

The fear of mother's milk in the era of HIV:
A qualitative study among HIV positive mothers and health
professionals,
Addis Ababa, Ethiopia

“He is hungry and wants milk, but what can I give him?”

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**Centre for International Health
Faculty of Medicine and Dentistry
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This thesis is submitted in partial fulfilment of the requirements for the degree of Master of
Philosophy in International Health at the University of Bergen, Norway



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Dedication

In loving memory of

*My late Father Teshome and
My late Grand Father Tafese*

Abstract

Background: Breastfeeding remains normative and vital for child survival in the developing world. However, the knowledge of HIV transmission through breastfeeding has become an enormous public health dilemma, and has brought to the forefront of attention the controversy linked to whether breastfeeding can safely be promoted in high HIV epidemic areas.

Exclusive replacement feeding can fully prevent postnatal transmission of HIV infection in children, however, it is neither acceptable nor a feasible option in the developing world. As a result of the dilemmas linked to infant feeding among HIV positive women, the World Health Organization in 2001 published a set of guidelines that promoted modified infant feeding alternatives for HIV positive mothers, where mothers were advised to avoid all breastfeeding if replacement feeding was acceptable, feasible, affordable, sustainable and safe. To our knowledge, no studies have qualitatively explored the challenges of HIV positive infant feeding women and health professionals who are counselling HIV positive women on infant feeding choices in a context where mothers' milk has been increasingly feared as safe nutrient for a baby.

Aim: This study aimed at exploring the experiences of HIV positive mothers and their counsellors related to infant feeding choices and adherence to the chosen infant feeding methods in the context of PMTCT programs.

Methods: The study was conducted in two governmental hospitals in Addis Ababa, Ethiopia, from June to August 2007. Qualitative data triangulation was used as a means of data collection. A total of 32 in depth interviews were conducted with 14 HIV positive mothers who chose breastfeeding, 8 HIV positive mothers who practiced replacement feeding, and 10 health professionals (counsellor nurses, and paediatricians) working in the infant feeding clinics. Participant observation and two case studies were also included. All interviews were audio recorded, transcribed and translated from Amharic to English. Manual data coding, categorizing and thematic analysis was performed to draw up on the emerging themes. The research received ethical clearance from the Regional Ethical Clearance Committee of the Addis Ababa Regional Health Bureau, Ethiopia. All informants gave oral informed consent.

Results: All informants expressed their fear of breast milk, and the way they handled the infant feeding situation was strongly influenced by this fact. The infant feeding choices and

practices of the HIV positive mothers in the study were moreover strongly influenced by the health professionals' advice, the immense fear of disclosure of their HIV status, and the related social surroundings. The challenging and continuously shifting WHO guidelines and the corresponding confusion both among counsellors and mother regarding what was optimal feeding alternative for HIV positive women had a great impact on the HIV positive mothers' difficulties in adhering to any of the infant feeding options. Whether HIV positive mothers chose replacement feeding or exclusive breastfeeding, the practice was highly uncommon in the local setting and hence created immense challenges for the women in terms of scrutiny and blame. The guidance and advice given to the HIV positive mothers in the two study hospital settings varied, but in both places, the fear of milk was found to be at the forefront of attention whatever the actual advice given to the women was.

Conclusion: Fear of breast milk challenged the choices and practices of infant feeding among HIV positive mothers and the health professionals supporting them. The study indicates that the latest international infant feeding recommendation that brings breastfeeding back as the main infant feeding method for HIV positive women, will meet great challenges in implementation. This is in a context where both HIV positive mothers and counsellors for years have been told that breast milk contains HIV that can infect babies with a highly morally condemned and non-curable disease.

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Acronyms and abbreviations

AIDS - Acquired Immunodeficiency Syndrome

ANC - Antenatal clinic

ARV - Antiretroviral

ART- Antiretroviral Treatment

CSA - Central Statistical Agency

CSWs- Commercial Sex Workers

DHS - Demographic and Health Survey

GDP - Gross Domestic Product

HAPCO- HIV/AIDS Prevention and Control Office

HIV - Human Immunodeficiency Virus

MOH - Ministry of Health

MTCT - Mother to Child Transmission

NGOs- Non-Governmental Organizations

NVP- Nevirapine

PCR- Polymerase Chain Reaction

PHC- Primary Health Care

PMTCT - Prevention of Mother to Child Transmission

SMX-TMP- Sulfamethaxazole-Trimethoprim

TFR- Total Fertility Rate

UNAIDS - United Nations AIDS Programme

UNFPA- United Nations Population Fund

UNGASS- United Nations General Assembly Special Session

UNICEF - United Nations Children's Fund

VCT - Voluntary Counselling and Testing

WHO - World Health Organization

Acknowledgement

First and foremost, I would like to say Praise the Lord!

There are a number of people to whom I am indebted and whom I wish to thank for making this research happen. I would like to thank my informant mothers who were willing to sit and talk to me despite their enormous challenges, busy schedules and restless babies on their laps.

My heartfelt gratitude also goes to the staff and administration of Yekatit 12 Hospital and Zewditu Memorial Hospital for allowing me to do my research there; and above all for creating a conducive environment for my informant mothers and me. I would also like to thank my research assistants, nurse Sinidu and nurse Ferdos.

I have insufficient words to express my gratitude to my supervisor, Professor Astrid Blystad. Your priceless inspiration and encouragement from the very beginning has been a wonderful experience. Your comments and suggestions encouraged me to think critically. And above all, your friendship and warm messages of support in those rainy, dark, cold days were very comforting. Thank you!!

The staff members at the Centre for International Health, University of Bergen created a pleasant working environment and made me to realise that our cultural differences are so enjoyable and educational. Many thanks!

I would also want to thank the Norwegian Agency for Development Cooperation (NORAD) for granting me the scholarship to pursue my study in Norway. Likewise, I would like to thank Save the Children, Norway for partially supporting my fieldwork costs.

My heartfelt gratitude also goes to my dear friends and colleagues at Fantoft, and the Abesha community in Bergen. Thank you for creating a sociable environment and making my stay unforgettable.

Finally I would like to thank my family for their love and warmth and for the confidence that they have in me. My only sister and my best friend, Nolawit, I love you!

Preface

At the beginning of 2005, as part of my career as an assistant lecturer in Nutrition at Debu University, Ethiopia, I was sent to attend a training course arranged by the then LINKAGES/Ethiopia project on 'Essential Nutrition Action'. The training focused on infant and young child feeding. As part of the module, infant feeding in the era of HIV was included. In that context, we were given the chance to visit Zewditu Memorial Hospital located in Addis Ababa, the capital of Ethiopia. At that time, the infant feeding and counselling clinic at the hospital was among the few existing in the country, and was furthermore the pioneer where different research projects on infant feeding were undertaken.

During our visit, my group was able to meet with a couple of HIV positive mothers who were either feeding their infants formula milk or breastfeeding. My colleague and I got the chance to interview a mother who breastfed her infant for a few weeks, and who was later formula feeding her infant. During our discussion with the woman, it was easy to see that the child on the mother's lap was emaciated and weak. The mother told us that she had learnt of her HIV status during the last months of her pregnancy. As part of the exercise of the training course, we asked the mother how she was preparing the infant formula that she was giving to her child. I was struck by the mother's answer: *"It is very expensive to buy tinned milk. My child is growing and has started to demand more. One tin is not even keeping her for a week. Because of that I have started to add more water than what I have been told."* My colleague asked her why she had stopped breastfeeding her child as she knew that buying formula milk would be too expensive. The mother replied his question with another question: *"What was the alternative? To continue to breastfeed and infect my child with HIV?"*

This was the moment when I realised how extremely challenging infant feeding in the era of HIV is for mothers, particularly women living in low-income contexts like Ethiopia. This experience left me with many unanswered questions, and motivated me to learn more about how HIV positive mothers experience the challenges of infant feeding in the context of the WHO-initiated concept of the prevention of mother-to-child transmission of HIV. When I was later admitted to the M.Phil programme in International Health at the University of Bergen, I was given a unique opportunity that paved the way for answering at least some of the questions that had troubled my mind since my course attendance. I particularly wish to assess issues related to how HIV positive women were told to cope with the infant feeding

challenge, what they were informed to do in the programme for the prevention of mother-to-child transmission of HIV, and what they practically ended up doing in their desperate struggle to save their beloved children from HIV infection.

► *The quote on the cover page is taken from an interview made with an HIV positive mother who was replacement feeding her 5 months old infant.*

1. Introduction

The World Health Organization (WHO) estimated that in 2007 there were 2.5 million (2.2-2.6 million) children under the age of 15 living with Human Immunodeficiency Virus (HIV) worldwide. Of these children, 420,000 were estimated as new infections in the year 2007. Ninety percent of the HIV infected children live in sub Saharan African countries (UNAIDS/WHO. 2007: pp1-8)

World wide 90% of the HIV infections in children are consequences of the so-called 'Mother to Child Transmission' (MTCT) of HIV which can occur during pregnancy, labour and post partum through breastfeeding (WHO/UNAIDS/UNICEF 1998; Nduati, John et al. 2000: p 1167; Dabis and Ekpini 2002: p 2098; WHO 2004: p1). If there are no specific interventions that are initiated to reduce the risk of MTCT of HIV (with breastfeeding up to 18-24 months) the over all transmission rate was estimated to reach 35% (De Cock, Fowler et al. 2000).

Postnatal transmission of HIV through breastfeeding has been deemed the factor where we find greatest discrepancy between developing and developed world in terms of HIV transmission to children (De Cock, Fowler et al. 2000: p1176; Dabis and Ekpini 2002; WHO 2004). Through the use of replacement feeding, postnatal HIV transmission was avoided in the developed world. This alternative has however not been equally easy to opt for in low-income contexts. This has produced a dilemma of weighing the benefits of replacement feeding vs. breastfeeding.

In order to tackle this substantial public health dilemma, international organizations (e.g. the World Health Organization, United Nations AIDS Program) have been suggesting modified infant feeding options in an attempt to reduce the risk of postnatal HIV transmission. Based on the 2001 recommendation (WHO. 2001), avoidance of all breastfeeding by HIV infected mothers to whom replacement feeding was acceptable, feasible, affordable, sustainable and safe (otherwise known as the 'AFASS criteria') was recommended. For HIV positive mothers who did not fulfil the criteria to replacement feed their infants, exclusive breastfeeding with early cessation, heat-treated expressed breast milk and wet nursing were the alternatives (ibid). However, the revised international infant feeding recommendation for HIV positive mothers living in resource constrained settings (WHO. 2007) suggests exclusive breastfeeding

by all HIV infected mothers as the prime infant feeding choice for HIV positive mothers living in resource constrained settings who don't fulfil the AFASS criteria to practice exclusive replacement feeding (WHO. 2007). This revision considered research findings from African settings which evaluated the consequences of the available infant feeding alternatives for HIV positive mothers (predominantly exclusive breastfeeding and exclusive replacement feeding). Increased child morbidity and mortality associated with replacement feeding and the increased child mortality and morbidity associated with early cessation of breastfeeding were the major findings which urged the revision (WHO. 2007). However, in sub Saharan African countries exclusive breastfeeding is not common. Rather mixed feeding patterns, which increase the risk of HIV transmission, are widely practiced (de Paoli, Manongi et al. 2002; Piwoz and Humphrey 2005).

Our study has assessed the experiences of HIV positive mothers who are struggling to choose and to adhere to the WHO's recommended infant feeding options as well as the experiences of health personnel regarding infant feeding in the context of PMTCT of HIV. The study was conducted during the time when the recent infant feeding recommendation for HIV positive mothers which suggested exclusive breastfeeding by all mother who don't fulfil the AFASS criteria was published (WHO. 2007), albeit not yet implemented in Ethiopia. Hence, we were able to explore HIV positive mothers' and health professionals' beliefs and perceptions about breast milk in a context of long standing campaigns informing about breast milk and its potentials in transmitting HIV infection to infants through breastfeeding.

2. Background information and Literature review

2.1 Mother to child transmission (MTCT) of HIV

Mother to child transmission of HIV, medically referred to as vertical transmission, is known to be responsible for more than 90% of HIV infections in children world wide (WHO/UNAIDS/UNICEF 1998; Perez, Orne-Gliemann et al. 2004: p1147). The transmission can occur during pregnancy, during delivery and post partum through breastfeeding (De Cock, Fowler et al. 2000; Nduati, John et al. 2000: p1167; Dabis and Ekpini 2002: p2098; WHO 2004: p1). Because children primarily acquire HIV from their HIV infected mothers, the incidence of paediatric HIV infection gives an indication of HIV infection in women of child bearing age (WHO/UNAIDS/UNICEF 1998: p7).

If no specific interventions are carried out to reduce the risk of HIV transmission rate, as written in the previous page, reaches 35% (De Cock, Fowler et al. 2000). Antiretroviral (ARV) combination therapy given to women during pregnancy and labour and to the infant during the first weeks of life, elective cesarean delivery (before the onset of labour and rupture of membranes), and avoidance of all breastfeeding have been documented to reduce MTCT of HIV rates to <2% in industrialized countries (Mofenson 2000; WHO 2004: p5).

The difference in risk of MTCT of HIV in high income and low income countries has been attributed to multiple factors; but breastfeeding contributes the bigger proportion of the discrepancy (De Cock, Fowler et al. 2000: p1176; Dabis and Ekpini 2002: p2100; WHO 2004: p7). Between 5% and 20% of infants born to HIV positive mothers are infected after birth, primarily during the phase of breastfeeding (WHO 2004). In theory, therefore the best way to avoid postnatal transmission of HIV infection in children born to HIV infected mothers is the complete avoidance of breastfeeding. However, in practice complete avoidance of breastfeeding has proven to be a far more challenging issue in the developing world than in the developed world (WHO. 2001: p13).

The estimated rates of HIV transmission from mother to child during pregnancy, labour and breastfeeding are presented in the following table.

Table 1. Rates of mother to child transmission of HIV

Time	Rate of HIV transmission
Pregnancy	5-10%
Labour and delivery	10-20%
Breastfeeding	5-20%
Overall without BF	15-30%
Overall with BF to 6 months	25-35%
Overall with BF to 18-24 months	30-40%

Source: Adapted from De Cock et al., (2000) Prevention of mother-to-child HIV transmission in resource-poor countries –Translating research into policy and practice. JAMA; 283: 1175-82

2.2 Breastfeeding and HIV transmission

It is well established that breastfeeding provides substantial benefits to both children and mothers. Breast milk contains all the essential nutrients for health and growth of infants, and it contains anti-infective properties which are not present in breast milk substitutes (Latham and Preble 2000; WHO. 2001). Moreover, breastfeeding was estimated to prevent about 13% under-5 child deaths (Jones G., Steketee R W. et al. 2003: p67).

Breast milk has also been documented to enhance the child's quality of child's life beyond its nutritional aspects. The psychological benefits of breastfeeding have been pointed out for both mother and child (Latham 1999: p1304; Read 2003: p1196; WHO 2004: p3). If a women exclusively or almost exclusively breastfeeds during the first six months, and has not resumed menstruation, it has been document that in a normal cohabitating couple there will be less than 2% risk that the woman becomes pregnant again (WHO. 2001: p3). Breastfeeding thus enhances child spacing and with it the life chances of the born child. Most importantly, breastfeeding has been accepted as the biological norm (Latham 1999: p1304).

MTCT of HIV through breastfeeding was recognised at a point when it was documented that children got HIV infection from mothers who were infected postnatally through blood transfusion or through heterosexual exposure (Palasanthiran, Ziegler et al. 1993: p441; Ziegler, Palasanthiran et al. 1993). Later HIV transmission through breastfeeding has been documented through a number of studies (see e.g. Bobat, Moodley et al. 1997; Nduati, John et al. 2000; Read 2003; Iliff, Piwoz et al. 2005).

After HIV transmission through breastfeeding has been established, different studies have been conducted to estimate the risk of transmission. Miotti et al. (1999: p746) have in their study in Malawi shown that HIV transmission through breast milk was higher during the early months of breastfeeding. Their findings indicate that the rates of HIV transmission were 0.7% (months 1-5), 0.6% (months 6-11), 0.3% (months 12-17), and 0.2% (months 18-23) in the first 2 years of life (ibid). The increased risk of HIV transmission during the early months of breastfeeding was also shown by a randomized clinical trial study in Nairobi, Kenya (Nduati, John et al. 2000).

2.2.1 Factors associated with increased HIV transmission during breastfeeding

Exclusive breastfeeding, which means the sole feeding of a woman's breast milk to a baby, has been documented to be adequate for infants during the first six months of their lives (WHO. 2001: p 3). Exclusive breastfeeding is defined as "*giving the infant no other food or drink, apart from breast milk (including expressed breast milk), with the exception of drops or syrups consisting of vitamins, mineral supplements or prescribed medications*" (WHO 2004: p iv). Hence, the WHO recommends exclusive breastfeeding for the first six months of life for the general population and HIV positive mothers who opted for breastfeeding (WHO. 2001). Moreover, in the era of HIV where maintaining the benefits of breastfeeding has to be weighed against the prevention of HIV transmission, exclusive breastfeeding has been brought out as a most important practice (Coovadia, Rollins et al. 2007).

Prolonged breastfeeding, in practice implying prolonged mixed feeding, is estimated to cause one third to one half of all new infant HIV-1 infections through out the world (Ghosh, Kuhn et al. 2003: 2465; Kourtis, Butera et al. 2003: 786; Read 2003: 1198). In sub Saharan African countries, where prolonged breastfeeding is the norm, the problem of MTCT has reached

frightening proportions. What is more, in the most parts of the world exclusive breastfeeding under six months of age is low and it is estimated to be around 23% (WHO 2004: 3). Lauer et al. (2004: 4) in their review of breastfeeding patterns and exposure to sub optimal feeding in developing countries found that among infants of age less than 6 months only 24.9% are exclusively breastfeed, i.e. 71.2% of the infants are partially breastfed.

While estimating the risk of HIV transmission through prolonged breastfeeding, different studies indicated that the cumulative HIV transmission from mother to her child increases along with the duration of breastfeeding. That is the longer the breastfeeding practice, the higher cumulative HIV transmission risk (Leroy, Newell et al. 1998; Miotti, Taha et al. 1999; Embree, Njenga et al. 2000; Nduati 2000; Becquet, Bequet et al. 2007). Furthermore, the Breastfeeding and HIV international transmission study group (BHITS) conducted a meta-analysis of results based on nine trials (Coutsoudis, Dabis et al. 2004). They found that late postnatal transmission contributed to at least 24% and possibly to as much as 42% of the over all MTCT of HIV-1 infection; which indicates the contribution of prolonged breastfeeding implying mixed feeding (Coutsoudis, Dabis et al. 2004: p 2161).

2.3 Prevention of Mother to Child Transmission (PMTCT) of HIV

PMTCT of HIV program is a WHO's intervention program which is targeting prevention of HIV transmission from mothers to their children that is spreading globally. A number of specific interventions have been identified, and make up this large health prevention measure. A four branched comprehensive approach was recommended to reach the goals that were specified in the Declaration of Commitment on HIV/AIDS of the United Nations General Assembly on HIV/AIDS to reduce the proportion of infants infected with HIV by 50% by 2010 (WHO. 2003: 2). The following strategies were incorporated in this declaration:

- Primary prevention of HIV infection among parents to be
 - Preventing unwanted pregnancies among HIV infected women
 - Preventing transmission from HIV positive women to their children
- and
- Providing care for HIV infected mothers and their infants (WHO. 2006: p 11).

The third component of the strategy is comprised of voluntary counselling and testing services (VCT) to pregnant mothers, antiretroviral (ARV) drugs for HIV positive women at the onset of labour and to the infant within 72 hours after delivery, safer delivery practice, and infant feeding counselling and support (WHO. 2003: p11).

