding practice*

g) *Baby was left in other people's care while mother was at work*

Appendix 2: Focus group discussion guide

Introduction

Welcome to today's focus group discussion. I am planning to gather information to write my academic paper (dissertation) in partial fulfillment of my master degree program at the University of Nairobi, Kenya. I asked you to gather here because I would like to hear from you about your opinions and ideas on mother-to-child transmission of HIV, infant feeding in the first six months, breast milk alternatives, and prevention of mother-to-child transmission of HIV. Everything you are thinking of is important to me. There is no right or wrong answers. I value your opinion.

Ground rules

Before we begin, below are some of the group rules that I will like us to observe;

- Be respectful
- No put downs or insults
- One person speaks at a time
- Be honest
- Maintain confidentiality/do not mention names

Focus Group Discussion (50-60 minutes)

1. Are you aware that a child can be HIV positive?
2. Could you please tell us some of the ways a child get HIV?
3. If a mother is HIV-positive, can her baby get HIV from her?
4. How is a baby of HIV-infected mother supposed to be fed for the first six months of its life?
5. Can the baby get HIV when breastfeeding?
6. How can the baby get HIV when breastfeeding?

7. What other milk can be given to the baby to prevent him from getting HIV?
8. In your community, are there mothers who do not breastfeed their babies?
9. If a mother, for one reason or another decided not to breastfeed her baby, how would the community view her?
10. How can HIV transmission from mother to child be prevented?

Wrap up (5 minutes)

I greatly appreciate all of your thoughts and ideas. You have been a big help, and I want to thank you very much for all the information you have shared with me today. Thank you once again for your participation, I really appreciate you.

Appendix 3: Key informant interview guide

Introduction

Welcome to this key informant interview. I am planning to gather information to write my academic paper (dissertation) in partial fulfillment of my master degree at the University of Nairobi, Kenya. I am here because I would like to know about the HIV services offered by this facility, the PMTCT services, uptake of the services by the mothers and presence of any socio-cultural practices/misconceptions that affect uptake of the services, and challenges facing implementation of the PMTCT program in this facility. You are the expert, and I can learn from you.

Ground rules

Before we begin, below are some of the ground rules that I will like us to observe;

- Be respectful
- Be honest
- Maintain confidentiality/do not mention names

Key informant interview (30-40 minutes)

1. What HIV services/commodities are offered in this facility?
2. What range of PMTCT interventions are offered in this facility?
3. What has been the community response to these PMTCT services?
4. Are there any socio-cultural practices/misconceptions in the community that affect uptake of the PMTCT services?
5. What challenges/constraints did you encounter during implementation of the PMTCT program?

Wrap up (5 mins)

I greatly appreciate all of your thoughts and ideas. You have been a big help, and I want to thank you very much for all the information you have shared with me today. Thank you once again for your participation, I really appreciate you.

Appendix 4: Consent explanation for the mothers

Introduction

My name is Dr. Lily Lejeng, I am a postgraduate student at University of Nairobi pursuing a master degree in Public Health.

I am conducting a study on “Knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending antiretroviral therapy centers in Juba, South Sudan”

Purpose of the study

To assess knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending the ART centers in Juba.

Risk

There are no risks involved by participating in this study.

Benefits

The study is purely for academic purpose and will not be used for any monetary gain.

There may not be any direct benefit to you as a participant. You will not be given any reward or payment for taking part in the study, however, the information gathered from you will be used to put recommendations that will help you get adequate information on how to prevent your child from getting HIV infection. Any results that will benefit you will be communicated to the hospital administrators.

Basis of participation

You are free to consent or not to consent to participate in this study and if you felt like withdrawing from the study while being interviewed, you are free to do so without any punishments. You and your child will continue to get the services you are entitled for even if you decided not to participate in the study.

Procedure

If you agree to participate in the study, you will be asked questions about yourself, mother-to-child transmission of HIV, risk factors associated with HIV transmission through breastfeeding, breast milk alternatives, prevention of mother-to-child transmission of HIV, and the way you fed your baby during its first six months of life. You will have to choose from the available answers. The interview may take between 20-25 minutes.

