

Infant feeding in the context of HIV infection:

*Mothers' experiences and programme implications for maternal
and child health services in Tanzania*

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“A good mother is a mother who breastfeeds her child” (a quote from interviews, 2004)

Dedication

To my husband Melkizedeck

Our children; Kaka Kelvin, Master Evance and Dada Nancy

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Executive Summary

The documentation of breastfeeding as a source of HIV infection in babies has come to represent a public health dilemma in countries with a high prevalence rate of HIV and where breastfeeding is the standard norm and essential to child survival (DeCock et al. 2000; WHO 2003). UNAIDS estimated that 630,000 infants are HIV infected through their mothers every year, 280,000 being infected through their mother's milk (UNAIDS/WHO 2004). The HIV prevalence in the antenatal population in Tanzania was 9.6% among pregnant women in 2005. Mother-to-child transmission (MTCT) of HIV contributes to about 5% of the HIV prevalence in Tanzania (Ministry of Health 2005).

This study aimed to generate knowledge on infant feeding and infant feeding counselling to HIV-positive mothers that can strengthen programmes for prevention of mother-to-child transmission of HIV (pMTCT) and policy development in Tanzania. More specifically the study investigated HIV-positive mothers' experiences connected to choice of and adherence to the particular infant feeding methods recommended in pMTCT programmes. It also explored the challenges experienced by nurses as counsellors in pMTCT programmes, and hence, developed counselling tools to strengthen the knowledge and performance of counsellors and the adherence to infant feeding choice among HIV-positive mothers. Finally, the study evaluated the effectiveness of the counselling tools in strengthening the quality of counselling and the adherence to infant feeding choice among HIV-positive mothers.

The study used an explorative qualitative research design employing qualitative triangulation mainly in-depth interview, focus group discussions and participant observation. The study was composed of a formative research part and an intervention part. The formative research focused on the customary infant feeding concepts and practices in the Kilimanjaro region, as well as on mothers' and counsellors' experiences with infant feeding recommendations in pMTCT programmes. The intervention study focused on the development of culturally-sensitive counselling tools ('job aids') to be employed by nurse-counsellors during the counselling of women linked to pMTCT programmes, as well as by HIV-positive mothers for reference on how to perform safer infant feeding. The formative research findings contributed to the identification of the key messages to be communicated and illustrated in relation to infant feeding method. The intervention study also assessed the

impact of the developed counselling tools on mothers' infant feeding knowledge and practice.

The findings revealed that there is a gap between intentions and infant feeding practices in the context where the social expectations to breastfeed are high, and where kin and neighbours are part of the decision-making team surrounding infant feeding. The study highlighted the tension between the competing concerns of the medical and social risks involved in the choice of infant feeding methods. The findings pointed to the expectations from the environment that a mother should breastfeed and not breastfeeding was seen as a serious failing of motherhood and might be interpreted as a sign of HIV infection. Other methods were practiced in hidden. Furthermore, the study argues that the feeding methods recommended might be difficult to adhere to whether a mother chooses exclusive breastfeeding or exclusive replacement feeding. The nurse-counsellors expressed a lack of confidence in their own knowledge of HIV and infant feeding, as well as in their own skills in assessing a woman's possibilities of adhering to a particular method of feeding. The nurse-counsellors were found unable to give qualified and relevant advice to HIV-positive women on how best to feed their infants. They were confused regarding the appropriateness of the feeding options they were expected to advise HIV-positive women to employ, and perceived both exclusive breastfeeding and replacement feeding as culturally and socially unsuitable. However, most counsellors believed that formula feeding was the right way for an HIV-positive woman to feed her infant.

Furthermore, the nurse-counsellors were in general not comfortable in their newly gained role as counsellors and felt that it undermined the authority and trust traditionally vested in nursing as a knowledgeable and caring profession. The study argued that the condition under which counsellors are expected to provide quality care needs careful consideration, and indicated an urgent need for pre- and post service training and support structure necessary to promote professional confidence and skills for nurse-counsellors. The findings showed that the national and international guidelines on infant feeding conflict with local knowledge and reality constructions, and it suggested that strategies to increase safer infant feeding practices among HIV-positive women should be culturally relevant.