The revised WHO (2006) guideline described the base of this comprehensive PMTCT approach as:

“The routine offer of HIV testing and counselling to pregnant women, ARV prophylaxis for PMTCT and counselling and support for infant feeding, and is underscored by ART, care and support for women living with HIV, their children and families” (WHO. 2006: p 12). The main focus of this study is the implementation of the safer infant feeding practices, which is one of the central pillars in PMTCT of HIV.

2.3.1 International guidelines on HIV and infant feeding

Infant feeding recommendations for HIV positive women living in resource poor settings have been continuously revised starting from 1992 until the recent international guideline which was published in 2007 (WHO 1992; WHO. 2007). These continuous revisions have been made in an attempt to develop and support the safest infant feeding options for HIV positive mothers. The first round of infant feeding recommendation promoted breastfeeding by HIV positive women living in areas where the infant mortality rate due to infections is high (WHO 1992).

The guidelines were however criticized for publicizing a different policy for the poor and the rich. Moreover studies came during this phase out that indicated a significant reduction of HIV transmission with the use of replacement feeding (Nduati, John et al. 2000). On this ground, the guidelines were rewritten with a new introduction and emphasis on ‘infant feeding alternatives’ for HIV positive women during the year 2001 (WHO 2001). The diverse alternatives were to be presented and informed about so that women could make their own informed choices based on their individual life circumstances. Most importantly, at this point avoidance of any breastfeeding by HIV positive mother was officially recognized as the prime way of avoiding HIV transmission during postnatal period. The 2001 WHO infant feeding guideline stated the above consensus as follows:

“When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life. To minimize the HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking in to account local circumstances, the individual women’s situation and the risk of replacement feeding (including infections other than HIV and malnutrition).” (WHO. 2001: p12).

As the findings of the present thesis will indicate, the statement above has had tremendous impact on perceptions and practices related to infant feeding. We shall indeed argue that the consequences have been devastating in a global child health context.

With new research and program evidence of the problematic consequences of the 2001 guidelines (WHO. 2001), a new set of guidelines were updated in 2006 (WHO. 2007). The findings and experiences that brought forward the revision of the 2001 international infant feeding recommendation were the following:

- Increased mortality rate occurs in infants who are formula fed compared to infants who are breastfed
- Mixed feeding increases the risk of HIV transmission compared to exclusive breastfeeding, while exclusive breastfeeding by HIV positive mothers up to six months is documented to decrease the risk of HIV transmission
- Early cessation of breastfeeding (before 6 months) is associated with increased risk of infant morbidity and mortality rates (WHO. 2007: p11).

Following the new evidences, the international infant feeding recommendation was hence again revised. The revised document reads as follows:

“Exclusive breastfeeding is recommended for HIV-infected mothers for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) for them and their infants before that time. When replacement feeding is AFASS, avoidance of all breastfeeding by HIV-infected mothers is recommended. At six months, if replacement feeding is still not AFASS, continuation of breastfeeding with additional complementary foods is recommended, while the mother and baby continue to be regularly assessed.” (WHO. 2007: p9).

The AFASS criteria were brought to the forefront of attention when the 2001 guidelines were published and were given renewed emphasis with the updated guidelines. The box below sums up their content.

Box 1. The AFASS criteria are used to assess whether HIV positive mothers are able to successfully replacement feed their babies or not. The conditions which have to be met include the following:

- **Acceptable:** The mother perceives no problem in replacement feeding. Problems may be cultural or social, or be due to fear of stigma and discrimination
- **Feasible:** The mother (or family) has adequate time, knowledge, skills, resources, and support to correctly mix formula or milk and feed the infant up to 12 times in 24 hours.
- **Affordable:** The mother and family, with community or health system support if necessary, can pay the cost of replacement feeding without harming the health and nutrition of the family.
- **Sustainable:** Availability of a continuous supply of all ingredients needed for safe replacement feeding for up to one year of age or longer.
- **Safe:** Replacement foods are correctly and hygienically prepared and stored, and fed preferably by cup.

Source: Adapted from (WHO 2003: p10)

2.3.2 International recommended infant feeding options for HIV positive women

2.3.2.1 Exclusive breastfeeding

Different studies have been conducted to determine the contribution of exclusive breastfeeding in reducing MTCT of HIV (Coutsoudis, Pillay et al. 1999; Iliff, Piwoz et al. 2005; Coovadia, Rollins et al. 2007). Coutsooudis and colleagues published a path breaking study from South Africa in 1999 which illustrated the benefit of exclusive breastfeeding in reducing postnatal MTCT of HIV through breastfeeding (Coutsoudis, Pillay et al. 1999). In this study exclusive breastfeeding proved to carry a significantly lower risk (almost half the risk) of postnatal HIV transmission when compared to mixed feeding (Coutsoudis, Pillay et al. 1999: p 474).

Later, other studies came out confirming the benefits of exclusive breastfeeding in reducing postnatal HIV transmission. Another highly influential study, a non randomized control trial conducted in South Africa, showed that exclusive breastfeeding carried a transmission rate of

4% from 6 weeks¹ after birth up to 6 months (Coovadia, Rollins et al. 2007). Moreover, the study carried out by the same group showed that mixed feeding with especially infant formula or solids carries a higher risk of HIV transmission than mixed feeding with water or other non-food fluids. This study emphasized the enormous benefits of promoting exclusive breastfeeding for HIV positive women who opt to breastfeed their infants (Coovadia, Rollins et al. 2007).

The establishing of safety linked up with exclusive breastfeeding regimes despite highly encouraging results hardly avoided obstacles in an HIV and infant feeding context. Factors like presence of breast infection (mastitis) and maternal nipple lesion have for example been linked with increased risk of MTCT of HIV transmission during breastfeeding (Embree, Njenga et al. 2000; John, Nduati et al. 2001). Coovadia and colleagues (2007) identified a significant association between the presence of mastitis and an increased risk of HIV transmission in their study conducted in South African study. Moreover, advanced Acquired Immunodeficiency Syndrome (AIDS) illness, and acquisition of new HIV infection during breastfeeding have also been identified to increase the risk of HIV transmission during breastfeeding (Dabis and Ekpini 2002: 2098; Read 2003: 1198; Coutsooudis 2005: 958). These findings were associated with increased maternal viral load during breastfeeding. Likewise lower maternal CD4² counts during the first six months was also found to imply a significant increase in the risk of HIV transmission to the infant during breastfeeding (Embree, Njenga et al. 2000; Coovadia, Rollins et al. 2007).

While promoting exclusive breastfeeding has been re-established, the promotion of early and abrupt cessation of breastfeeding has been part of the central strategies to decrease the risk of HIV transmission. Early and abrupt cessation of breastfeeding has taken place in a context of normative prolonged breastfeeding, and hence mixed feeding patterns (WHO. 2001). A strong justification in supporting early breastfeeding cessation among HIV positive women in minimizing the risk of postnatal HIV transmission has been provided by different studies from

¹ The reason the period measured starts from about six weeks and not from birth is because this is the time at which it is usually possible to differentiate HIV transmission during delivery from transmission during breastfeeding (WHO, 2006: p 2)

² CD4+ lymphocytes (a type of white blood cell) are keys to both humoral and cell-mediated immune responses. They are the main target cells for the HIV. Their number decreases with progression of HIV infection, and their level is used as a marker of severity of the infection (WHO, 2004: p iv)

African settings (Coutsoudis 2001; Leroy et al. 2003; Iliff et al. 2005). Kuhn and Stein (1997: 929) indicate that in locations where infant mortality rate is as high as between 60-100 per 1000 live births, HIV infected mothers who stop breastfeeding early have fewer adverse outcomes than who don't breastfeed at all. Similar study suggested that shorter breastfeeding rather than not breastfeeding at all could be less stigmatizing, more satisfying to the mother, a more realistic and desirable alternative in many settings.

These studies also have however emphasized measures that have to be taken while recommending early cessation of breastfeeding. This has not the least implied that women who exercise early cessation of breastfeeding have to be socially supported at the time, and have to have safe and nutritionally adequate alternatives (Iliff, Piwoz et al. 2005: p706).

The recently revised international infant feeding guideline do recognise the extreme difficulties involved in early and abrupt cessation and recommends continued breastfeeding beyond six months of age when discontinuation of breastfeeding and replacement feeding is not acceptable, feasible, affordable, sustainable, and safe (WHO. 2007: p4). This recommendation is supported among other study findings from the Zambia exclusive breastfeeding study (ZEBS) which has identified higher infant mortality among infants who were breastfed only for four months than in infants who continued breastfeeding beyond four months (Sinkala M., Kuhn L. et al. 2007).

Furthermore early and rapid cessation of breastfeeding carries with it risks on both mother and infant in terms of physical and emotional trauma (Piwoz and USAID. 2001: p10). It has also been indicated that infants experiencing early and rapid cessation of breastfeeding may get dehydrated, may refuse to eat, and are in danger of weight loss and malnutrition (Piwoz and USAID. 2001: p10). Mothers, on their side may experience a large number of challenges including breast engorgement, mastitis, increased risk of unwanted pregnancy, and stigma (ibid).

Previously, other modified infant feeding alternatives were also recommended for HIV positive mothers (WHO 2004: pp17-18). The guideline indicated the use of home-modified animal milk for HIV positive mothers who opt for replacement feeding. On the other hand, the use of expressed and heat-treated breast milk, wet nursing/surrogate mother or the use of breast milk bank were suggested as modifications of breastfeeding (ibid). However, according

to the revised infant feeding document for HIV positive mothers, the use of these alternatives is no longer recommended (WHO. 2007: p6).

2.3.2.2 Exclusive replacement feeding/ Formula feeding

To avoid postnatal transmission of HIV from HIV positive mothers to their infants, replacement feeding has been spelled out as an ideal practice (WHO. 2001). In the developed world avoidance of all breastfeeding has been practically possible to implement and as a result, post natal MTCT of HIV is avoided. In resource limited settings, however, where nourishing an infant adequately with replacement feeding is not possible for the large majority, not breastfeeding significantly increases child mortality (Wilfert and Fowler 2007: 165).

As a result, the promotion and use of formula feeding for HIV exposed infants in resource constrained settings still continues to raise controversies because of the risk of increased child mortality and morbidity following inappropriate use of formula feeds (Kuhn, Stein et al. 2004: p11). When considering choosing formula feeding, however, parents in resource constrained settings have to consider whether or not the AFASS criteria is fulfilled (WHO 2004; WHO. 2007).

Different studies have been conducted in an attempt to identify a type of infant feeding which can result in a better rate of HIV-free survival with a decreased infant mortality rate. A randomized clinical was conducted in Kenya by assigning infants to one formula feeding and one breastfeeding group respectively (Mbori-Ngacha, Nduati et al. 2001). In this study, the first two years mortality rate was similar between the two groups. However, HIV-free survival at the age of two years was significantly higher in the formula feeding group (Mbori-Ngacha, Nduati et al. 2001).

Newell et al., (2004) conducted a pooled analysis of African studies related to formula vs. breastfeeding. However, neither their findings detected a significant difference in mortality rates between children who were born to HIV positive mothers and were 'ever-breastfed' and 'never-breastfed' (Newell, Coovadia et al. 2004). Furthermore, increasing number of studies have demonstrated the risks linked to replacement feeding (Thior, Lockman et al. 2006; Coovadia, Rollins et al. 2007).

Like wise, Kuhn et al., also assessed the risk of unmodified/customary breastfeeding vs. formula feeding among HIV positive women (Kuhn, Stein et al. 2004). The results were among the first to suggest that in communities where infant mortality rate is greater than 100 per 1000 live births, “*formula feeding is strongly contraindicated*”. They indicated that formula feeding could be “*fair*” in balancing excess mortality when balanced with prevention of HIV infection from breastfeeding, but only in areas where infant mortality is between 40 and 100 per 1000 live births (Kuhn, Stein et al. 2004: p11).

Another important study that has demonstrated the risk of formula feeding in low-income contexts was the investigation following a diarrhoea outbreak in Botswana (Creek et al. 2006). Among the victims below one year of age half were not breastfed, and were receiving free infant formula from Botswana’s national program for prevention of mother to child transmission of HIV (Creek 2007). Moreover, it has been suggested that consideration should have to be taken regarding water quality, sanitation, hygiene, and nutrition for children who are not breastfeeding (ibid).

Considering the full picture which is increasingly indicating the risk of formula feeding in resource constrained settings, WHO has recently recommended formula feeding as a secondary choice for mothers living with HIV (WHO. 2007). The choice of formula feeding is promoted merely for the ones who can fulfil the AFASS criteria.

2.3.3 ARV drug use and infant feeding

The use of a combination of several ARV drugs and complete avoidance of breastfeeding has been shown to have the most effective effect in reducing MTCT of HIV. As a result it has become possible to reduce MTCT to less than 2% (Carpenter, Fischl et al. 1997; European-Study 2001). In areas of the world where breastfeeding cannot be safely avoided, several studies are investigating the effect of using ARV drugs during breastfeeding periods (see also e.g. HIVNET012, SAINT, DITRAME plus, Thai PHPT, PETRA studies).

If HIV positive pregnant women are eligible for initiation of Highly active antiretroviral treatment (HAART) however the WHO recommends that they start taking ARV drugs for their own health that is it has a focus beyond the health of the infant. Initiation of ART in pregnant women has a multiple benefit of reducing maternal morbidity and mortality. It has an encouraging effect in reducing MTCT of HIV and enhances child survival by the mere fact

of keeping the mother alive (WHO. 2006). Some ongoing studies are indicating the multiple and promising benefits of initiating ART during breastfeeding (ibid)

2.3.4 HIV and infant feeding counselling

Counselling and support regarding the different feeding options and choices were recommended for HIV positive women to take place throughout pregnancy, labour and delivery, and through the first two years of the infant's life (WHO. 2001). In the previous international guideline (2001), counselling about infant feeding options for HIV positive mothers was recommended as:

“All HIV-infected mothers should receive counselling, which includes provision of general information about the risks and benefits of various infant feeding options, and specific guidance in selecting the option most likely to be suitable for their situation. Whatever a mother decides, she should be supported in her choice.” (WHO. 2001: p13).

However, the updated recommendations are simplified and emphasize only on explaining well the two main infant feeding options for HIV positive women; namely exclusive breastfeeding and replacement feeding. This has been done to make the counselling process easier and more comprehensible; and reduce the time needed for counselling (WHO. 2007: p4). This last point has been emphasized as proper counselling and support for HIV infected mothers and has been found to be one of the major problem areas in the implementation of PMTCT programs in the developing world (de Paoli, Manongi et al. 2002: p147).

Unavailability of adequately trained health professionals who are equipped with knowledge about the risks associated with the various infant feeding options in the context of HIV, as well as lack of follow up and support have been identified as major obstacles (de Paoli, Manongi et al. 2002: p144; Leshabari, Koniz-Booher et al. 2006: p2).

A study conducted in Tanzania to assess the counsellors' perspective on HIV and infant feeding dilemmas indicated that the problem is not only a confusion for HIV positive mothers but the infant feeding scenario also implies a confusion to the counsellors (de Paoli, Manongi et al. 2002: p147). What is more, not every PMTCT infant feeding counsellors are trained in the subject matter (de Paoli, Manongi et al. 2002).

In sum, the 2001 recommendations of WHO proved to be very difficult to implement in practice in the developing world, and indeed the program was seen to impose enormous damage in the field of infant nutrition, morbidity, and mortality (Doherty, Chopra et al. 2006: p93).

2.5 Rationale of the study

Breast milk is the core source of infant nutrition worldwide (WHO 2004). The documentation of HIV in breast milk and the documentation that breastfeeding cause from 5% to 20% of HIV infections occurring through mother to child transmission (De Cock, Fowler et al. 2000) has led to a fear of breast milk and confusion surrounding the safety of breastfeeding.

In developing countries, where alternatives to breastfeeding are very challenging but for the very few, the emergence of HIV has made the decision about infant feeding extremely difficult for HIV positive mothers as well as for infant feeding counselors working in PMTCT clinics (Dabis and Ekpin 2002: p2098; Kourtis, Butera et al. 2003: p789). There has been great uncertainty related to whether or not breastfeeding can be promoted in high HIV-1 prevalence areas (Engebretsen, Wamani et al. 2007: p2). With the knowledge that exclusive breastfeeding rates are very low and that mixed feeding which increases the risk of HIV transmission is a common practice (Coutsoudis, Pillay et al. 1999; Iliff, Piwoz et al. 2005; Coovadia, Rollins et al. 2007), realistic and safe infant feeding options have seemed to be nonexistent for both women and their counselors.

In recent years, international guidelines have been developed, and modified in several attempts to minimize the risk of postnatal HIV transmission through breastfeeding. After years of promoting replacement feeding, the very latest international guideline suggests breastfeeding by all HIV infected mothers who can't fulfill the so-called AFASS criteria to replacement feed their infants (WHO. 2001; WHO. 2007). The frequently changing international guidelines further confuse the ones who have to relate to the guidelines in desperate attempts to avoid transmitting the virus to infants.

Different studies from sub Saharan African countries strongly indicated that adherence to the WHO's recommended infant feeding option have been difficult to attain to in context where the HIV positive mothers desperately try to avoid disclosure of their HIV status (de Paoli, Manongi et al. 2002; Kiarie, Richardson B A. et al. 2004; Leshabari, Blystad et al. 2007).

No qualitative studies has to our knowledge been published which is assessing the experiences of HIV positive mothers and infant feeding counsellors related to infant feeding in a context of the international infant feeding guidelines in an Ethiopian setting.

In an attempt to contribute in filling this gap, this study has assessed the complexity and confusion surrounding the infant feeding choices among HIV positive mothers' and their adherence to their infant feeding choices in a context where the 2001 (WHO. 2001) international infant feeding recommendations were still practiced. The challenges faced by the nurse counsellors and other health professionals were also addressed.

2.6 Aim and Objectives of the study

2.6.1 Major Aim

To produce knowledge that can be employed to improve the prevention of mother to child transmission program (PMTCT) of HIV in Ethiopia.

2.6.2 General objective

To identify challenges associated with infant feeding in the context of PMTCT of HIV in Addis Ababa, Ethiopia.

2.6.3 Specific objectives

- To explore experiences of HIV positive mothers related to breastfeeding in a context of the PMTCT program
- To explore experiences of HIV positive mothers associated with exclusive replacement feeding in a context of the PMTCT program
- To generate knowledge on the practices and experiences of health professionals working in HIV and infant feeding counselling clinics

3. The research context

3.1 Background information about Ethiopia

Ethiopia is an ancient country embracing a rich diversity of peoples and cultures. Palaeontological studies have identified Ethiopia as one of the cradles of mankind. The country maintained its independence during the colonial era in Africa, and thus has a very different history from most other African nations. It is characterised by a great variety of peoples/ethnic groups, and over 80 different languages are spoken in the country today (CSA [Ethiopia]. and ORC Macro. 2006: pp1-3). Christianity and Islam are the main religions of the country, in which Orthodox Christianity comprises 51% of the population, 33% are Muslims and 10% are Protestants. The remaining section of the population follows a diversity of other faiths (ibid).