Confidentiality

Your names will not appear on the forms and all the information you provide will be treated with utmost respect and used only for the purpose of the study.

Information sharing

The findings of the study will be shared with colleagues and staff in the school of public health and other students from institution of higher learning. A copy of the dissertation will be given to the School of Public Health Library, College of Health Sciences Library, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee as well as the Ministry of Health, Republic of South Sudan. A manuscript will be produced from this research for publication in a scientific peer reviewed journal and will also be published in South Sudan Medical Journal for

academic purposes.

Important findings will also be shared with the hospital administrators to help them put measures that will make you get full and accurate information regarding infant feeding in the context of HIV, and hence help you make decisions that are for the best of your children.

Contact information

You may ask any question about the study now or you can contact me at any time for more information about the study on the following numbers +211956431534 / +254705980155, or my Supervisors: Prof. Joyce Olenja and Dr. Rose Okoyo Opiyo, at the School of Public Health, University of Nairobi through the secretary Mrs. Jane on this number +254202724639, or the Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee through P.O. Box 20723 – 00202 Nairobi, Telephone +25420272527, Extension 44102 and Email luonknh_erc@uonbi.ac.ke.

Appendix 5: Consent form for the mothers

Having read the consent explanation and/or explained to about the study, its purpose and what it entailed and also given opportunity to ask questions, I hereby AGREE / DISAGREE to participate in this study. I understand that I have the right to withdraw from the study at any time, my names will not be included in the questionnaire, answers given are confidential and the information will only be used for the purpose of this study.

Participant's signature or fingerprint Date.....

I, Dr. Lily Lejeng / Research assistant confirm that I have explained the relevant parts of the study to the participant.

Principal investigator/Research assistant signature..... Date.....

Appendix 6: Consent explanation for the mothers of the FGDs

Introduction

My name is Dr. Lily Lejeng, I am a postgraduate student at University of Nairobi pursuing a master degree in Public Health.

I am conducting a study on “Knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending antiretroviral therapy centers in Juba, South Sudan”

Purpose of the study

To assess knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending the ART centers in Juba.

Risks

There are no risks involved by participating in this study.

Benefits

The study is purely for academic purpose and will not be used for any monetary gain.

There may not be any direct benefit to you as participants. You will not be given any reward or payment for taking part in the study, however, the information gathered from you will be used to put recommendations that will help you get adequate information on how to prevent your child from getting HIV infection. Any results that will benefit you will be communicated to the hospital administrators.

Basis of participation

You are free to consent or not to consent to participate in this study and if you felt like withdrawing from the study during the discussion, you are free to do so without any punishments. You and your child will continue to get the services you are entitled for even if you decided not to participate in the study.

Procedure

If you agree to participate in the study, you will be asked questions about mother-to-child transmission of HIV, infant feeding in the first six months of life, breast milk alternatives, and prevention of mother-to-child transmission of HIV. Each one of you will get chance to share her opinion. The discussion may take between 50-60 minutes.

Confidentiality

Your names will not appear on the forms and all the information you provide will be treated with utmost respect and used only for the purpose of the study.

Information sharing

The findings of the study will be shared with colleagues and staff in the school of public health and other students from institution of higher learning. A copy of the dissertation will be given to the School of Public Health Library, College of Health Sciences Library, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee as well as the Ministry of Health, Republic of South Sudan. A manuscript will be produced from this research for publication in a scientific peer reviewed journal and will also be published in South Sudan Medical Journal for academic purposes.

Important findings will also be shared with the hospital administrators to help them put measures that will make you get full and accurate information regarding infant feeding in the context of HIV, and hence help you make decisions that are for the best of your children.