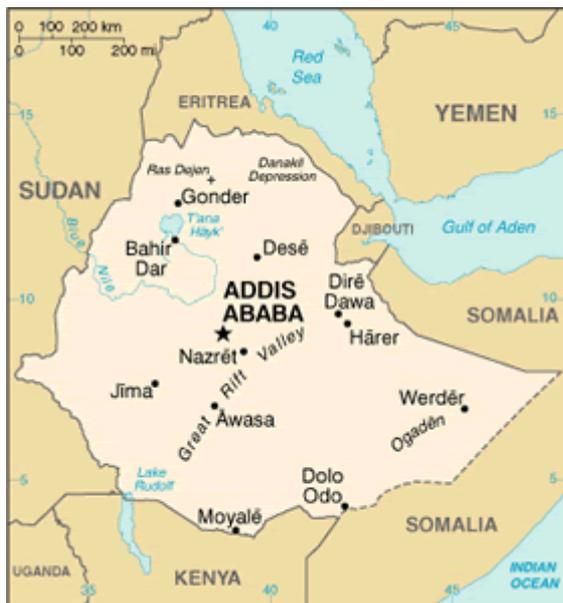
Ethiopia is located in eastern Africa and covers a total area of 1.1 million square kilometres. Its bordering countries are Djibouti, Eritrea, Sudan, Kenya and Somalia. The terrain of Ethiopia includes a massive highland complex of mountains and dissected plateaus divided by the Great Rift Valley. The topographic features range from the highest peak at 4,550 meters above sea level to valleys located 110 meters below sea level. With this topographic variability the climatic conditions of the country naturally also vary, with temperatures as high as 40 degrees Celsius in the low-lying areas to below 10 degrees Celsius in the highlands (CSA [Ethiopia]. and ORC Macro. 2006: p 1).

In 2007, Ethiopia's population was estimated at around 77 million with an annual growth rate of 2.0% through to 2025 (CSA [Ethiopia]. and ORC Macro. 2006: 8). Children below 15 years of age account for 43% of the total population. An estimated 84% of the Ethiopian population live in rural areas. In the year 2003, the estimated life expectancy was 53 years for men and 55 years for women (ibid).

Ethiopia is one of many low-income countries in the world, with a per capita gross national income of US \$110 (CSA [Ethiopia]. and ORC Macro. 2006: p2). Agriculture contributes 54% of the gross domestic product (GDP), and provides work for about 80% of the population and more than 90% of the country's exports (ibid).

Until 1974, when the Marxist revolution took place, Ethiopia was ruled by successive emperors and kings with a feudal governmental system. The military took over the running of the country between 1974 and 1991. Presently the country has a federal system consisting of nine national regional states and two administrative states (CSA [Ethiopia]. and ORC Macro. 2006). Addis Ababa is the capital of Ethiopia and is located in the central highlands of the country.

Figure 1: Map of Ethiopia³



3.2 The health system in Ethiopia

During the last century, the Ethiopian health system has been under continuous change, to a large extent following the political shifts that have characterised the country. The application of fragments of ‘modern’ medicine dates back to the beginning of the 16th century. However, modern medicine organised by the government was initiated at the beginning of the 20th century, when the government took full responsibility for running a modern health service system in Ethiopia (Berehane Y., Hailemariam D. et al. 2006: pp227-229). The modern medical services were however urban-centred, reaching only small segments of the country’s largely rural-based population (ibid).

³ Source: <http://wikitravel.org/upload/en/f/fb/Et-map.png>. Accessed February 26, 2008

Following the communist revolution in 1974, emphasis was given to the formulation of a health policy that would reach broader parts of the population. Through new policy formulations, emphasis was placed on strategies that to a larger extent incorporated disease prevention and control, and that implied community involvement (Berehane Y., Hailemariam D. et al. 2006: p235). Currently, the health services are based on a policy that seeks to provide comprehensive and integrated Primary Health Care (PHC) in health institutions at community level. It also emphasises health promotion and disease prevention, with a focus on communicable diseases, nutritional disorders and environmental health problems (ibid).

The health system in Ethiopia however remains underdeveloped and characterised by poor health indicators (CSA [Ethiopia]. and ORC Macro. 2006: p 4). The overall health-related picture is characterised by the severe challenges existing in the developing world. Access to health care services is still very limited in large parts of Ethiopia, and those who have access might not get quality health care because of a lack of trained health professionals, a poor infrastructure, and a lack of equipment and medication etc. (ibid).

The Maternal Mortality Rate (MMR), which is a major indicator of a country's development, still remains high in Ethiopia with a figure of 673 per 100,000 live births (CSA [Ethiopia]. and ORC Macro. 2006: pp100-123). The 2005 Demographic and Health Survey (DHS) reveals that infant mortality and under-five-years mortality is 77 and 123 per 1000 live births respectively (ibid). Only 24% of Ethiopia's population have access to piped water and only 38% of the country's population have access to a toilet facility (CSA [Ethiopia]. and ORC Macro. 2006: p 23).

3.3 HIV epidemiology in Ethiopia

In Ethiopia the first HIV infection was reported in 1984 (Berehane Y., Hailemariam D. et al. 2006: pp447-450). In the early phase of the epidemic, female commercial sex workers (CSWs), soldiers and truck drivers were central in the spread of the HIV infection (ibid). Heterosexual transmission and mother to child transmission today contribute the major portion of HIV transmission in the country. In the late 1990s perinatal HIV transmission was estimated to contribute about 25% of all new infections. HIV infection in women has in recent years increased and has become higher than in men. This in turn has increased the risk of MTCT of HIV (Kloos and Hailemariam 2000: pp19-20). Women in the age range of 15-24

years are presently the most affected segment of the population (MOH 2007a: p3). Little is known about the contribution of other routes of HIV transmission including blood transfusions, medical procedures and harmful traditional practices (ibid).

According to the single point prevalence estimate made by the Federal HIV/AIDS Prevention and Control Office (FHAPCO) in 2007, the national HIV prevalence in Ethiopia was 2.1% (1.7% of men and 2.6% of women) (MOH 2007b). Urban HIV infection rates are far higher than those in rural settings (7.7% urban and 0.9% rural) (ibid).

There are an estimated 977,394 people living with HIV in Ethiopia (MOH 2007b). Of these, children under the age of 15 years constitute 6.6% (ibid). According to the Ethiopian Ministry of Health report in 2006, the national ANC HIV prevalence was 8% (MOH 2006: p34). A recent report revealed that the national ANC coverage was 52.1% in the year 2007 (MOH 2007c).

Addis Ababa: the study setting

Addis Ababa is the capital of Ethiopia and is one of the administrative seats of the country. The city is located in the central part of the country and it is the centre of political activity in the country. The city is subdivided into 10 sub-cities containing a total of 99 urban neighbourhood associations called *kebeles*⁴. The city is also the major commercial centre of the country, and has an employment structure that is different from the rest of the country.

According to demographic indicators, the population of the city is 3,059,000 people (MOH 2007c: p5). The total fertility rate (TFR) is 1.4, being the lowest TFR in the country and far lower than the national TFR figure of 5.4. The under-five child mortality rate of Addis Ababa is 72 per 1000 live births, which again is lower compared to the national figure of 123 per 1000 live births. This could be partly related to the higher health and sanitation-related services offered in Addis, and the higher literacy rates among women in the capital (ibid).

According to the single point HIV prevalence estimate in June 2007, the total HIV prevalence in Addis Ababa was 7.5% (6% in the male and 8.9% in the female population). In the same

⁴ Source: http://www.addisababacity.gov.et/Sub_cities.htm. Accessed February 15, 2008

year, there were an estimated 165,577 HIV positive individuals, 6,223 HIV positive pregnancies and 808 HIV positive births in Addis Ababa (MOH 2007b). In 2003, the ANC estimated HIV prevalence in the city to be 12.4%. As the first place for the launch of the PMTCT services in the country, Addis Ababa now has a fairly broad coverage of the service, with a total of 47 PMTCT service-rendering health institutions including governmental hospitals, health centres and private clinics (MOH 2007c).

3.4 PMTCT in Ethiopia

In Ethiopia, even though it has been recently estimated that 52% of pregnant women attend ANC at least once, only 16% of deliveries are attended by health professionals (MOH 2007c: p13). Likewise, only 19% of mothers come to health facilities for postnatal care services (PNC) (ibid).

The first National PMTCT guideline was published in 2001 by the Ministry of Health. At that time there was only one research project delivering PMTCT services for HIV positive mothers, and that was located in the capital, Addis Ababa. Not until 2003 did other health institutions start to deliver the service. The last update indicates that presently a total of 408 health facilities (hospitals, health centres and private clinics) that provide PMTCT services (MOH 2007c: p46).

The Federal HIV/AIDS Prevention and Control Office (FHAPCO) of Ethiopia released a new version of the PMTCT guidelines in July 2007 (MOH 2007a). The major changes in the new guidelines are firstly that this guideline incorporates the new international HIV and infant feeding recommendations suggesting exclusive breastfeeding by all HIV positive mothers who do not manage to replacement feed their infants (a more detailed description of this is found in Chapter Two), and secondly that it most importantly incorporates the practice of the routine provision of HIV counselling and testing using a so-called 'opt-out' approach. The opt-out approach implies that:

“All women coming for ANC, labour and delivery and postpartum follow up, if not tested during current pregnancy shall be routinely informed about the benefits of HIV testing for mother and baby in a group or on individual basis and shall be told that their routine

laboratory check up includes HIV testing unless they say “NO”. The right to say “no” shall be clearly communicated” (MOH 2007a: p20).

This approach is recommended for all ANC clients comprising mothers coming for ANC or labour and immediately postpartum (ibid). This new approach will most likely lead to a situation where far more women than previously get to know their HIV status during their visits to ANC.

The international PMTCT strategies which are recommended by the WHO (see section 2.3) are also adopted and being practised in the country. The focus of this study is on preventing the HIV transmission from mothers to their children, and more specifically the infant feeding dimension of the preventive strategy.

3.5 Infant feeding in Ethiopia

In Ethiopia, breastfeeding is almost universal. The 2005 DHS showed that nearly 96% of Ethiopian children were breastfed. However, mixed feeding including prelacteal feeds was a common practice. The survey demonstrated that only one in every three Ethiopian infants of 4-5 months old was exclusively breastfed; and just over two-thirds of the infants who were less than two months old were exclusively breastfed (CSA [Ethiopia]. and ORC Macro. 2006: p145). Generally, liquids including water, juice, formula and other animals' milk were the food items introduced early in infants' lives (ibid).

According to the DHS conducted in 2005, breastfeeding for up to the first two years of a child's life is a common practice in Ethiopia. It has also been indicated that the mean duration of breastfeeding was 25.5 months. However, prolonged breastfeeding was more prevalent in the rural population than in the urban settings (CSA [Ethiopia]. and ORC Macro. 2006: p 148).

3.6 The two study hospitals

3.6.1 Zewditu Memorial Hospital⁵ (ZMH)

Zewditu Memorial Hospital (ZMH), which was established in 1972, is a governmental hospital with a total of 160 beds. During August 2007, there were 50 doctors and 145 nurses employed at the hospital⁶. This hospital was the first health institution where PMTCT of HIV services was initiated. The start-up was in January 2004. ZMH is a referral hospital and is located in Kirkos sub-city (one of the nine sub-cities in Addis Ababa).

At ZMH, PMTCT services encompass pre test and post-test counselling, follow-up during pregnancy and single dose Nevirapine during labour for the mother as well as for the infant at birth. Employing the opt-in approach, every ANC attending mother is offered the opportunity of getting HIV tested during each consequent visit to the hospital and also at the follow-up visits. Consequently, HIV positive mothers discuss the infant feeding options they have chosen with the PMTCT counsellors. At the hospital's PMTCT clinic, hospital delivery is strongly encouraged. If HIV positive mothers do not manage to deliver in health facilities, they are encouraged to bring their babies to the hospital within three days of delivery, or if possible earlier, in order to receive the medication.

After delivery, mothers will be told to return to the hospital on the sixth week to start getting the infant feeding follow-up service provided for HIV positive mothers. However, before six weeks the mothers do not receive any follow-up regarding infant feeding. When these mothers come to the 'HIV and infant feeding follow-up clinic' they are offered services including growth monitoring (infants will be weighed and measured to assess their growth and nutritional status), advice on the specific infant feeding option a mother has chosen, and Sulfamethaxazole-Trimethoprim (SMX-TMP), commonly called Cotrimoxazole⁷, a

⁵ The hospital was named after the late Empress Queen of King Zewditu (1876-1930)

⁶ The data was found through personal communication from the two hospitals' record offices.

⁷ Cotrimoxazole (CTX), also known as Sulfamethaxazole-Trimethoprim (SMX-TMP), is a broad-spectrum antimicrobial agent that targets a variety of aerobic Gram-positive and Gram-negative organisms and protozoa. WHO recommends that HIV exposed infants take CTX prophylaxis starting from the age of 4-6 months in order to protect the occurrence of Pneumocystis Carinii Pneumonia (PCP), which is believed to cause significant morbidity and mortality in HIV infected children.

prophylaxis for the infants. Vaccination follow-up of these babies is carried out at a different clinic. Therefore, this particular clinic attends only to the HIV related aspects of infants' health. However, HIV positive mothers coming with their infants are advised to attend the adult HIV follow-up clinic which is situated at the same hospital. This service also includes the provision of HAART if the HIV positive mothers are eligible.

The 'infant feeding and HIV follow-up clinic' at ZMH was part of the hospital's pediatric department and was established in January 2004. The clinic was open only on Friday afternoons. At the clinic there were three nurses who were trained in PMTCT. The training had an infant feeding counselling module. There was also one pediatrician running the programme.

The most widely practised infant feeding option found at ZMH was *exclusive replacement feeding* with either infant formula or cow's milk. Neither the hospital nor any non-governmental organisation offered infant formula to the mothers who attended the PMTCT clinic at the hospital.

Up to the first six months, mothers came to the clinic every week. Once the babies reached six months of age, the follow-up took place every third month until the babies reached one year and six months. At the beginning of the follow-up, mothers were told about the availability of HIV tests for their babies starting from the third month. However, mothers can have their babies HIV tested whenever they are willing to do so. The HIV virology test, Polymerase Chain Reaction (PCR), is usually carried out after the third month of the baby's life. When babies reach one year or more, the last HIV test is carried out, and children are formally declared either HIV negative or HIV positive. HIV positive babies will be sent to the paediatrics ART follow-up clinic and babies with negative test results will discontinue their follow-up and the medication (cotrimoxazole).

3.6.2 Yekatit 12 Hospital

Established in 1924, Yekatit 12 Hospital is one of the governmental hospitals that have been providing PMTCT services since August 2004. It is a 205-bed hospital and employed 30 doctors and 165 nurses in August 2007. The PMTCT service offered to mothers, starting from the first ANC encounter until delivery, is to a large extent similar to that described for ZMH.

In Yekatit 12 Hospital, there was no separate HIV and infant feeding follow-up clinic nor a particular day during the week assigned for this service. However HIV and infant feeding counselling services were given in connection with the paediatric ART follow-up, when HIV positive mothers arrived at the hospital for their appointments regarding their babies' follow-up. The infant feeding counselling and follow-up also comprises Cotrimoxazole prophylaxis and growth monitoring services.

The clinic was established in October 2007 with the initiation of paediatric ART treatment in the hospital. There was one paediatrician and two nurses at the clinic who were trained in paediatric ART who were also providing the infant feeding counselling services. However, the nurses were not trained in PMTCT of HIV nor underwent any infant feeding training regarding HIV.

A paediatrician was in charge of evaluating infants coming to the clinic. However, detailed infant feeding counselling was given by nurses working in the clinic during the mothers' first visits as well as during subsequent visits. Infants started the follow-up at the clinic when they were six weeks or older. Other services available were similar to those described for ZMH. At both hospitals, infant feeding counselling for HIV positive mothers in principle followed the national guidelines, which were the national version of the WHO's 2001 infant feeding guideline for HIV positive mothers.

In contrast to ZMH, *exclusive breastfeeding for the first 4-6 months* was the dominant infant feeding option practised by the HIV positive mothers at Yekatit 12 Hospital. However, most mothers stopped breastfeeding earlier than six months. Neither the hospital nor any organisation offered formula milk for mothers attending the hospital.

4. Methods

4.1 Study design

4.1.1 Qualitative research

Qualitative methods can produce a wealth of in-depth information. Patton (2002: 14) describes the purpose of qualitative methods as *"approaching fieldwork without being constrained by predetermined categories of analysis contributes to the depth, openness, and detail of qualitative inquiry"*. Pope and Mays (2006: p4) write that qualitative research tries to interpret social phenomena, and seeks to identify: *"the meanings people attach to their experiences of the social world and how they make sense of the world"*.

A characterising feature of qualitative methods is that it is studying people in their own natural setting. It is quite common to employ different qualitative methods in one research venture such as a combination of observation, participant observations, in-depth interviews and focus group discussions. Qualitative research methods have fruitfully been used to identify the multifaceted human behaviour in diverse health care contexts (Pope C. and Mays N. 2006: p4).

The major aim of this study is to gain in-depth knowledge about the experiences of people who in their daily lives experience the challenging phenomenon of infant feeding with the knowledge that the HIV in their breast milk can be transmitted to their infants. The aim was to explore how living with HIV and protecting newborn infants from HIV was handled and experienced within the context of PMTCT programmes in Addis Ababa. The issue of infant feeding in the era of HIV is a very complex phenomenon that demands that we grasp the socio-cultural context within which the biomedical knowledge of HIV transmission and the international recommendations regarding the subject matter are located. In an attempt to generate knowledge about the experiences of the women and of health personnel on this complex subject matter, a qualitative research design was selected. With its possibility for in-depth questioning, for probing and for adjusting the questions in the course of the research, the qualitative approach was found to be the most feasible in this context.

4.1.2 Qualitative triangulation

This study employed both triangulation of data sources (different categories of informants were interviewed) and triangulation of data collection methods. Triangulation, as described by Pope and Mays (2006: p87), involves the use of “*results from either two or more different methods of data collection (e.g. interviews and observations) or, more simply, from two or more data sources (e.g. interviews with members of different interest groups)*”. The last form of triangulation is commonly known as source triangulation. The analyses of data on the same topic by two or more different sources of information (for example HIV positive infant feeding mothers and their counsellors) might challenge the researcher in harmonising the different accounts. However, source triangulation can be extremely fruitful in making the findings of a phenomenon more comprehensive (Pope C. and Mays N. 2006: pp87-88). HIV positive infant feeding mothers and health professionals constituted the different categories of informants.

The purpose of applying the methods triangulation is to draw upon the benefits of different methods as each reveals different aspects of empirical ‘reality’ (Patton 2002:247), and also is considered a good way of ensuring the entirety of a set of data (Pope C. and Mays N. 2006: p87). In-depth interviews, case studies and participant observations were used as the data collection methods in the present study. The aim was to assist the researcher in generating sets of data produced by different approaches that would assist in generating a richer data set.

4.2 Data collection

4.2.1 Recruitment of research assistants and informants

4.2.1.1 Recruitment of research assistants

Research assistants were recruited at both hospital settings, Yekatit 12 and Zewditu Memorial Hospital. Two research assistants from each HIV and infant feeding clinic and one major assistant were recruited in each hospital. All the research assistants were nurses, and were practising infant feeding counselling in the respective hospitals.

4.2.1.2 Recruitment of informants

HIV positive mothers with infants

HIV positive infant feeding mothers were recruited from both hospitals by the researcher and the respective research assistants. The inclusion criteria used for the recruitment of informants included:

- HIV positive infant feeding mothers who had a baby of less than one year of age and who were willing to participate
- HIV positive mothers with prior visits to the HIV and infant feeding clinics.

When mothers expressed their willingness to participate, all the research ethical issues were discussed with the proposed informant and informed oral consent was received from each informant. Except for one mother at Zewditu Memorial Hospital, all the women who were asked to participate agreed to contribute to the study. The mother who did not wish to participate had breastfed her child for four months. She told us that she did not want to talk about her experience at all. This was found to be very understandable and was obviously accepted without any further comment or question. A total of 22 HIV positive women were recruited as study informants.

Health personnel

The second category of informants consisted of health personnel. All health professionals working in the respective hospitals who were connected with infant feeding services for HIV positive mothers were included. The departments where the health personnel were recruited were: HIV and infant feeding follow-up clinics at ZMH, PMTCT clinics at both hospitals, and the pediatrics ART clinic at Yekatit 12 Hospital. All agreed to be interviewed. During the data collection period one PMTCT counsellor nurse at Yekatit 12 hospital was on annual leave and was not included in the study. A total of eight nurses and two pediatric doctors were recruited as informants in the study.

Data collection was undertaken from June 2007 to August 2007. The different data collection methods employed in the study are presented in the following section.

4.2.2 In-depth interviews

Qualitative interviews help a researcher to grasp another person's perspective "*with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit*" (Patton 2002: p341). Data collection through in-depth interviews was conducted with a total of 32 study informants. A total of 14 HIV positive mothers who breastfed their infants and eight HIV positive mothers who replacement fed their infants were interviewed. Moreover from the second category of informants 10 health professionals (eight nurses and two paediatricians) who were working in connection with PMTCT of HIV were interviewed. One husband of an HIV positive mother who chose to exclusively replacement feed her baby was accompanying his wife during her interview and was willing to participate in our discussion.

All interviews were conducted using semi-structured interview guides. The interview guides included open-ended questions with a set of potential questions for follow up/probing. Three different interview guides were used for the three different groups of informants: HIV positive mothers who breastfed their infants, HIV positive mothers who replacement fed their infants, and health professionals. (See interview guides, Appendix I). The interview guides were modified in the course of data collection. The interview guides were initially prepared in English but were translated into the local language, Amharic, which is the national language of Ethiopia. All the interviews were conducted in Amharic. Both the researcher and all the study informants were fluent in Amharic.

Before the actual data collection was initiated, the researcher spent about one week becoming familiarised with the research settings and with the staff. This period also helped the researcher and the research assistants to discuss the project both in terms of content and in terms of practicalities, such as preparing places where the interviews could be carried out without disturbance. All the interviews were conducted at the premises of the study hospitals. Nurses' offices were used for the individual interviews. These offices were situated in quiet areas and were experienced as comfortable for the mothers in terms of confidentiality.

The research assistants of the respective hospitals introduced the researcher to eligible mothers. Once the mothers had expressed their willingness to participate in the study, the researcher contacted them and explained the content of the study as well as the research

ethical premises on which it was founded: voluntary participation, confidentiality, anonymity, and their right of withdrawal from parts of or the entire research venture. All study informants gave oral informed consent to participate. Written informed consent would not have been easy to obtain. Rather than offering reassurance about the participants' rights, such demands for signatures would have made the participants uneasy about what the research could be used for.

The interviews started with informal discussions. For example, conversation about how the babies were doing, where they lived and how life was getting very expensive these days were common topics that the mothers liked to talk about. All informants were asked whether they would be willing to have the discussions audio recorded. All were willing and every interview was audio recorded. Occasionally we had to interrupt the interview because of crying babies or to change the batteries of the audio recorder. The interviews took an average of 55 minutes.

4.2.3 Participant observation

Authors describe the benefit of participant observation in qualitative research methodology in slightly diverse ways. Dahlgren and colleagues (2004: p72) mention in their book four important purposes of participant observation:

- as a starting point to know a setting and research context
- as a way of evaluating whether people do what they say they do
- to point out issues which are difficult to find out through interviews
- to capture phenomena in detail.

The researcher was allowed to carry out participant observation at both hospitals. At Zewditu hospital it was relevant for the researcher to be present every Friday afternoon, while at Yekatit 12 the researcher was present every morning from 9:00 am usually until 12:30 am. This possibility of continued presence made the research environment comfortable for the researcher. Being present and participating in the day-to-day activities of the clinics helped the researcher to establish and maintain fairly close contact with the staff working at the clinics, and more importantly supported the understanding of what took place at the clinics. It also eased the recruitment of the research informants.

Participant observation in this study motivated a fairly radical shift in the study focus. The initial theme for the study had been to explore in detail HIV exclusive breastfeeding in

general and the early and abrupt cessation of breastfeeding in particular as prescribed by the WHO infant feeding guidelines for HIV positive women. The period of participant observation however yielded extensive knowledge about the manner in which most HIV positive women struggled for and opted for replacement feeding of their infants. This knowledge implied the addition of a research question related to replacement feeding, and in fact eventually implied the generation of a body of knowledge that shifted the study focus to the fear of breast milk in the era of HIV. Knowledge gained from the period of closely watching and participating in the daily work at the clinic which facilitated close contact with the HIV positive mothers therefore raised new questions that in the course of the research shifted the study focus into a direction that emerged as more immediately relevant for the field of study.

Participant observation furthermore helped the researcher keep in touch with the informants recruited to the study during follow-up visits. The presence in the clinics for more than two subsequent months was also a great opportunity to meet informant mothers for a second time. During those times informal discussions were had and clarification of issues which had been vague during the earlier formal interviews was requested. During these informal meetings it turned out that some mothers were very happy to have another session to talk and follow up the discussions we had had. There were two mothers who brought their elder children for HIV tests at this point and fortunately they were both HIV negative, which made these encounters particularly memorable.

This experience did not only give the researcher a chance to observe closely the real life situations as they emerged from the talks with the women when they visited the clinic, but also gave the researcher the opportunity to learn from the observation of emotional outbreaks, frustration etc. from both mothers and health professionals. During the period of fieldwork the researcher shared their limited working space and therefore also their pain and confusion.

The researcher was writing 'field memos' whenever possible during the day without interfering with the ongoing activity of the clinics. Later in that day the memos were added to other memos for early analysis. Participant observation took place throughout the study period.

4.2.4 Case studies

Case studies have been used to illustrate individual cases in clinical care. This data collection method can be employed through a variety of qualitative methods such as interviews, document analysis and non-participant observation (Pope C. and Mays N. 2006: p112). The interviews are commonly extended and/or repeated. The present study used individual interviews as a data collection method. Pope and Mays (2006; p112) describe how case studies evolved in the medical field of research in the following manner: *“The medical approach to understanding disease has traditionally drawn heavily on qualitative data and, in particular, on case studies to illustrate important or interesting phenomena”*.

The stories of two HIV positive breastfeeding mothers are included in the present study. These two mothers chose to exclusively breastfeed their babies for the first couple of months and to stop breastfeeding abruptly as prescribed by their PMTCT counsellors. Detailed interviews were conducted before they stopped breastfeeding concerning their preparation and their decisions. A week after they both stopped breastfeeding a second meeting was arranged at the hospital premises and the mothers were interviewed about their experiences related to the process. Both mothers explicitly stated that they were happy about participating in the study and were excited to tell their stories which they had not been able to tell anyone else.

4.3 Data analysis

4.3.1 Data transcription and translation

Qualitative research commonly results in a massive amount of data from interviews, observational notes and the researcher’s own records of ongoing observations and early attempts at analyses in the form of a field diary (Patton 2002; Pope C. and Mays N. 2006: p63). All the interviews were audio recorded and the data were transcribed by professional transcribers. To maintain the confidentiality of the information and to avoid any possibility of identification of the informants, caution was taken while recording to avoid any information that could reveal the identity of the informants. To ensure the quality of the transcripts, and to ensure the verbatim documentation of the content, the researcher carefully checked the transcripts against the original recording. This was a time-consuming process.

Before the second interviews were carried out, all interviews were carefully listened to and were compared with their respective transcripts to search for issues that emerged which should be used to modify and add points to the interview guide before the second interviews.

Since data collection was conducted in Amharic, translating the data into English was conducted by the researcher. Checking the transcribed data, translating them into English and entering them electronically gave the researcher an opportunity to absorb and become familiar with each interview and to engage in the analysis of the data. The data analysis indeed started with the very first interview.

4.3.2 Data coding, categorizing and analysis

Once the data were transcribed and translated, the researcher went through all the data transcripts and field notes trying to make sense of the huge array of data by sorting and interpreting it. This first of all involved reading and re-reading all the data sets in order to identify an initial set of themes. The data were systematically searched for recurring themes, as well as for views or experiences that were different or that contradicted the main emerging patterns. Following that initial process, the text was coded and categorized. Line-by-line manual coding was carried out with extensive input from the supervisor using the margins of the sheets of paper containing the transcribed data. The initial coding employed terms that were close to the language the informants used. In this process a separate code book was used.

Once the coding was completed, the data were read and re-read to remove non-relevant material which was not related to the research topic. This made the data more manageable. After this, lists and categories of codes were made and the codes were grouped together in linked patterns. In categorizing the themes, the researcher continuously made sure that all the codes had been accounted for or compared. The procedure of analysis employed in the present study drew upon the principles of thematic content analysis as described by Pope and Mays (2006: pp67-70).

The analysis of the data continued in the next phase through an assessment of how the categories were interconnected, searching for relationships and links in emerging themes. This process was also supported by using figures and diagrams to visualise the relations. Ultimately the emerging themes were used in writing up the findings. Repeated reviews of the raw material as well as of the coded material helped to ensure that there were no major points

or ideas missed in the process. All the raw material and coded material was kept in a safe place to ensure its confidentiality and safety.

4.4 Limitations of the study

The relatively small numbers of participants who were included in the present study prevents the use of statistical analysis to generalise the findings to the target population. It would have been potentially fruitful to include home visits to explore further the living conditions and the infant feeding situations of the informants. However, due to time constraints the researcher was not able to conduct home visits to the informants.

4.5 Ethical considerations

Following the approval of the research proposal at the University of Bergen, the proposal was submitted to the Addis Ababa Regional Health Bureau Ethical Clearance Committee. The ethical clearance committee reviewed the proposal and permitted the research to be carried out. During the approval process, the consent form was translated into the national language, Amharic. The Regional Health Bureau wrote a permission letter which was addressed to every concerned body (see Appendix II). This letter was used as a reference when contacting the hospitals. Each hospital director subsequently wrote a permission letter to the departments concerned.

Since HIV infection remains a highly sensitive issue, ensuring the confidentiality of the informants remained a very real concern during data collection and transcription. Each informant gave their oral consent for participation in the study as well as for recording of the discussion. Most of the mothers were a bit anxious about the recorder as they were afraid of the possibility of the recorded discussion being released to the media. However through detailed clarification, all the mothers agreed to the recording. All the health personnel were immediately willing to be audio recorded when asked. During the recording of the interviews, the names of the informants were not recorded and anonymity was ensured throughout the entire process.

In addition to the principles of anonymity and confidentiality, the principles of voluntary informed consent and the right of withdrawal without any consequences were also raised and explained thoroughly before each interview session started.

5. Study Findings

In this chapter, the challenges and the paradoxes the HIV positive women with infants experienced are presented. We are talking about scenarios of confusion regarding infant diet that emerged from the discussions with both the HIV positive mothers and the hospital staff. All the quotes and cases presented in the chapter are from interviews with HIV positive infant feeding women and their counsellors/health professionals in PMTCT programs. We have chosen to present parts of the material in the form of quotes to reveal glimpses of the experiences and thoughts of the informants. All names are fictitious.

A brief introduction to the findings

The difficult nature of the infant feeding choices and practices was located at the centre of attention during interviews. Infant feeding choices for HIV positive mothers were generally found to be confusing and challenging, and no single infant feeding choice was easy and comforting to make.

What is more the confusion found among the HIV positive mothers also emerged among health professionals working in PMTCT-ANC clinics, and postnatal infant feeding follow up clinics. The experienced unfit nature of the infant feeding recommendations for the HIV positive mothers, hence also found to have challenged health professionals. In this chapter the detailed experiences, challenges and confusions of both infant feeding HIV positive mothers and their counselors is presented.

This chapter is divided in two sections. The first section reflects the concerns that arose regarding the choice of infant feeding among HIV positive mothers. Throughout the data collection period the “*fear*” of breast milk due to its potential HIV transmission emerged as a major driving force behind thoughts and practices related to infant feeding among the HIV positive mothers. This fear, moreover profoundly affected the counselling of the health professionals working either in PMTCT clinics or in infant feeding follow up clinics. This chapter will try to shed light on how this “*fear*” was expressed in the discussions with the HIV positive mothers and their counselors.

As we shall see, behind every story of infant feeding choice and practice there were important at work dynamics. As is the character of many African social systems, a mother's decisions regarding child bearing and rearing are strongly influenced by others. Custom and cultural practices empower the mothers' social surroundings like mother in laws and grand mothers, in a manner that implies involvement of significant others in infant feeding decisions. Hence, the infant feeding decision an HIV positive mother makes, largely, depends on the depth of the involvement of people in her social surroundings. The second section of the chapter examines the attempts made to implement the international infant feeding recommendation among HIV positive mothers

To gain a brief understanding of who the informants of the study were, a few background characteristics are presented before we dive into the confusion surrounding infant feeding in the era of HIV as it emerged in the present study.

Background characteristics of study participants

The mothers who took part in the present study were in the age range between 22 and 39, and came from different parts of Addis Ababa town. Only two of them had managed to go through high school and finish, and three of the mothers have never had any formal education at all. Most of the mothers (18/22) were followers of Orthodox Christianity, two were Protestant and the remaining two were Muslims. The majority of the mothers were 'stay at home' moms and did not have a formal job outside their home areas (18/22).

The large majority (19/22) of these HIV positive infant feeding mothers had disclosed their HIV status to at least one person. The mothers disclosed their HIV status either to their husbands, to family members or to friends who lived with HIV. The common reason for disclosure of their status to their husbands was the pressure placed on couples for such disclosure in order to establish whether only one or both were infected. Three mothers had not disclosed their HIV status to anyone. The disclosure status of HIV positive mothers who breastfed and who did not breastfeed was not different. Two mothers disclosed their HIV status widely through media, and were presently paid to teach people about HIV/AIDS.

The majority of the informants (16/22) were married, and some (5/22) were divorced. All the 5 divorces were linked to disclosure of their HIV status. One mother was a widow because of HIV.

Almost half (12/22) of the mothers had started taking antiretroviral (ART) medication for treatment of their HIV infection. All the mothers who were replacement feeding their children were on ART while only 4 out of 14 who breastfed their children were on ART. Except for the three mothers who discovered their HIV status after delivery, all got to know their HIV status during the ANC follow up. Only two mothers knew their HIV status before the pregnancy. Eighteen out of twenty two pregnancies were not planned.

The second category of informants constitutes health professionals working in PMTCT and infant feeding clinics. Ten health professionals were interviewed. They were in the age range of 25 to 40 years, and the majority (7/10) were married. The major proportions of the informants in this group were women (7/10). Eight were nurses and two were paediatricians. All of the interviewed health professionals were practicing infant feeding counselling. Their period of practice in PMTCT and infant feeding counselling ranged from three months to more than three years.

5.1 The “CHOICE” of infant feeding

Case I

Almaz is a 27 years old HIV positive mother. She has a 9 months old daughter. Almaz does not have work or any kind of income, and lives with the help of her family and friends. She has known her HIV status since her 3rd month of this pregnancy when she was tested at the ANC clinic in a health centre. It took place during her first visit to the clinic. At that day, nurses were giving health education about being tested for HIV. Almaz was in the group and she agreed to get tested. She remembers the moment she came to know her result as:

“I had no doubt that I was HIV negative, I was the only one who agreed to get tested. But my result was HIV positive. That was the darkest moment in my life. I had nothing left except to cry and scream.”

The counsellor nurse tried to calm her down. She told her about the infant feeding choices that Almaz could opt for. She respected the nurse counsellor’s proposal of

breastfeeding her infant, and decided to exclusively breastfeed her baby for the first six months.

Almaz remembered that moment and said:

“I was in a shock and didn’t hear what the nurse was telling me about which infant feeding method was good and which one was not. When she asked me to choose, I said ‘I will breastfeed’. I thought that was it and that it would be easy.” Almaz got her PMTCT follow up every month until delivery. She felt she was prepared to breastfeed her baby for the first six months.

During labour, it was very difficult to get a hospital bed, and she had to go to three hospitals because the first two had no beds. Finally, she was lucky to deliver at a hospital, and her baby was given Nevirapine (NVP). Just after delivery, the midwife learnt that Almaz decided to breastfeed her baby. Almaz said:

“The nurse almost screamed at me saying ‘Why are you going to breastfeed your baby. You took NVP and you have a great chance of having an HIV negative baby. Are you going to give your baby your disease?’ At that point I was happy that the delivery went well, but I couldn’t bear the thought that I was going to infect my baby.”

At the time of delivery Almaz hence found herself in a situation where she had to change her infant feeding decision without any prior preparation. She had been ready to breastfeed her baby, but she quickly had to switch to replacement feeding. She had no bottles, no formula or cow’s milk, and above all she found no good reason to tell her family for not breastfeeding her infant. She nonetheless started replacement feeding her baby with a cup of milk the nurse brought to her from the hospital cafeteria.

(Case from Yekatit 12 Hospital)

5.1.1 Fear of breast milk

It is well established that breastfeeding implies an experience where mothers and babies intimately bond through the sharing of mothers’ own body product to raise their children. Mothers cherish this experience globally. Breastfeeding up to and even beyond two years of a child’s life is a common practice in most sub Saharan African countries including Ethiopia. HIV, however, has seriously complicated this intimate life experience between a mother and

her child. Breastfeeding has been transformed from a pleasant experience to an experience associated with fear of transmission of a deadly and morally condemned virus. The knowledge of having HIV in their breast milk seriously places a shadow over the infant feeding experience.

HIV positive mothers who experienced that they were given the chance to choose their infant feeding option freely without any influence were very rare. The influence by the counsellors was very strong. In all cases, the manner in which the child was eventually fed was influenced by the knowledge that there is HIV in the milk and by the manner in which the counsellors made proposals surrounding infant feeding method. Almaz's case was hence not particularly different from the others, but emerged as rather 'representative' of many of the women's stories in the sense that the counsellor's propositions were located at the centre of the decision making. This in turn was mainly associated with the knowledge of the presence of HIV in breast milk. In the mothers' view their infant feeding choices had however been influenced by a range of factors which directly or indirectly affected their decision and, in turn their practice. That is, the proposals regarding infant diet made by the PMTCT counsellors made up merely one side of a complex scenario in the decision making process.

What was preached during the time of data collection was the "right" of every HIV positive mother to make a so-called "informed choice" about the kind of infant feeding option she wished to opt for. However, in actual practice informed choice in relation to the various infant feeding options spelled out in the WHO guidelines played a minimal or no role, as most counsellors did not present them as choices to the mothers. This was partly related to the fact that they knew that there were no real existing choices for the women, and partly because of their fear of an HIV transmission to the baby, which tended to overshadow a consideration of breastfeeding options.

The fear of mother's milk and the choice of replacement feeding

The fear of breast milk as a vehicle of HIV transmission from mother to child greatly affects HIV positive mothers' infant feeding decisions and practices. Many mothers were indeed so afraid of the breast milk that they chose to replacement feed their babies with either infant formula or cow's milk despite the likelihood of actually succeeding. An HIV positive mother who replacement fed her infant said:

“When the nurse told me that I have HIV in my breasts, I became so scared of breastfeeding. I didn’t have savings to buy tin milk, but I couldn’t feed my child my breast milk which is filled with my virus.”

Beyond the fear of not having enough funds for infant formula, these mothers also took the social risks of not breastfeeding, not the least its consequence in their family and communities. They took the risk of being looked at as *“a bad mother”* in the community. However, many of these women still regarded themselves as fortunate of being able to prevent HIV transmission through breastfeeding, which was the driving force behind their decision. *“Anyone who tells me to breastfeed is my enemy. I have no more to say.”* This was a response given by an HIV positive mother who was replacement feeding her baby. This mother did not only express her hatred towards breastfeeding in words. Her body language and facial expression clearly revealed her disgust for her breast milk that was infected by the vicious virus.