Contact information

You may ask any question about the study now or you can contact me at any time for more information about the study on the following numbers +211956431534 / +254705980155, or my Supervisors: Prof. Joyce Olenja and Dr. Rose Okoyo Opiyo, at the School of Public Health, University of Nairobi through the secretary Mrs. Jane on this number +254202724639, or the Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee through P.O. Box 20723 – 00202 Nairobi, Telephone +25420272527, Extension 44102 and Email luonknh_erc@uonbi.ac.ke.

Appendix 7: Consent form for the mothers of the FGDs

We have been explained to about the study, its purpose and what it entailed and also given Opportunity to ask questions and we hereby AGREE / DISAGREE to participate in this study. We have decided to keep confidentiality of whatever we have discussed as a group and not reveal each other disclosure of whatever we discussed.

We understand that we have the right to withdraw from the study at any time, our names will not be mentioned, answers given are confidential and the information will only be used for the purpose of this study.

Participants' signature or fingerprints..... Date.....

I, Dr. Lily Lejeng confirm that I have explained the relevant parts of the study to the participants.

Principle investigator signature Date

Appendix 8: Consent explanation for the key informants

Introduction

My name is Dr. Lily Lejeng, I am a postgraduate student at University of Nairobi pursuing a master degree in Public Health.

I am conducting a study on “Knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending antiretroviral therapy centers in Juba, South Sudan”.

Purpose of the study

To assess knowledge on MTCT and practices of infant feeding among HIV-infected mothers attending the ART centers in Juba.

Risks

There are no risks involved by participating in this study.

Benefits

The study is purely for academic purpose and will not be used for any monetary gain. There may not be any direct benefit to you as a participant. You will not be given any reward or payment for taking part in the study, however, the findings of this study will provide information to the health authorities and health practitioners in the Republic of South Sudan on the practice of exclusive breastfeeding in the PMTCT programs. It will also help in evaluation of adequacy of the current infant feeding counseling in the context of HIV, and hence provide knowledge that will be used in capacity building of the counselors to help HIV-infected mothers make decisions that are best for their children.

Basis of participation

You are free to consent or not to consent to participate in this study and if you felt like withdrawing from the study while being interviewed, you are free to do so without any penalty.

Procedure

If you accept to take part in the study, then you will be asked questions about the HIV services offered by this facility, the PMTCT services, uptake of the services by the mothers, presence of any socio-cultural practices/misconceptions that affect uptake of the services, and challenges facing implementation of the PMTCT program in this facility.

Confidentiality

Your names will not appear on the forms and all the information you provide will be treated with utmost respect and used only for the purpose of the study.

Information sharing

The findings of the study will be shared with colleagues and staff in the school of public health and other students from institution of higher learning. A copy of the dissertation will be given to the School of Public Health Library, College of Health Sciences Library, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee as well as the Ministry of Health, Republic of South Sudan. A manuscript will be produced from this research for publication in a scientific peer reviewed journal and will also be published in South Sudan Medical Journal for academic purposes.

Important findings will also be shared with the hospital administrators to help them put measures that will make the HIV-infected mothers get full and accurate information regarding infant feeding

in the context of HIV, and hence help them make decisions that are for the best of their children.

Contact information

You may ask any question about the study now or you can contact me at any time for more information about the study on the following numbers +211956431534 / +254705980155, or my Supervisors: Prof. Joyce Olenja and Dr. Rose Okoyo Opiyo, at the School of Public Health, University of Nairobi through the secretary Mrs. Jane on this number +254202724639, or the Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee through P.O. Box 20723 – 00202 Nairobi, Telephone +25420272527, Extension 44102 and Email 1uonknh_erc@uonbi.ac.ke.

Appendix 9: Consent form for the key informants

Having read the consent explanation and explained to about the study, its purpose and what it entailed and also given opportunity to ask questions, I hereby AGREE / DISAGREE to participate in this study. I understand that I have the right to withdraw from the study at any time, my names will not be mentioned, answers given are confidential and the information will only be used for the purpose of this study.

Key informant signature Date.....

I, Dr. Lily Lejeng confirm that I have explained the relevant parts of the study to the participant.

Principle investigator signature..... Date.....