HIV positive mothers who replacement fed their children experienced that they sacrificed the breastfeeding experience for the benefit of their children; in order to protect them from HIV infection. A mother who was in her late twenties and experiencing pregnancy for the first time said:

“Some mothers say that babies might not know you if you don’t breastfeed them. But I think my baby knows me even if I haven’t breastfed him. When I get closer to where he sleeps, he smiles. There is nothing that I missed from not breastfeeding.”

Hardly any of the mothers who were replacement feeding their babies had a permanent income. Some relied on the income of their partners, some relied on their relatives and friends, and some relied on passers-by. As a consequence of the immense fear of breast milk and of the belief in very high rates of transmission, there were some mothers who opted for formula feeding even though they simply had no funds for buying the tins. Some of these mothers begged on the street in order to buy replacement milk. A 28 years old HIV positive mother said:

“I know Ethiopian people are good and they won’t let you down. Especially if you tell them that you have the virus and a baby. You will not suffer that much. You will get what is needed for that day. The next day you go out for the same thing. Of course, it is hard to be out there

and beg. But what can you do? Kill your baby? It is difficult until bad days pass (ken eskiyalf yalefal).”

The fear of mother’s milk and the choice of breastfeeding

Women who choose to replacement feed were, as we have just seen the victims of people’s scrutiny for not living up to standards of being good mothers. On the other hand, HIV positive mothers who breastfeed their babies were the victims of the fear of breast milk. For these mothers’ the knowledge about the potential for *”infecting their child through their breast milk”* was not easy to tolerate, and many women in fact decided to stop breastfeeding at a very early point.

All HIV positive mothers who breastfed their children (14/14) bitterly shared their challenging experiences during breastfeeding. They expressed the experience of breastfeeding as most taxing. Some mothers said that breastfeeding by an HIV positive mother was a *“sin”*. A mother who had breastfed her child for 4 months said:

“I don’t even want to talk about those four months that I breastfed my child. I was cursing myself. Every time the breastfeeding reminded me that I am HIV positive and that my breast milk was filled with the virus. It is my sin, and I am the one who is being punished, but transferring it to my child is also a sin. What else can it be?”

Another woman who had breastfed her child said:

“If God gives me a second chance to live the last two months over again, I would rather stop eating and buy tin milk (formula milk) for my child. I cannot believe I was breastfeeding my child knowing that I have the virus in my breast milk. If you were a judge, you might have sent me to jail. I almost killed him.”

This statement came from a woman who decided to discontinue breastfeeding at the age of two months. She was one of the cases that I followed closely through the process of discontinuation of breastfeeding. When she came for her first visit at the clinic after she had stopped breastfeeding she was shaking and was asking the nurse about the probability of her child becoming HIV negative. Her talk was shadowed by fear as she was convinced that her child has already been infected through her milk. She added:

“I was sure that I was going to continue breastfeeding for six months, but knowing that I am poisoning my child can’t even give me peace of mind. You feel like you are a criminal doing

something bad to your own child. That was how breastfeeding was for me, and now I don't even want to think that I breastfed for one second."

Beliefs related to MTCT of HIV

Generally, all the mothers (22/22), including both the ones who breastfed and the ones who replacement fed their babies, advised other HIV positive mothers not to breastfeed. This was linked to their conviction that HIV with great ease passes from mother to child, and that it is very difficult to avoid transmission of the virus. One mother brought this point forward by saying:

"If a child who was breastfed by an HIV positive mother becomes HIV negative, it is by miracle; not because of what science says."

Health professionals also expressed their great fear about breast milk. This fear was also reflected in their daily practices. It was observed during the fieldwork period that health professionals who were working in infant feeding follow up clinics had one question repeated for all HIV positive mothers who were breastfeeding, namely *"why are you breastfeeding?"* A male paediatrician expressed his feeling about breastfeeding when he was talking to an HIV positive mother by saying:

"No! No! An HIV positive mother should not breastfeed. That is it! Even if we say the transmission rate through breastfeeding is one in three, it should not happen. No child should be exposed to HIV infection through breastfeeding."

5.1.2 "I thought I didn't have a choice"

What emerged during the course of the study was the limited knowledge about the actual risks related to both breastfeeding and to replacement feeding. As stated above, the majority (20/22) of the HIV positive women in the study got to know their HIV status during the current pregnancy. They hence had little or no experience with HIV and infant feeding. The new knowledge of being HIV positive, the uncertainty of pregnancy in itself, and the required difficult modifications in infant feeding practice together placed an enormous burden on the women, and made them overwhelmed and confused. They simply could not take in all the relevant knowledge in a situation where they were preoccupied with the shocking news of their HIV status. What is more, the information given to the HIV positive women was, as was indicated above, not characterised by an objective presentation of infant feeding options from

which the mother was to choose and be supported in her choice. The information that was given reflected the position of the individual counsellor and was not consistent either within or between health institutions.

A 30 years old HIV positive mother who breastfed her baby because she didn't know about the possibility of replacement feeding said:

“I thought there was no choice other than breastfeeding. If she (the counsellor) had told me that I could buy formula milk from the beginning, I would have done that long ago. I thought it was normal for an HIV positive mother to breastfeed her baby.” Then she added:

“I am very lucky that my child is HIV negative. If he were positive, I know what I would have done, I would have killed myself. But thanks to God, He saved me and my baby.”

Some mothers, especially those who replacement fed their children, believed that breastfeeding is automatically transmitting HIV to a baby and is therefore almost forbidden. An HIV positive mother who was replacement feeding her five months old baby said:

“What else do we have? We do not breastfeed our children because we have the virus in our milk. The only choice left is to buy NAN (formula milk) or cow's milk. That is what I know and that is what I have thought.”

In contrast to this statement, a 27 years old HIV positive mother who replacement fed her baby because she had received little or no information regarding the possibility of an HIV positive mother can breastfeed said:

“In the beginning, I had very little information about HIV and infecting my child. This is my first pregnancy and I got to know my HIV status when I was six months pregnant. I had very little time even to cope with the bad news. When I was told that there is something called transmitting the virus to my baby through breastfeeding, I said 'no breastfeeding'. I thought one sip of breast milk infects my baby and I never knew that one could give breast milk only and get an HIV free child! As you can see, my baby looks like she is three months old, though she is seven. I did not have enough money or anyone to support me. When I see my neighbour's child who is the same age as mine, he is so big and beautiful. His mother is breastfeeding him. I wish I had been told about solely breastfeeding for at least 4 months.”

A couple of women (2/22) mentioned that a child born to an HIV positive mother can be breastfed if a mother can bear the pain and worry of infecting her child, but even these mothers were certain that it is very difficult for an HIV positive mother to breastfeed. On the other hand, they wished to tell other HIV positive women that breastfeeding is also possible and that it does not necessarily imply HIV infecting the infant. One mother said:

“We are living proofs that a child can be breastfed and be healthy. I breastfed my child, but in the beginning I did not know about HIV transmission through breastfeeding. They told me that I have HIV and they said I can breastfeed. It is from the radio that I learned the secret.”

5.1.3 Fear of disclosure

A burden beyond their fear of transmitting the HIV virus to their child was the women’s fear of disclosing their HIV status. Although most of the informants had disclosed their status to one or two persons, the large majority of the HIV positive informants in the study had not disclosed their HIV status widely in the community, and the fear of full disclosure of the stigmatized condition was immense. Breastfeeding indeed found to be an important “*mask*” chosen by some HIV positive mothers, and disclosure did emerge as a major factor influencing the infant feeding decision. One of the HIV positive mothers who breastfed their infants said:

“I chose to exclusively breastfeed my baby up to six months because I couldn’t find any good reason not to. I was planning a story to tell my husband as to why I would not be breastfeeding, but I was not strong enough to do that when the baby came. Above all his mother would have torn me apart. I have told no one that I have HIV, not even my husband. Because of that I had to breastfeed my child for about four months.”

In most cases mothers tried to make up a convincing story so that people, including their family members, would not question their “*strange*” (*gira yetegaba*) infant feeding practice. As most mothers explained, all the infant feeding options presented for the HIV positive mothers are “*unacceptable by the society*” (*ahun man yaminalina new*). By creating good and credible explanations, the mothers hence tried to keep the trust of people including the family and friends. One mother said:

“To survive and live you lie. What else can you do? You build your fence with piles of lies; yes, you lie.” Another mother added: *“My mother is a nun and if she knows that I have HIV, I am sure she will run out of my house and throw herself into a hole. Because of that I told her*

that I have diabetes and I can't breastfeed. She believed me but sometimes her friends make her suspicious."

"My breasts are dry", "I have diabetes", "I have tuberculosis" "doctors told me not to breastfeed", "my baby refused to suck", "I delivered by operation (cesarean section)", and "I am weak and don't have enough milk" were the reasons most frequently mentioned by the mothers. However, the so-called "stories" or "lies" fabricated by these HIV positive mothers did not make them immune from the questions constantly raised by their family and friends.

Mothers revealed why they did not want to disclose their status to their husbands. A mother who was weeping stated: *"If I have told my husband that I have HIV, he would have thrown me out right away and I have nowhere to go. I have no other relatives to rely on, so I am still keeping quiet my pain, my nightmare in order to hide my sin. I had to breastfeed my baby knowing that I was killing him. I did this to protect myself, but that is killing me inside."*

Health professionals also raised the concern regarding disclosure of HIV status. They brought up two different thoughts about supporting HIV positive mothers about disclosing their status to their partners. Most (6/10) of the health professionals interviewed stated that the women should take time to think about the consequences of disclosing their status before doing so. Most importantly disclosing to husbands had to be given thorough thinking.

A nurse PMTCT counsellor said:

"As part of our job we advise mothers to come with their husbands after their HIV positive test result. But some say 'I am not going to tell him'. It is only the woman who knows her situation, therefore we start supporting her decision. That does not mean that we completely agree with her. Some need our help in making up stories, and we help them. For mothers who do not want to disclose their status, I think it is important to listen to and to understand what they are telling us. I think it is not an urgent matter, it can wait."

Other health professionals (4/10) argued that husbands should become aware of their wives' HIV status immediately. They suggested that the husbands should also come to the health institutions to get tested. The dual purpose of knowing their status was brought up. Firstly, husbands can protect themselves from HIV infection if they are HIV negative, and the secondly they can protect their children together with their partners for example by covering

the expenses of formula feeding. Even if some counsellors believed in the importance of immediate disclosure, experience had challenged their stand. To highlight this, a male PMTCT counsellor said:

“Most mothers are not willing to tell their husbands. Every time they are here, they come up with a reason why they came alone. They tell you that ‘he is out of town’, ‘he had to go to work today’, ‘he said he will come next time’ and so on. You cannot do anything about these things. But I believe it is important that their husbands get the test too.”

Even if the mothers were breastfeeding to hide the secrets about their HIV status, either aspects of the PMTCT of HIV package such as giving Cotrimoxazole syrup to their babies and monthly regular clinic visits complicated their challenges in hiding their HIV status. The daily syrup that was to be given to the infants up to one year or more (until HIV transmission is ruled out) bothered the mothers every day. Almost all the mothers who had not disclosed their HIV status to their family members told that adhering to the daily dose of cotrimoxazole was difficult. A mother said:

“I know this medication is helping my baby. But I am dying of fear. If someone is going to see the bottles, or see when I give it to my baby, they will know I have HIV. If there is someone at home, I drop that dose. I know that is not good for him, but I have no choice.”

5.1.4 Health professional’s influence

In most developing countries, like countries in sub Saharan Africa, health professionals have a very high status, and are very prominent in terms of influencing choices and practices of people. The possibility of influencing the patients’ decisions was also strongly reflected in the PMTCT services where mothers had to make a variety of decisions. The case of Almaz which is presented at the beginning of this section also sheds light on the importance of health professionals’ suggestions regarding infant feeding choices for HIV positive mothers.

All the mothers (22/22) mentioned that they believed in what health professionals told them to do. A mother said:

“I don’t worry that much about what will be good for my child and what will not be good. Nurses and doctors worry for our babies and us. They give us medications to protect our children, they tell us not to breastfeed, and they educate us on how to live like normal people. So, what else can I change? We listened to what we were told and we did what we were told to do. They do that for us, and we should respect that.”

Moreover, mothers substantially related their infant feeding choices to the expectations of health professionals. For most mothers going along with what health professionals suggested was very important. The following statement came from an HIV positive mother who replacement fed her baby. She said:

*“I asked the nurse to tell me what I was supposed to do, to breastfeed or not. I was thinking that I would breastfeed because I knew I could not afford formula or cow’s milk. However, the nurse told me that breastfeeding has a huge danger. I told the nurse that I have no income and I was living with relatives. I was expecting that she would say ‘then you can breastfeed’. But she did not. I said ok. Since they are the ones who know everything next to God, I did not mind (**ke egzer betach hulun yemiyawku enesu nachew biye**). However, it was more complicated than I expected. There were days when he cried and I had nothing to put in to his mouth, nothing! Sometimes, he is hungry and he wants milk, but what can I give him?”*

Mothers hence largely relied on health professionals to make the decisions for them about infant feeding choices. One mother said:

“The nurse told me that I have HIV. Since I knew nothing about the virus, I asked her what I should do. She told me to buy cow’s milk and I started feeding my child cow’s milk. I have told no one that I have HIV.”

Health professionals themselves also testified to their influential role in HIV positive mothers’ infant feeding choices. All of them mentioned that mothers themselves push them to decide their infant feeding choice. A female nurse counsellor said:

“There are mothers who come here and ask us to decide what to do. I try to tell them that the decision should be made by themselves. They often say ‘you know what is best for my child’. It is very difficult for us. I know how difficult situations are for them; even living a normal life is difficult. But, you can’t tell her to breastfeed. If you do so and the baby gets HIV, they will blame you. On the other hand, since we have nothing to provide and support them with, it is hard to say ‘don’t breastfeed’. We have to make a difficult decision, even if replacement feeding remains the best choice to protect a baby.”

Most of the health professionals however believed that it is good to influence some of the mother’s decisions. A PMTCT counsellor explained why it was right to influence some mother’s infant feeding choices as:

“There are some mothers who are not given the chance to choose between the different infant feeding options. It is easy (for us) to see whether she can manage or not. We use our ‘hidden right’ to influence. If for, example, you tell this mother not to breastfeed she will not say ‘no’. She will tell you that she can manage. But when you see her for follow up, you regret that you were the one who advised her. So to prevent these cases, we do sometimes enforce decisions on some mothers, by telling them to breastfeed.”

A nurse counsellor who was the head of department of infant feeding counselling clinic added:

“Let us say that a mother comes and she is poor looking and doesn’t have phone number to contact. For mothers like her, we do not even tell the existence of another choice than breastfeeding. When the time comes (when the baby is six months old) we will explain to her about the risk of continuing breastfeeding.”

Health professionals’ influence seemed to follow a pattern where they were particularly involved in making decisions for the HIV positive mothers who were poor. HIV positive mothers who were poor were hence left almost without any choice. To elaborate on this point, a quote from a nurse counsellor is presented as follows. She said:

“Some mothers have no choice other than breastfeeding. When you support their decision and tell them to breastfeed, you can easily see the happiness on their faces. That shows me that these mothers need us to back up their only possible decision. It is sometimes true that you might be struggling with your own feelings towards that feeding practice. It is very difficult to tell an HIV positive mother to breastfeed. But you can feel the position they have given you, and you should use that to the advantage of that mother and her child.”

5.1.4.1 Differing infant feeding counselling scenarios: The case of Zewditu and Yekatit hospitals

Infant feeding choices varied not only among HIV positive and among various counsellor individuals, but also to a large extent between the two governmental hospitals where the study was conducted. These two hospitals are situated less than 5 kilometres apart. The following case description indicates the difference observed between the two health institutions.

Case II

The question “*If you are given the chance to propose an infant feeding option for an HIV positive mother, which one will you choose?*” was asked during each interview with health professionals working in Zewditu Memorial Hospital and Yekatit 12 Hospital.

At Zewditu Memorial hospital, all the counsellors interviewed (4/4) replied “*Replacement feeding*” to the question. A female nurse counsellor from this hospital elaborated on her answer by saying:

“Why should an HIV positive mother breastfeed when it is known that HIV can be transmitted through her milk? I mean, imagine that baby with HIV coming to our clinic to get ART from his young age. I cannot understand that. Therefore I would say HIV positive mothers should be strong enough not to breastfeed at all. That is the only choice if we want an HIV free generation.”

Moreover, a revision of the infant feeding registry for HIV positive mothers shed light on the apparent difference observed in the infant feeding advice given by health professionals. At Zewditu Memorial Hospital, a total of 654 infants had follow-up in the clinic from the start (January 2004 up to August 2007). A substantial majority (80%, 527/654) of the infants in the PMTCT program were hence exclusively replacement fed with either infant formula or cow’s milk. A nurse counsellor was asked about the difference between mothers who chose replacement feeding and breastfeeding. Her reply was:

“There are very few mothers who practice breastfeeding here and we all are happy about that. They are not that many.”

Generally, in Zewditu hospital exclusive replacement feeding was the primary choice of infant feeding practice among HIV positive mothers. In line with their counsellors’ advice, HIV positive mothers who had follow up in this hospital were also observed to be strong “*believers*” in replacement feeding as the only way to save their children’s lives. This was their stand despite all their experienced challenges and consequences of replacement feeding.

However, there were some mothers who refused to replacement feed at Zewditu. These mothers were honest about their poverty and their life situation at home which made it difficult for them to get enough formula and moreover made them liable of disclosure if they didn't breastfeed. It was observed that making a decision of exclusive breastfeeding in Zewditu was quite challenging. A mother from this hospital who chose to exclusively breastfeed her baby for the first six months recalls:

"I have been told not to breastfeed at least one hundred times, but I refused. I am working as a daily labourer carrying my baby on my back. Even if I eat little, he can get good milk from me. But if I said I would buy cow's milk, hunger would have killed my child. His father left us alone long ago and I am struggling to pay my house rent and feed my other children."

Since the majority of this clinic's clients replacement feed their babies, the situation was not experienced as very comfortable for the mothers who chose to breastfeed their babies. A mother who was breastfeeding her child remembered:

"I was happy that my baby was getting food. But, every time I came here, I felt ashamed to tell my friends that I was breastfeeding. Some of them even said 'if you are eating yourself, how come you can't manage to buy cow's milk for your baby'. That was the major reason why I stopped breastfeeding at the fifth month. I didn't want to be called 'a mother who breastfeeds to kill her child'."

A similar question *"If you are given the chance to propose an infant feeding option for an HIV positive mother, which one will you choose?"* was raised among health professionals working in the follow up clinic at Yekatit 12 Hospital. Unlike at Zewditu Memorial Hospital, half of the health professionals working in this clinic (3/6) replied *"exclusive breastfeeding"*. A male nurse PMTCT counsellor said:

"I think those who can afford formula milk will not usually come to our hospital. So we choose breastfeeding for our clients."

An HIV positive mother who was breastfeeding her child for 6 months and who had not heard about replacement feeding said:

"I haven't been told about replacement feeding, and what I knew was breastfeeding and I was happy about that. It would have been difficult to buy cow's milk. When I

asked the nurse whether I was the only one breastfeeding or not, she told me that there were many other mothers who were breastfeeding. I don't feel loneliness."

Moreover, a document revision of the infant feeding follow up registry at this hospital revealed that breastfeeding by an HIV positive mother was a choice by more than half (99/189) of the HIV positive mothers who had follow-up between October 2006 and August 2007.

A social dimension that strengthened the women's decisions was also sensed at Zewditu. Zewditu Memorial Hospital HIV and infant feeding clinic had its own room for the mothers in the PMTCT programs and, most importantly, counselling tools like flow charts were available. This in turn resulted in a convenient environment for mothers. When they queued they discussed similar issues. They talked about their infant feeding choices, the challenges they were facing, and above all, they cherished negative HIV tests of their babies. A mother who was coming to this clinic for 7 months said:

"I sometimes miss my sisters in here (other HIV positive mothers coming to this clinic). When we come for our follow up, we discuss so many things. I learn a lot from them, they even taught me how to read and prepare formula milk. We are like families. It is because of these people that I am this strong today. When you come here you start to realize that everything is possible."

As it has been described in the above cases, there was a major difference between the two hospitals regarding HIV and infant feeding practices. However, at both hospitals the practiced infant feeding options for HIV positive women were either replacement feeding or exclusive breastfeeding. Other infant feeding options for HIV positive women recommended by the WHO like expressed and heat-treated breast milk, and wet nursing were not discussed or made relevant to the women at these two hospitals.

5.1.4.2 The "rumour" of the new WHO guideline

At both hospitals, however, health professionals revealed their fear about tomorrow when the new HIV and infant feeding recommendation takes over the counselling where "*breastfeeding by all HIV positive mothers*" is brought to the forefront. At the time of the data collection, the new international infant feeding recommendation for HIV positive women (WHO 2006) was

still in a phase of only “rumour”. However, the coming policy shift was raised during most interviews with the health professionals. Infant feeding counsellors had varying opinions about the prospects of relating to new guidelines.

A nurse counsellor at Zewditu Memorial Hospital said:

“I am really hoping that the new recommendation is only for discussion; not for actual practice. How can we tell these mothers? They have been told repeatedly about the risk of HIV transmission through breastfeeding, and now all of a sudden breastfeeding is ‘good’ again. Do you think they are going to trust us anymore? This is very challenging for our career.”

However, some health professionals at Yekatit 12 Hospital welcomed the “rumour” regarding the new HIV and infant feeding recommendation. They emphasized the benefits of recommending breastfeeding for all. However, they also mentioned that those who could afford it should still be able to choose to replacement feed. A nurse counsellor at this hospital said:

“I believe these new recommendations will bring some difference and peace. If the media is going to talk about it and emphasize exclusive breastfeeding, I see hope and relief. If that is so, it will not take long to convince a mother that breastfeeding can save her child’s life. I am looking forward to it, and I hope we will then be able to minimize the degree of our confusion. As a consequence, we will be able to help these vulnerable mothers rather than confuse them.”

5.1.5 The AFASS criteria’s ‘Affordability’

As described in chapter three, the AFASS criteria are criteria that ideally are to be fulfilled before an HIV positive mother starts replacement feeding her infant. The following quotations from an HIV positive mother who chose replacement feeding and from a counsellor describe how the real circumstances were experienced among the informants of this study.

Struggling to adhere to exclusive replacement feeding

“I remember, the nurse said ‘can you buy tin milk or cow’s milk?’ I said yes I would try. That was all that I was asked about.”

This was a brief statement by an HIV positive mother who was replacement feeding her child. The woman could not read or write and she even struggled preparing the first tin of formula milk. The mother added:

“I didn’t know how to prepare the powder. If I was to ask someone else, she might have said ‘why are you not breastfeeding?’ The first week, I tried to taste it before giving it to my child. Then I came here and asked the nurse to show me. When the baby got older, her consumption increased and I shifted to cow’s milk. It was so expensive to keep her even for a week. Last month she was admitted to hospital because she had diarrhoea. I thought it was HIV, but they told me it was because of dirty milk. I only had one bottle, but now I got a new one for her.”

It is not entirely obvious that the mother in the above story was asked whether she can buy replacement milk or not, and it is not very likely that she was asked about every aspect that is required in an assessment of fulfilment of the AFASS criteria (affordability, feasibility, acceptability, sustainability, safe). Such a scenario was very frequently found among mothers who chose to replacement feed their babies.

Regarding the economic challenges in replacement feeding, a mother revealed her experience by saying:

“...hmmm It has always been a challenge. I sometimes did not have a bottle of milk to keep him through a night. When I had nothing to give him, I used to stare at him through the whole night. Sometimes I was scared he would die from hunger. A bottle filled with gruel, water, and tea with sugar helped me escape those days. At the beginning, I started buying powdered milk. That did not last long, and I was out of money after the third tin. Then I started him with cow’s milk. He does not still like it, but he takes it when he is hungry. Even if I have some money, you cannot guarantee the cow will have enough milk. The owners may tell you ‘the cow refused and we have nothing today’. You start going here and there, and you might end up having nothing for that evening. It is terrible.”

Because of economic challenges, half of the HIV positive mothers who replacement fed their infants revealed their secret temptation; the temptation to breastfeed. They said that there were moments when they were very tempted to start breastfeeding. Those moments, a mother illustrated:

“A devil comes to your ear and tells you to breastfeed your baby (seytan be jorosh meto atibiw atibiw yilishal). It tells you that it is difficult to find milk tomorrow. I had many moments like this. But I used to distract myself by going somewhere without the baby.”

Health professionals also voiced the difficulty of fulfilling the so-called AFASS criteria. A nurse infant feeding counsellor stated:

“Even if you meet a mother who can afford buying replacement milk and a couple of bottles for six months, you will still have the other two or three components of the criteria unfulfilled. You cannot be sure even when a mother tells you she will keep the bottles clean if she will really manage. Moreover, even when she tells you she is sure she will find money for the first months you will never feel quite assured. You have no other way than believing in what they tell you. I think that is all we can do. It is her choice. If a mother says ‘I can afford it’, you can advise her on how to keep it safe.”

A male counsellor working at Yekatit 12 Hospital explained the issue of the AFASS criteria from his experience in quite clear terms:

“I have never met a single mother who fulfils the AFASS criteria. It is something that is written, but is never practiced. I think it is not practical at all. For example if an HIV positive mother tells you that she is going to replacement feed her baby despite her economic conditions, you can’t force her to breastfeed. But in her case, you both know that she can’t manage. From my experience and from what I have seen, the criteria are just for discussion and for flavouring the training sessions. If she can afford it, that is what we ask. The other components of the criteria are just asked out of pure formality.”

Throughout the data collection period participating in the clinics provided the researcher with a good opportunity to see how assessment of the ‘AFASS’ criteria were influencing the infant feeding choices of the mothers. It was readily noticed that “affordability” was the one point emphasized whereas the other four components: acceptability, feasibility safety and sustainability remained literally untouched. Particularly at Yekatit 12 Hospital events where the full descriptions of the AFASS criteria were raised were very rare. On the other hand, at Zewditu Memorial Hospital, mothers were at least asked about the various components of the criteria, but this took place in an atmosphere that was so strongly in favour of the replacement feeding that it is difficult to see how the assessment had any true practical function or implication.

5.2 Experienced barriers to adherence of chosen infant feeding method

After choosing an infant feeding option, the HIV positive mothers' challenge remained significant. As a consequence of their HIV status, they didn't only face the life changing disease, but the surrounding community, their families etc were not in favour of them. The HIV positive mothers revealed that the precautions related to following their infant feeding decisions affected their daily lives in a very substantial way. It challenged their motherhood feelings and it severely affected their social connections in their community. They felt that they failed to fulfil what was expected of them as a mother, and as a community member.

5.2.1 Challenges of customary mixed feeding patterns

5.2.1.1 Exclusive Breastfeeding; not a norm

As it has been discussed in chapter two exclusive breastfeeding up to the age of six months has enormous benefits to infants. What is more, exclusive breastfeeding has been found to have a minimum HIV transmission risk when compared to mixed-feeding with other liquid or solid food items. However, mixed feeding practices are well prevalent in sub Saharan African countries including Ethiopia

National surveys conducted in Ethiopia reveal that mixed feeding patterns are a common phenomenon. This practice, as it has been described, can start even before initiation of breastfeeding as prelacteal feeds. Most of the mixed feeding practices are attributed to the beliefs and values and are deeply embedded in local culture. Prelacteal feeds, like fresh butter, are believed to cleanse the infants' intestines. Moreover, from early age infants are expected to be "*thirsty*" and they are entitled to get supplementing water.

These practices, however, create difficulties for HIV positive women who are breastfeeding. The WHO's infant feeding recommendations emphasize that breastfeeding by an HIV positive mother should be exclusive as we have revealed in chapter two. However, in real circumstances, the challenge remained enormous. HIV positive mothers who chose to exclusively breastfeed their infants were harshly confronted by this fact.

“When I told my mother she can’t give fresh butter to the baby, she screamed at me and even laughed at me saying ‘are you trying to teach labour to your mom’ (mit lenatwa astemarechat)? We fought all the way until I stopped breastfeeding and she even used to curse me when the baby was crying for simple reasons. But she will never tell me what she did when I left the baby home with her.”

This was how a 34 years old HIV positive woman challenged by her mother. This HIV positive mother tried to exclusively breastfed her child, and tried to adhere to what she has been told. However, she did not hide her failures in doing so. Through probing, she added: *“I once saw my mother giving a spoonful of herbal mixture. I acted as if I had not seen it. After that I stopped leaving the baby with my mother.”*

Not only family members challenged these women. Neighbours, close relatives and even guests could act very challenging. An HIV positive mother who was breastfeeding her baby for four months stated:

“One day my baby was crying badly! My neighbour (we share a common wall) came with a kind of herbal mixture wrapped in a piece of plastic and told me to give it to the baby. I said no. She did not say a word in the beginning. She was just staring at me. She returned three times. Finally, she threw the thing on my face and left my home. She never came back, and she never even greets me now. She was annoyed with me.”

Health professionals also witnessed the challenges associated with mixed feeding. All said that exclusive breastfeeding was an enormous challenge for mothers who were trying to hide their secret by breastfeeding. They also pointed out that, escaping mixed feeding was one of the major benefits for mothers who chose to replacement feed.

Nurse counsellors noted that it was commonly difficult to get true information about additional nutrients given to the infants. A counsellor revealed his concern by saying: *“When my clients who are breastfeeding are asked about exclusive breastfeeding, they say ‘yes I managed or I didn’t give anything’. However, you cannot trust that information because they might have been afraid of telling their failure to us. But in case you have time and you probe further, a mother will tell you ‘yes, one day I was not around and someone else did it’ and so on. As a mother of two kids I know it is very difficult to avoid mix feeding.”*

5.2.1.2 The challenge of early cessation of breastfeeding

To describe the challenge implied in the demand for early and abrupt cessation of breastfeeding, a case of an HIV positive mother who stopped breastfeeding when her baby reached the age of 4 months is presented. This case is chosen not because it is different, but because it emerged as a typical scenario with reference to early and abrupt cessation of breastfeeding.

Case III

*“I remember it was Wednesday. I went to the follow up clinic to fetch Cotrimoxazole. I was very eager to get my child weighed so that I can see her progress. I reached there on time and was queuing with mothers like me, mothers who were ill-fated (mothers with HIV positive children (**egzer yetalebachew**)). I was breastfeeding my baby, and she was happy playing. Then it was my turn and the nurse called me in. The doctor was there and asked me how my child was doing. I said ‘thank God everything is good and she is growing’. He was reading my card while I was talking to him. Then he asked me ‘do you want your baby?’ I said that of course I do. I told him that she is the only reason for me to live. Then he stopped looking at the card and said ‘if you want your baby and if you want her to be healthy, you have to stop breastfeeding today. She is four months old and that is enough. Now you can go out and do what you have to do to save her life. We don’t want to see your child infected and coming to take the medication (ART)’.”* The woman continued:

“I was expecting that they would tell me to stop at six months. That was what they said in the beginning. I was not ready at all. I did not have money. That day I even had to walk home because I did not have money for a buss. It was shocking for me. But, when he said ‘we don’t want to see your child infected’, I felt a very sharp pain in my throat. He was right and he said that to save my child. I agreed to stop, but I told him that I did not have money to buy what was needed. He advised me to try as much as I could. I knew the situation I was in at that time could not give me any solution as her father stopped giving me anything and he is HIV negative. He goes out early in the morning and comes home late in the evening, drunk,” The woman continued:

“...I left the clinic thinking what to do. I did not go home directly. I went to see my friend and asked her for some money. My baby felt something and started crying. I said no breastfeeding. I was able to get 20 birr (approximately 2 dollars) from my friend. With that money, I bought a bottle and a litre of cow’s milk. Then my nightmare started. She refused to suck the bottle, she was screaming, and was very angry with me. When she cried, I cried with her. When she was irritated, my husband was screaming at me and telling me to give her my breasts. He once said ‘you cursed lady, you are disturbing me, and I can’t sleep. You both can go to hell’. That was when I realized I should not think that my baby has a father. The challenges were everywhere; my breasts were hurting, my baby was not eating and could not stop crying, and I had to find a way to get money for food for my daughter. But I didn’t dare to breastfeed her again.” The mother continued:

Thank God, after three days, she started taking cow’s milk, and she was gradually getting used to the bottle. Do not ask me how I suffered. I wish I had money to buy her tin milk (formula milk). I think that tastes like breast milk. Later she became fine and my breast pain disappeared’... ‘I forgot that I had to make up something to tell my families and friends. They were so curious and were so tough. I gave different reasons to different people. They can ask you suddenly about why you stop breastfeeding your child so early, and you do not even get time to think about what to say. I do not care anymore, but I think they became very suspicious after that. But for me it was all about my baby. If she is fine, the rest is no problems.”

The above case describes the challenges informants in the study raised regarding early and abrupt cessation of breastfeeding. The age at which these mothers stopped breastfeeding varied from 2 months (1/14 mothers) in the earliest case to six months (2/14 mothers) which were the latest time of discontinuing breastfeeding. The remaining mothers (11/14) stopped in the age range between 2 months and 6 months. It was however only two mothers who appeared to manage to stop breastfeeding according to their plan.

Health professionals’ advice, however, was not the only reason why these mothers stopped breastfeeding in an abrupt and rapid manner as in the case above. Guilty consciousness knowing the role of breastfeeding in the transmission of HIV infection was mentioned very frequently. An HIV positive mother who stopped breastfeeding at 2 months said:

“I can’t take it anymore. The guilt is killing me, and God knows about what happened before. Now I am ready to stop and I will do whatever it takes. I am dying inside.”

Another HIV positive mother described her experience of breastfeeding as follows:

*“Every time the baby was sucking my breasts I felt like throwing up (**tuten sisib sayew wodelay yilegn neber**) I now regret what I did, but God is merciful and he didn’t see my sin. She (the nurse) told me that he (the baby) is negative.”*

An important concern the mothers raised was a lack of information regarding how to stop breastfeeding and retain their child’s health, especially the women from Yekatit 12 Hospital (9/14). These mothers wished if they had been told about how to manage everything from replacement feeding for their child to engorged and painful breasts.

Five of participants from Zewditu Memorial Hospital mentioned that they were told to exercise bottle-feeding of their breast milk. They were given two weeks to train their infants with breast milk, and mentioned that they were taught how to prepare formula/cow’s milk using visual images. Such teaching sessions were also observed during participant observation. At this hospital’s clinic, infant feeding counselling charts for HIV positive mothers were also present, and nurses were using the materials to explain the preparation of infant formula etc. for the mothers.

5.2.1.3 If a mother is alive, and “healthy” why bottle-feeding?

The HIV positive mothers held the HIV responsible for not being able to be “*real mothers*”. They described “*a real mother*” as a mother “*who breastfeeds*”. An HIV positive mother who was replacement feeding her baby said:

“What irritates and discomforts me is peoples ‘why are you not breastfeeding’ question. It is a headache, but you have to expect it everywhere. You might be at your home or in church; they ask you the same thing. That constantly reminds you that you are deficient.” This mother added:

“But you can’t blame anyone. They are right! How can a woman be a mother without breastfeeding her child? She is incomplete without it.”

People did not only question these mothers. They also tried to disprove their ‘cover’ for not breastfeeding. A 30 year old HIV positive mother who replacement fed her child narrated her experience as follows:

“It was my daughter’s baptism day and everyone was at my place. I was not breastfeeding my baby. She started crying and I gave her a bottle. People around asked me why I was not giving her my breasts. I told them I was bottle-feeding her because my breasts did not have enough milk. My elder sister stood up immediately, came with warm water, and started massaging my breasts. She was trying to express my breast milk. I did not even try to stop her. Then she told me to put my nipples in to my baby’s mouth. I had nothing to say, and had to do what she told me to do. Since my breast was new for the baby, she did not take it immediately. Instead, she started playing with it. Then I told them she does not like my breasts. I was praying to God so that she would not be able to suck. That became a day of horror. What do you call these people? They are enemies and won’t let you live your life?”

Apart from the psychological and social challenges, these HIV positive mothers faced economic difficulties. Either family members or non-governmental organizations supported only three out of the eight mothers who were included in the study who were replacement feeding. A couple of the women who were receiving support from NGOs had disclosed their status to the public, in fact they said that was why they got the support.

Not breastfeeding a newborn infant considered them as “evil mother” (*chekla lij yematateba seytan*), and secondly people were suspicious about these mothers’ HIV status and they categorized them as “liars (*washo*)”.

6. Discussion

The study reveals that infant feeding choices and practices of informants was strongly influenced by a serious fear of breast milk. Regardless of what the international infant feeding guidelines recommended for HIV positive women, these mothers and their counsellors dealt with infant feeding practices in a manner that was dominated by the knowledge that there is HIV in the breast milk and HIV transmission can take place through breastfeeding.

This chapter has two sections where the first section presents the discussion of the major findings of the study, and the second discusses the methodological approach applied in the present study.

6.1 Discussion of the main findings

The following discussion is divided into three sub-sections. The first sub section discusses what has been found to be “the fear of breast milk”, and discusses how this fear affected the choices and practices of infant feeding among HIV positive mothers and their counsellors in resource-constrained setting. The second sub section mainly puts light on the challenges regarding the attempts to adhere to the “one size fits all” recommendations from international organizations. The last sub section discusses the findings of our study in relation to the theoretical framework described by Scheper-Hughes and Lock (1987) as the “three bodies”, relating to the individual body, the social body and the political body.

6.1.1 The fear of breast milk

Our findings suggest that the fear of breast milk was by far the most central factor behind infant feeding choices and practices of the HIV positive mothers. Most HIV positive mothers in this study in fact believed that breastfeeding was almost equivalent to infecting their child. This affected their infant feeding choices and their actual infant feeding practices greatly. Our findings hence demonstrate that breastfeeding by an HIV positive mother has become a fearful and painful experience. What is naturally a cherished experience of closeness and warmth, which is a core sign of the motherhood experience has become filled with extreme anxiety, worry and a sense of hopelessness.

During the last century, it has, according to Cecil Helman (2007) been reported that breastfeeding has been declining worldwide. In his book “Culture and Health” Helman described this decline in breastfeeding practice as “*the greatest nutritional crisis*” found globally (2007: p70). For the decline, different factors were held accountable. These included; modernization/urbanization, employment of women, and the periodic huge advertising campaign undertaken by Western manufacturers in the developing countries promoting bottle-feeding. In the last two decades, especially in sub Saharan African countries, HIV transmission through breastfeeding has moreover contributed to the enormous uncertainty regarding breastfeeding, and hence held as one of the accountable factors causing decline in breastfeeding world wide (Helman 2007: p70). Findings from the present study confirm Helman’s writings. Despite enormous economical constraints and socially restricting situations, many HIV positive mothers chose not to breastfeed their infants for the fear of transmitting HIV to their babies.

Earlier studies conducted among HIV positive mothers who are breastfeeding their infants have not been as explicit in their documentation of the breastfeeding experience itself and the immense fear linked up with it. However, some qualitative studies conducted in sub Saharan African countries, specifically in Tanzania and Ethiopia (Leshabari, Blystad et al. 2007; Moland and Blystad 2007) demonstrated the pain and fear associated with breastfeeding. However, the current study demonstrated the fear of breast milk reflected by HIV positive mothers and their health professionals to an even stronger degree. In our study, hence the fear of breast milk was the pillar factor found to have influenced HIV positive infant feeding mothers and health professionals’ infant feeding choices and practices. Leshabari and colleagues in their study expressed the experiences of HIV positive mothers who chose to replacement feed their infants as; the mothers’ practices “*illustrate the tension experienced between the medical knowledge of HIV transmission through breastfeeding*” (Leshabari, Blystad et al. 2007: p552). They have also pointed out the tension was because of the conveyed message through counselling and mothers’ desire to practice breastfeeding. Likewise, Moland and Blystad (2007) also demonstrated that the beliefs regarding infant feeding and HIV are confused among HIV positive mothers and their counsellors who were included in their study mainly from Eastern African countries. The confusion, as they described it, could be more linked up with the distorted assumption HIV positive mothers and their counsellors have towards the risk of HIV transmission through breastfeeding (ibid).

As a consequence of the immense fear of breast milk, some HIV positive mothers in our study chose to replacement feed their babies with out any permanent income and surely without fulfilling the AFASS criteria. These mothers trusted passer-by people to fulfill their needs, since they simply could not bear the thought of breastfeeding their infants with knowledge of the virus in their breast milk. Other studies have also indicated that HIV positive mothers who live in resource-limited settings choose to replacement feed their babies without fulfilling the AFASS criteria (Doherty, Chopra et al. 2007: p1794). However, Doherty and colleagues (Doherty, Chopra et al. 2007) in their study linked the choice of formula feeding in their study participants to the free provision of formula feeding and poor counselling. Yet, the method of data collection they used is different from ours and hence we cannot give a full comparison of our findings. However, the poor counselling could be linked up with distorted messages regarding breast milk (Doherty, Chopra et al. 2007: p1796).

The HIV positive mothers who saw no other option than to breastfeed their infants for the first couple of months commonly experienced an enormous degree of fear, which, as we saw, commonly led them to stop breastfeeding early. According to our study findings, the HIV positive mothers didn't only stop breastfeeding as a planned result of the WHO recommendation of early and abrupt cessation of breastfeeding (when replacement feeding is AFASS) (WHO. 2001). Rather, most of the mothers stopped breastfeeding either because they learnt about HIV transmission through breastfeeding or more importantly because they eventually became overwhelmed by the fear of HIV transmission and decided to discontinue breastfeeding. This finding of our study is consistent with findings from a study conducted in Zimbabwe (Lunney, Jenkins et al. 2008). In their study, Lunney et al., (2008: p351), pointed out that HIV positive mothers stopped breastfeeding simply because of the "*mothers' knowledge about HIV transmission*"; which raised fear of breast milk and breastfeeding. Moreover, HIV mothers in our study who breastfed for couple of months without knowing the actual risk of HIV transmission through breastfeeding regretted their acts when they found out that HIV can be transmitted through breastfeeding. These mothers, however, held health professionals responsible for not telling them the fact and believed that they were giving poison to their infants. This finding of our study complements another qualitative study conducted in South Africa (Seidel, Sewpaul et al. 2000). In their study, an HIV positive mother who was breastfeeding her child for eleven months expressed her breastfeeding experience as "*...I though I was breastfeeding, but I was breast-poisoning*" which is very

similar as pointed out by some of HIV positive mothers in our study (Seidel, Sewpaul et al. 2000: p27).

Another important factor, which proved to determine HIV positive mothers' infant feeding choices, was the influence of health professionals. Our findings showed that health professionals had quite a considerable impact on the infant feeding choices and practices of the HIV positive mothers. Studies conducted in Tanzania (de Paoli, Manongi et al. 2002) and in South Africa (Seidel, Sewpaul et al. 2000) have also emphasized the influence of health professionals in the choices and decisions HIV positive women made. This should be related to the position given to health professionals in combination with the extreme vulnerability and confusion experienced by the women. Seidel G and colleagues (2000: p30) points out that in many sub Saharan African countries, people have been observed to take the recommendations made by health professionals as important and final words; which in turn affects mothers ability of decision making. Piwoz et al (2006: p6) likewise indicated that "*mothers place a high level of importance on the advice of health workers. Mothers trust information they receive from these workers and believe it is accurate and beneficial for their infant's health*". Similarly, in our study the information given by health workers was observed to even instantly change the decisions of the mothers.

However, the tendency towards options of replacement feeding for mothers who can barely handle the situation cannot be understood without a continuous reference to the fear they have of breast milk. Some of the health professionals did not hide their own fear that breast milk could infect the child, and felt they had to promote replacement feeding. A study carried out in Tanzania suggests that the risk present when health professionals have too little training may "*compromise the health of infants if counselling is based on personal attitudes*" which can easily be subjected to bias (Piwoz, Ferguson et al. 2006: p7). Similarly, in our study, the little or no training experience regarding HIV and infant feeding counselling was found to largely contribute to an already confused infant feeding practice. The minimal training regarding infant feeding in the era of HIV made the health workers guidance dependent upon what they thought was right, which could obviously be compromised by the fear that they have towards breast milk.

Consequently, the difference in practices of infant feeding among the study health institutions that was observed in our study should be partly attributed to the personal beliefs of the respective health professionals. Hence, the practice of infant feeding guidance in a particular health institution is not necessarily more than the outcome of beliefs and experiences of the counsellors and other health professionals working in health institutions. At one of our study hospitals, Zewditu Memorial Hospital, most of the infant feeding counselors had training regarding PMTCT of HIV through breastfeeding. However, the core participants of the clinic at Yekatit 12 Hospital did not have any formal PMTCT training including infant feeding counselling. Similar findings were also seen in a study conducted in different eastern African countries by Moland and Blystad (2007). They have clearly shown that there was a difference between health institutions rendering PMTCT services regarding infant feeding choices and practices, even in a particular Ethiopian setting (ibid). That means that practical differences in infant feeding recommendations between health institutions can be biased by personal beliefs.

In light of the infant feeding guidelines that were at work during my fieldwork, HIV positive mothers who are living in Ethiopia and in other similar sub Saharan African settings barely have choices for feeding their newborn infants. HIV positive informants included in our study hardly had choices. Whatever they decided to do was strongly shadowed by their immense fear of their breast milk.

6.1.2 The generalizing guidelines

The “one advice for all” nature of infant feeding recommendations worldwide has strongly contributed to the complexity and confusion of infant feeding. Infant feeding recommendations for HIV positive mothers that consider all HIV positive mothers in a similar package, which largely ignore local and cultural meanings attached to infant feeding practices except for a little visible feasibility criteria. Taking into account the complex nature of social and cultural relationships around the globe, including in sub Saharan African countries, the attempts to apply a global infant feeding recommendation was found to have confused HIV positive mothers as well as their counsellors. Our study findings suggest that, almost all infant feeding HIV positive mothers and their counsellors felt quite certain about what the recommendations meant in terms of knowing that they indicated a scenario of HIV in the milk that had to be avoided if you could afford and manage it. Infant feeding counsellors, especially, were curious to know ways to assessing mothers’ ability to a certain infant feeding recommendation, but found it very difficult within the limited time available. Rather, they all

felt there was no choice at all. Hence, we argue that the international infant feeding guidelines that forwarded “choice” of infant feeding for HIV positive mothers living in the resource constrained settings, like Ethiopia, missed the point that these mothers practically have no choice. Based on the findings from our study, we raise the following points to enlighten our argument.

First, according to the latest international guidelines in PMTCT, a sound infant feeding choice is located at the core of the intervention program aimed at minimizing HIV infection in children (WHO. 2007). In sub Saharan African countries, complete avoidance of breastfeeding in the aim to prevent MTCT of HIV did however show far more pitfall than merits (Coovadia, Rollins et al. 2007). If replacement feeding is not possible to implement for the large majority of HIV positive women, what is left will be breastfeeding.

It has been long since it was documented that breastfeeding is the only feasible and safe infant feeding option in most resource constrained settings. However, after the research documented HIV transmission through breastfeeding, the practice of breastfeeding by an HIV positive mother led to an enormous dilemma, breastfeeding a newborn infant and hence ensuring the baby nutrition and proper growth or protecting their infants versus HIV transmission. The WHO provocatively promoted “informed choice” in relation to infant feeding option remade by the HIV positive mothers (WHO. 2001). Anyone with a minimum of knowledge on most of the African HIV positive woman’s life situation will however ask what kind of choice WHO is actually referring to. The large majority of women obviously have no real choice in relation to type of infant feeding method.

What is more, in almost all sub Saharan African countries including Ethiopia, breastfeeding is almost universal. What is more important is that cultural norms and practices are highly linked up with this motherhood experience (Helman 2007; Leshabari, Blystad et al. 2007). This culturally embedded practice is located at the very core of being a “*true mother*”. The mothers themselves, their family members and the members of the community place great value on the breastfeeding mother. Our study findings clearly adds to the evidence that breastfeeding is the only acceptable practice of feeding a newborn infant in the Ethiopian setting. All mothers and health professionals acknowledged that not breastfeeding was socially and culturally highly unacceptable. For the mothers in our study breastfeeding was perceived more as a mark signifying motherhood, and was less referred to in terms of its

medically acknowledged benefits for children. Likewise, (Helman 2007: p71) stated the following point which emphasizes the importance of society as: *“Like other human activities, breastfeeding does not take place in a vacuum; it is always shaped by the cultural, social, religious and economic environment in which it takes place”*.

Secondly, it has been well documented that replacement feeding of either formula milk or modified animal milk are both an inconvenient and culturally unacceptable alternative for HIV positive mothers living in sub Saharan African countries; and is highly linked with social stigma (Hartmann, Berlin et al. 2006). Our findings add evidence to this scenario: HIV positive mothers who opted for replacement feeding suffered the consequences, and some even felt the need or pressure to breastfeed in between. Economical challenges and social stigma associated with replacement feeding were the most commonly encountered problems. Recent studies conducted in other African countries indicate that there is greater risk of child mortality and morbidity following replacement feeding than it is for the child to die of HIV following breastfeeding (Thior, Lockman et al. 2006; Coovadia, Rollins et al. 2007). What is more, most HIV positive mothers are often not in a position to make independent decisions as a result of poverty and economic dependence on their partners (Coovadia and Bland 2007: p1118). These challenges will continue to raise controversies regarding replacement feeding in most sub Saharan African countries including Ethiopia into the unforeseeable future.

Thirdly, lack of information, poor counselling and messages of avoidance of breastfeeding by HIV positive mothers in the developed world seemed to have shadowed the “counselling” process in terms of actually promoting the safer “choice” for HIV positive mothers (Coovadia and Bland 2007). Our findings clearly show that, as a result of poor counselling, HIV positive mothers chose inappropriate infant feeding alternatives for their social circumstances. The poor counselling had to be partly attributed to the lack of proper training that the health professionals had. Coovadia and Bland (2007) in their review analysis pointed out that *“health professionals in Africa have too easily accepted policies developed in the industrialized world”* which could partially explain the gap in the counselling process which exists in most developing countries. This obviously affects the quality of infant feeding counselling rendered to HIV positive mothers. Hence, the dilemmas experienced by the women should also be seen in terms of being counselled by a health professional who did not know enough to properly assess the situation. These findings are consistent with research

carried out in Malawi (Piwoz, Ferguson et al. 2006), and Tanzania (Leshabari, Blystad et al. 2007) which clearly pointed out the urgent need of training health professionals.

Our findings did moreover show that from the HIV positive mothers' point of view very few would hear about AFASS beyond the economic assessment of mothers' ability to find money for the tins, which in turn makes one raise the question regarding the depth of the counselling. Very few HIV positive mothers would for example get the chance to hear about the other components, such as the feasibility, acceptability, sustainability, and safety of replacement feeding. This turned out to be most important in that people did not manage to replacement feed properly due to the social pressures, due to not being able to clean the bottles properly etc. Health professionals experienced that assessing mother's ability to successfully replacement feed her infant was a far more challenging issue than it seemed. They stressed the fact that the assessment tool depended on every mother's perception and understanding to the questions. The other problem is that there exists no parameter to evaluate the reliability of information the HIV positive mothers provide. This hence makes the criteria questionable.

At the end of the day, the gap between what was recommended that should be done and the actual practice led HIV positive mothers and their health professionals into states of confusion, which resulted in poorer adherence to certain infant feeding option. They all, whether infant feeding mothers or health personnel mentioned the difficulty of understanding and interpreting the international recommendations with reference to real life situations. Similarly, Doherty et al (Doherty, Chopra et al. 2007: p1792) in their study pointed out the following: *"the translation of the WHO/UNICEF recommendation into operational settings is a challenge for health workers and counsellors as there is little guidance on what the terms 'acceptable', 'sustainable', 'safe' and 'feasible' mean in practice"*.

Pointing out the complex nature of infant feeding modification, our findings strongly indicate that the very latest HIV and infant feeding guidelines which promote exclusive breastfeeding by HIV positive mothers who can't fulfill the AFASS criteria in the long run will fare much better than the WHO, 2001, guidelines preaching "choice". However, we are still left with an unanswered uncertainty about whether or not the shift is radical enough. As long as the replacement alternative is mentioned *"for those who fulfill the AFASS criteria"* (WHO. 2007) health professionals may still continue to emphasize this alternative.

6.1.3 The “Three bodies” versus infant feeding in the era of HIV

The conceptual framework the “three bodies” proposed by Scheper-Hughes and Lock (1987) seems to productively reveal various central dimensions of the problem at hand in PMTCT, and can assist in understanding the struggles of mothers and health personnel in a context of PMTCT of HIV. In their article, Scheper-Hughes and Lock (1987) investigated the body using different theoretical approaches and epistemologies. The basis for developing this analytical framework was the attempt to understand the bodily experienced relationship and interconnectedness of assumptions which were otherwise understood as separate entities (e.g. separation of mind from body, real from unreal) (Sheper-Hughes N. and Lock 1987). Their assumption of the body is as “*simultaneously a physical and symbolic artefact, as both naturally and culturally produced, and as securely anchored in a particular historical moment*” (Sheper-Hughes N. and Lock 1987: p7).

The “three bodies” represent three levels of analysis. First, “the individual body” is understood in sense of the lived experience of the body-self (Sheper-Hughes N. and Lock 1987: p7). According to the HIV positive women, they pass through extremely difficult experiences during the early infant months. Not the least it fundamentally challenged them in terms of the experience and living ideals of motherhood. The thought about the virus in their breast milk transformed their experience of motherly nature, intimacy in terms of sharing their milk product to ensure growth of the child. Rather their sensation of their breast milk was changed in to a feeling of poisoning the child with their milk, poisoning the child with a morally condemned virus. This filled the breastfeeding experience with anxiety and fear. For many this became so difficult that they could not bear it, and opted for replacement feeding throwing themselves into enormous challenges of both a economic and social character. This moves us to next level of analysis; “the social body”.

The second analytical level, “the social body” refers to the body as a natural symbol comprising nature, society and culture (Sheper-Hughes N. and Lock 1987: p7). As it has been described at the beginning of this section, breastfeeding is an experience that is enormously linked up with the culture and values of a society, and is hence guided and guarded by the people in the community. Based on the findings of our study, HIV positive mothers infant feeding decisions of either breastfeeding or replacement feeding and their chances of adhering

to their choice were highly influenced by their socio-cultural surroundings. The 'natural' dimension of breastfeeding is by every mother closely facilitated and constrained by what the society expects a "true mother" to do and to be. In our case, the ideal was to breastfeed, but not exclusively, but to mix with butter, water, herbs for medication etc. to ensure your child's growth, health and comfort. For the HIV positive mothers who were breastfeeding their infants, the customary mixed feeding became an enormous challenge as the social surroundings expected this, and particularly when the child was not comfortable it was perceived as highly unacceptable not to accept the advice deemed culturally appropriate. We can recall the woman who threw medicines at the HIV positive woman who refused to accept her offer of comforting medication in a situation where the woman's child was continuously screaming.

The third level in the model of Scheper-Hughes and Lock is the level of "the body politic" referring to the regulation, surveillance, and control of bodies (individual and collective) (1987: p7). At the local level, we have seen how the women have been closely watched and surveyed in ways that have had severe consequences for their bodily practices. In an HIV and infant feeding context, the international infant feeding recommendations for HIV positive mothers, described in the second chapter of this thesis, is however the aspect that overshadows other dimension when it comes to body politic. These recommendations, which hardly recognize the embedded and social values related with infant feeding, and which globally manages to transform the infant feeding experience of millions of HIV positive women is located at the heart of ruthless regulation or control over women's bodies. All the modifications demanded by the guidelines indeed were unacceptable by the society, as both not breastfeeding, breastfeeding exclusively and breastfeeding for merely a few months were all perceived as inappropriate and unacceptable. Most importantly, "the body politic" dimension did not seem to take into account the two other components of the analytical framework.

Scheper-Hughes and Lock described "the body politic" as "*the most dynamic in suggesting why and how certain kinds of bodies are socially produced*" (1987: p8). The nature of the dynamics of body politic, which in this case are dominated by the international infant feeding recommendations for HIV positive women, seem to be moving women into extreme sufferings in ways that continuously shift with the changing WHO guidelines. This 'dynamic'

nature of the guidelines implies adding an even greater uncertainty and burden on both HIV positive infant feeding mothers and their counsellors.

In a context of HIV and infant feeding, these “three bodies” emerge as almost inseparable; and they have influence on one another. However, the challenge coming in the form of “the body politic”-level, as international recommendations, seem to be the driving force of the others and at time of fieldwork seemed to be the one primary responsible for shaking motherhood images globally.

6.2 Methodological reflections

HIV, even if quarter a century has gone since its discovery, it is yet inseparable from stigma and discrimination associated with it. As a result, discussing infant feeding topics in the era of HIV becomes a sensitive issue that is embedded with in a particular social context. The sensitive nature of the study topic called for a considerable flexibility during the data collection process. Taking this in to account, we chose a qualitative approach as method of data collection for this study.

Qualitative triangulation was found very useful in generating a ‘grounded knowledge’ about the experiences of HIV infant feeding from the perspective of the core role players. Below a few comments are forwarded as a brief evaluation on each method employed in data collection.

Participant observation

To gain an in depth understanding of the “inside”, participant observation was chosen in an attempt to explore the sensitiveness and complexity of the topic. Fairly, long-term presence in the institutions working with infant feeding and HIV helped the researcher gain a fairly wide range of knowledge about the topic. During this period, participant observation alternated with observation, informal interviews, discussions and listening informally to personal experiences in a way that enriched the data material. Prior clinical experiences and brief exposure of the researcher to the present field as well as knowledge of the local language and customs were very important dimension during the participant observation period.

Gaining an overview over the complexity of the subject became most challenging during the fieldwork period. Above all, the experience during the participant observation gave the researcher an impression of the complexity of the study topic. This method also gave the researcher a unique opportunity to view the study topic in different angles; from HIV positive mothers point of view and from the side of health professionals' daily experience. The research setting was by far a school on its own where information of all kinds continuously reached the student from various sources, various settings, with various points of view. Knowledge was gained through continuous presence of the researcher.

Participant observation also helped the researcher to observe important research question about the experiences of HIV positive mothers who were replacement feeding. At the beginning, during the development of the research proposal, the researcher wanted to look at the challenges regarding early cessation of breastfeeding only. However, the large number of HIV positive mothers who were replacement feeding at Zewditu Memorial Hospital encouraged the researcher to include this perspective. This new research question was focusing on the experiences of HIV positive mothers who were replacement feeding. The new theme enriched the data set. This lesson was learned as a result of doing participant observation.

Another strength of doing participant observation was that, it facilitated the selection of study participants for the in depth interviews and case studies. There was a focus of continuous note taking, and keeping of records. However, this remained challenging as there was limited time and room to write down notes while at the clinics.

Another challenge could have been that a researcher involved in the daily activities of the clinics might have forced informant mothers to think that the researcher was part of the organization/the health system. As a result, mothers might have been selective and cautious in criticizing their dissatisfactions and worries regarding the clinics. To avoid this, the researcher tried to introduce herself and the aim of her presence thoroughly.

Participant observation should be of a long term, and although the researcher was present at the ward for more than two months, the period could fruitfully have been longer, particularly in light of the new WHO guidelines that were implemented not long after I left the field.

Individual in depth interviews

Thick descriptions and detailed information about the subject matter were opportunities gained from individual in depth interviews. The use of digital voice recorder with all the informants helped the researcher to concentrate on the discussion rather than attempting to make notes. The researcher noticed a trend where especially HIV positive mothers were worried about “*the recorder versus media*” at the beginning of discussions. However, after the first few minutes mothers seemed to forget about being recorded.

However, sometimes it was very difficult to bring informants to the study topic. At times the researcher had to interfere with the discussions which were not relevant to the research topic. HIV positive mothers, not the least the women who hadn't disclosed their status to anyone, openly expressed their fear, hopelessness, and challenges.

The fact that the interviews were carried out at the hospital could have implied a certain limitation in that the women linked the researcher to the PMTCT setting. If, however, home visits were to be included, the study would have been able to clearly visualize the real living situations of these HIV positive mothers and their infant feeding practices. However, due to shortage of time and due to the sensitivity of the study topic, the researcher only conducted interviews with HIV positive mother when they came for follow up.

Case studies

The two case studies where the researcher met breastfeeding mothers who were planning to discontinue breastfeeding early and abruptly helped the researcher to gain extensive experience and got a closer look at the true challenges at hand during the time it actually took place. Mothers came with their babies and their new bottles, babies were seen refusing to suck, crying and staring at their mothers' faces.

The main challenge in connection with the case studies was that mothers decided to stop breastfeeding suddenly. They were not prepared to stop breastfeeding at that particular time. As a result, the first session of our interviews were mainly focusing on addressing the mother's questions. However, their questions and needs assisted the researcher in

understanding the gap between what was real and practical, and what was stated in the papers and in the recommendations.

Credibility of findings

The researcher tried to capture multiple realities of those studied in the course field work and through trying to systematically analyzing the data giving attention to the credibility of the data.

Probing and asking follow up questions was a central part of the inquiry. However, in the course of an interview there were issues that were not investigated or followed up upon fully, and were missed by the researcher. Continuous modification of the interview guides helped the researcher grasp important new emerging ideas and this in turn increased the credibility of the study findings in the researchers' experience.

To raise questions about the researcher's pre-understanding are vital. As a matter of fact, in this research paradigm the human being is used as the primary instrument for data collection and a tool in the process of interpretation of the data (Patton 2002: p51). It was beneficiary to be a researcher in an area where the researcher was well acquainted with the language, with cultural values, and verbal and non verbal gestures. This ultimately brought an experience of being close to the informants' understanding, and it specifically helped the researcher to gain acceptance and trust from the informants of the study. This in turn was helpful to the researcher in enhancing her closeness with the informants, which eventually strengthened the trust and increased the openness of informants.

Every HIV positive mother who acted as informant was however introduced by the research assistants who were nurses from the clinics. Wearing a white gown and participating in the daily activities in the clinic moreover gave the mothers confidence to say, "*She knows us*" (*esua takenalech*), but it could also imply that the researcher was associated too closely with the activity of the clinic to be able to get out certain aspects of the information. Hence, being too close to the clinics might have given the informant mothers a feeling of being restricted in what they were telling the researcher. As a result, this might have affected the responses they gave, and they might have become cautious about not to say anything "bad" about the clinic and the staffs.

There is a general sense that the use of methods triangulation adds to the credibility of the research findings, since valuable information was gained through all the three main approaches.

The data was collected from different individuals and categories of individuals in two different hospital's PMTCT services; i.e. HIV positive mothers who breastfed their children, HIV positive mothers who replacement fed their children and health professionals including counselor nurses and pediatricians. Hence, the use of wide variety of sources for information (source triangulation) helps in strengthening the credibility of the research findings.

Patterns and trends of negative/contradicting cases were sought identified to increase the complexity of the material. As described by Patton, the understanding of negative patterns comes up by considering the instances and cases that do not fit with in the emerging pattern (2002: p554). In this study, it has been tried to identify the multiplicity and contradicting ideas among participants both between and with the different categories. This is also believed to enhance the credibility of the research findings.

Another challenges which might have negatively affected the credibility of the study findings is that we did not included 'important others', such as partners or mother in laws, who as we have seen, have direct influence on the infant feeding choices and practices of the mothers.

Relevance (Transferability/ applicability) of the study findings

As any qualitative study, the use of limited number of informants inhibits the use of statistical analysis which affects the representativeness of the study findings. Hence, we cannot hold that the responses of the study informants can be generalized to the whole field of HIV positive infant feeding mothers and their counselors. There is however little reason to think that these mothers were entirely different and experienced the challenges very different from other HIV positive mothers who were enrolled in PMTCT programs in urban Ethiopian settings.

HIV positive infant feeding mothers were purposively recruited with an attempt to include different groups from different categories. Only one mother who breastfed her child for four months declined from participating in the study. Hence, the majority of women who were asked to participate were willing to do so.

One of the hospitals where the study was conducted (Zewditu Memorial Hospital) was the pioneer in rendering PMTCT service in the country. This in turn helped to capture different segments of the population, which seems to enhance the transferability of the research findings.

Both hospitals were however located in a highly urban area where health services are generally available and both study hospitals were situated in areas where transportation is available from every part of the city. One should hence expect mothers in the rural areas to be confronted by challenges of a different kind in terms of services and communication than the mothers in the present study.

All the available and active health professionals working in the infant feeding clinics of both hospitals were recruited as informants for this study. This, in turn, puts light on the attempt to include the full range of informants relevant to the conceptualization of the subject under the study. The structuring of other government hospitals will most likely not have great differences from the hospitals that we conducted our research. Hence, the views and opinions of health professionals working in these clinics are likely to resemble the opinions, experiences and beliefs of other health professionals working in similar settings in the city. On the other hand, the involvement of only governmental hospitals might have biased the composition of our study participants. Nowadays, especially in Addis Ababa city, non-governmental hospitals and clinics are providing PMTCT services widely. For this reason, we might have missed HIV positive mothers who attended these non-governmental health facilities, who might possibly be different from those who are attending governmental hospitals.

Moral challenges

Hearing some of the informants' stories and witnessing their pain and tears was a challenging moments for the researcher. When some informants cried, instead of comforting them, the researcher was tempted to cry. However, these emotional moments opened up for very good discussions. The stories of hopelessness and stigma were the major reasons why mothers cried. The researcher was unable to provide an immediate help and that was painful.

Most importantly, mothers and health professionals expressed that they were happy with the discussions. Especially some HIV positive mothers expressed that they were very happy to have the conversations; to find some one to sit and talk to. This opportunity was an opening session for some of the HIV positive mothers who did not disclose their HIV status to their closer ones, and for those who had no one but their busy counsellors to talk to about their challenges.

7. Concluding remarks and recommendations

7.1 Conclusions

HIV positive infant feeding mothers with the knowledge of potential transmission of HIV through mothers' milk have developed an immense fear towards breast milk. This fear influences women's choices of infant feeding method, and their adherence to the recommended practice. The prevailing WHO/UNICEF guidelines at the time of fieldwork (the 2001 guideline on HIV and infant feeding) was not experienced as feasible in an Ethiopian context, and was moreover implemented in a confusing manner which added to the inappropriateness of both infant feeding choices and adherence to the choices. The international infant feeding guidelines emerged as highly unfit in the social, cultural and economic surroundings of the HIV mothers in questions.

The study findings indicate that health professionals working in the PMTCT programs, largely, have the same fear towards mothers' milk as HIV transmitting medium as the HIV positive women. This uncertainty and fear was reflected in their practices, and in the counselling services they provided.

The current international infant feeding recommendation (WHO, 2007) in our view moves in the right direction by suggesting exclusive breastfeeding by all HIV infected mothers who do not fulfil the AFASS criteria. Based on our findings from the present study, promoting breastfeeding in a society already sensitized about the risk of HIV transmission through breast milk will however face presumably enormous challenges in its way forward. This challenge can be manifested by a lack of trust toward health professional's advice, and with consequent poor adherence.

The most recent guidelines also inform HIV positive mothers about the risk of mix feeding. This will most likely provide the programs with another challenge. Since exclusive breastfeeding remains an enormous challenge as long as HIV positive infant feeding mothers live in social surroundings, fear of mixed feeding might push these mothers to choose replacement feeding even if they have not fulfilled the AFASS criteria. This is one of the new challenges brought stronger to the forefront with the new guideline.

7.2 Recommendations

The recent international infant feeding guideline recommending exclusive breastfeeding by HIV positive mothers who don't fulfil the AFASS criteria finally seems to acknowledge the importance of exclusive breastfeeding in minimizing the risk of HIV transmission and enhancing child survival in most developing countries where breastfeeding remains the only feasible infant feeding option for the large majority of women. However, proper introduction of the new guideline supported with new research findings becomes very important to smoothen the way forward for breastfeeding in a PMTCT of HIV context. Based on the findings of our research, we put forward the following recommendations:

- To strengthen the shaky trust health professionals and HIV positive mothers have in exclusive breastfeeding through proper education of the most recent HIV and MTCT research findings, and through continuous follow up training. This exercise will give the important role players in PMTCT of HIV a clear stand about safer infant feeding practices.
- The success of promoting exclusive breastfeeding is moreover dependent upon the media that plays an important role in the daily lives of millions of people. Using the media as one route of information passage will enhance the acceptance of the new international recommendations regarding safer infant feeding practices.
- Supervisions and standardization of practices between health institutions is very important to ensure uniform infant feeding counselling for HIV positive women.
- Intervention studies promoting exclusive breastfeeding in both the HIV positive and in the general population will become extremely important in a move to get everyone to work toward exclusive breastfeeding regimes disregarding HIV status. Working strong towards a general acceptance of exclusive breastfeeding has the enormous benefit of reducing the focus on women in a most vulnerable situation: the stigmatized poor HIV positive women with infants.

8. References

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Appendix I: Interview guides

1. Interview guide for HIV positive mothers who breastfed their infants

Interview No: _____

Location: _____

Introduction: Explain the content and purpose of the interview informed consent; assure confidentiality of information they are going to provide. Explain that the information they provide is important to help make decisions on prevention of mother to child transmission of HIV programs.

1. How is it customary to feed an infant in your area? Probe
 - breastfeeding, pre lacteal feeds, exclusive breastfeeding
 - Formula, cow's milk
2. What have you been told (heard, counselled) about exclusive breastfeeding? Probe
 - who (+ where, when) told you about exclusive breastfeeding
 - did you take Nevirapine prophylaxis
 - have you been told the chance of HIV transmission during breastfeeding (even after taking NVP prophylaxis)
3. How did you manage to feed your infant? Probe:
 - exclusive breastfeeding
 - meals before breastfeeding e.g. water, butter,
 - Have you manage to exclusively breastfeed
4. How was the breastfeeding experience?
 - thoughts of breastfeeding before pregnancy
 - the first breastfeeding experience after the knowledge of HIV status
 - the breastfeeding period as a whole
5. What age was your child when you stopped breast feeding completely? Probe
 - reasons for stopping breastfeeding at that age
6. What kind of food items have you started giving your baby? Probe
 - Porridge, gruel...
 - Do you still breastfeed occasionally
 - What do you do if the baby cries, becomes very restless during night times

7. How long did you give both breast milk and other feeds (like the one's she mentioned)?
 - For days or weeks or months
8. How did you manage to stop breastfeeding? Probe
 - for abruptness, separations,
 - night breast feeding (when the baby cried a lot during night time)
9. What problems did you face when you stopped breastfeeding? Probe for
 - Personal: engorged breast, crying baby, night feeding
 - Economic: lack of food, lack of money...
 - Environment: husband/partner attitude, extended family, neighbours (comments, pressures to resume breastfeeding)
 - Comforting the baby
10. How did you deal with those problems you mentioned earlier? Probe for
 - engorged breasts, family and crying baby
 - economic problems, if mentioned
11. How did you feed your baby during the process of stopping to breastfeed? Probe
 - foods given during cessation and the following months
12. What things or people were most helpful in the process of stopping to breastfeed?
 - Materials: Availability of food, money
 - Professionals: health workers
 - People: husband, extended family,
 - Psychological support
13. What was your experience with health care providers while stopping breastfeeding? Probe
 - Health workers who know your HIV status
 - Health workers who do not know your HIV status
 - pressure to resume breastfeeding
 - How did you deal with those problems?
14. Have you thought about resuming to breastfeed after cessation? Probe
 - Probe for experiences with this problem
15. In your opinion, what should be done to support HIV positive women to stop breast feeding early? Probe
 - Professional support

- Peer group support
16. Were you satisfied with the follow up counselling of health workers?
- Probe for if she was given information, helped during problems
17. Personal information (e.g. age, marital status, husband's/partner's HIV status...)

2. Interview guide for health professionals

Interview No: _____

Location: _____

Introduction: Explain the content and purpose of the interview informed consent; assure confidentiality of information they are going to provide. Explain that the information they provide is important to help make decisions on prevention of mother to child transmission of HIV programs.

1. How is it customary to feed an infant in this area? Probe
 - Breastfeeding, pre lacteal feeds (mixed feeding), exclusive breastfeeding
 - Formula, cow's milk
2. What are your views about HIV and infant feeding
 - Breastfeeding
 - Replacement feeding
3. What about the international and national infant feeding guidelines for HIV positive mothers?
 - Have you found them easy to implement
 - What about the guideline's practicality regarding your clients' situation
 - What about AFASS
4. What about AFASS criteria
 - is it practical
 - How many mothers who chose to replacement feed their babies fulfilled the criteria?
 - Do you assess all the components of the criteria
5. What are your views about early cessation of exclusive breastfeeding for HIV infected mothers? Probe for
 - The working definition of early cessation
 - How early, at what age of the infant

6. What about abrupt (rapid cessation) of exclusive breastfeeding? Probe for
 - Working definition of abrupt cessation of exclusive breastfeeding
 - How abrupt, for how many days/weeks/months can an HIV positive mother mixed feed
7. How successful is early cessation of exclusive breastfeeding among HIV positive women you work with?
8. What factors hinder early cessation of exclusive breastfeeding? Probe for
 - Infant and maternal factors
 - Family, society
 - Economic reasons
9. What problems do mothers face during early and abrupt cessation of breast feeding? Probe for
 - Engorged breasts, crying baby, feeds, separation
 - Unable to sustain replacement feeding
 - Stigma
10. How do you help mothers to deal with their problems? Probe for
 - Reassuring, comforting...
 - Counselling
 - Home based care if any
11. What is your opinion regarding breastfeeding by an HIV positive mother in general?
12. If you are given a chance to choose an infant feeding alternative for an HIV positive mother, what would you choose for her?
 - Exclusive breastfeeding
 - Replacement feeding
 - Why?
13. What is your view towards the up coming international infant feeding guideline for HIV positive mothers? (which recommends exclusive breastfeeding by all HIV positive mothers who don't fulfil the AFASS criteria)
14. Have you had any training on HIV and infant feeding? Ask for the length of the training)
 - The length of training
 - When?
15. In what way do you think the training equipped you?

Do you think the HIV epidemic has caused any change in the breastfeeding patterns?

- Probe for reasons (In what ways)

16. Personal information

- Work experience the PMTCT (VCT) clinic

3. Interview guide for HIV positive replacement feeding mothers

Interview No: _____

Location: _____

Introduction: Explain the purpose of the interview, make the respondent relax, assure confidentiality of information they are going to provide and thank them for their time. Make them feel that the information they are going to provide is very important to help make decisions on prevention of mother to child transmission of HIV.

1. How is it customary to feed an infant in your area?
 - Breastfeeding, pre-lacteal feeds, exclusive breastfeeding
 - How is the trend concerning mixed feeding
 - Formula feeding
2. How was the decision to replacement feed your baby
 - Why not breastfeeding?
 - health professionals role
 - family support
 - any supporting organizations
 - the issue of disclosure
3. Did you know a child born to HIV infected mother could still be infected despite not breastfeeding?
 - If yes, who told you
4. With what did you start feeding your baby?
 - formula
 - cow's milk
5. How was/is the experience of not breastfeeding
 - Based on what is expected from the society and family members
 - how did you manage others question
 - how was the cost and the materials, time

6. What is your opinion about breastfeeding by an HIV positive mother
 - what do you think the experience will look like
7. What methods did you use to help you to cope with problems that you faced?
8. Do you feel that you and your baby have missed something because you haven't breastfed your infant?
9. Were you in any situation which forced you to breastfeed your child in between
10. Did your baby get any sick episodes because of the replacement feeding that you are giving him?
11. How was the support that you get from health professionals
 - From the start
 - Now
12. Did/do you have any peer group support with mothers in the same condition that you are in?
13. What else do you want to add
14. Personal information Socio demographic characteristics

Appendix II: Ethical approval letters



Date: JUN-11-2007
Ref. Number A.A/4218/45

To: Whom it May Concern
Addis Ababa

The ethical review committee of the Addis Ababa health bureau has reviewed the research proposal entitled Challenges on presentation of MCF of HIV in early and abrupt cessation of exclusive Breast feeding.

Please find attached here with the two pages reviewed result of approval of the proposal.

With Regards,



Ademesh Wolde
Ademesh Wolde (Dr.)
Head
Health Bureau

ADDIS ABABA CITY ADMINISTRATION HEALTH BUREAU
ETHICAL REVIEW COMMITTEE

ETHICAL REVIEW FORM

Tel: 251 1 513911

P.O.Box 30738

Addis Ababa

CRITERIA/ITEM	RATING
1. consent form <ul style="list-style-type: none"> • Does the consent contain all the necessary information that the subject should be aware of? 	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> Requires revision <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Not attached
2. Are the objectives of the study clearly stated?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
3. Are the methods ethically sound? <ul style="list-style-type: none"> • Justice • Beneficence • Respect for a person 	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> Not well described <input type="checkbox"/> No
4. Are provisions to overcome risks well described and accepted? <ul style="list-style-type: none"> • DSMC 	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable
5. Are there provisions to provide standard/ best proven care?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> Not applicable
6. Are the safety procedures in the use of vaccines, drugs and other biological products acceptable?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> Not applicable
7. Are the procedures to keep confidentiality well described?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable
8. Are the proposed researchers competent to carry out the study in a scientifically sound way?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unable to assess
9. Does it have material transfer agreement?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> Not applicable
Recommendation	<input checked="" type="checkbox"/> Approved <input type="checkbox"/> Approved on condition <input type="checkbox"/> Not approved
Remarks	<p align="center"><i>Approved</i></p> 

ETHICAL COMMITTEE MEMBERS

Name	Signature
1- Dr Achamyelch Alebachew	 Dr. Achamyelch Alebachew
2- Dr Girma Wolde Michael	 Dr. Girma Wolde Michael