A complementary set of counselling materials was developed and included brochures on the three feeding methods that were found to be socially and culturally acceptable, a Question and Answer Guide for counsellors, and a toolbox for demonstration. The three brochures on exclusive breastfeeding, formula feeding and cow's milk feeding describe the steps to safe infant feeding, illustrated with images based on local ideas and resources. The brochures serve as reference material during infant feeding counselling in the ongoing pMTCT programme and as take-home material for the mother. The counselling tools increased the knowledge about infant feeding among mothers and strengthened certain aspects of infant feeding counselling compared with the counselling offered in the standard pMTCT programme. However, some clear limitations and challenges were revealed in the course of the study. These were particularly linked to limited counselling related to the risks involved in mixed feeding and counsellors' bias towards formula feeding among HIV-positive mothers. Further, poor judgement of the 'acceptability, feasibility, affordability, sustainability and safety' criteria (AFASS) of the various feeding methods in the particular infant feeding situation of each mother, compromised the quality of infant feeding counselling and hence, complicated the process of choice. The study calls for a critical assessment of the concept of informed choice which underlies the international infant feeding guidelines. Moreover, it argues for the need of a multi-dimensional behaviour change strategy involving both mothers and counsellors and if possible significant others who influence choice and decision-making processes.

The study discusses practical, research and policy measures and recommends locally appropriate interventions that facilitate promotion of exclusive breastfeeding to all mothers in the community and strengthening infant feeding counselling services as part of an attempt to reduce MTCT and stigma related to HIV and infant feeding methods.

List of original papers

This thesis is based on the following papers, which will be referred to in the text by their roman numerals.

Paper I: “Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania”. Published in *Journal of Social Aspects of HIV/AIDS Research Alliance (SAHARA)*, vol 4 no 2, May 2007.

Paper II: “HIV and infant feeding counselling: Challenges faced by nurse-counsellors in northern Tanzania”. Published in *BMC-Human Resources for Health Journal* July 24th 2007.

Paper III: “Translating global recommendations on HIV and infant feeding to the local context: The development of culturally sensitive counselling tools in the Kilimanjaro region, Tanzania”. Published in *BMC-Implementation Sciences Journal*, October 3rd 2006:1:22.

Paper IV: “Counselling tools in the promotion of safer infant feeding practices in the context of HIV: An evaluation study from Kilimanjaro region, northern Tanzania”. Submitted to *BMC- Health Services Journal*, July 2007.

Acronyms

ANC	Antenatal clinic
MTCT	Mother-to-Child Transmission of HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
MCH	Maternal and Child Health
MoH	Ministry of health
HIV	Human Immuno-deficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
VCT	Voluntary Counselling and Testing
ART	Antiretroviral Therapy
ARVs	Antiretroviral drugs
FGD	Focus Group Discussion
IBFAN	International Baby Food Action Network
SCT	Social Cognitive Theory
WHO	World Health Organization
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNICEF	United Nations Children Fund
USAID	United States Agency for International Development
MUCHS	Muhimbili University College of Health Sciences
KCMC	Kilimanjaro Christian Medical Centre

1. Background

The topic of this thesis is the problem of mother-to-child transmission (MTCT) of HIV (human immune-deficiency virus). It addresses in particular challenges associated with infant feeding in prevention of mother to child transmission programmes (pMTCT) in northern Tanzania. The general purpose of this study is to generate knowledge on infant feeding and counselling experiences in the context of HIV infection, and to design a culturally appropriate intervention to improve the quality of infant feeding counselling.

1.1 The magnitude of HIV infection in children

The number of children with HIV infection continues to increase worldwide. By 2006 more than two million children under the age of 15 were infected with HIV (UNAIDS/WHO 2005). The same report indicates that children constitute 14% (700,000 of 4.9 million) of new global HIV/AIDS infections, 18% (570,000 of 3.1 million) of HIV/AIDS deaths annually, and 5.6% (2.3 million of 40.3 million) of the persons living with HIV (UNAIDS/WHO 2005). 60% of the world's HIV-infected children live in sub-Saharan Africa, which is estimated to have only 10% of the world's population. MTCT accounts for the majority of HIV infection in children. Without any interventions about two-thirds of MTCT occurs during pregnancy or at delivery, and about one-third through unsafe breastfeeding practices (DeCock et al. 2000). About 90% of this MTCT infection occurs in Africa, where AIDS is beginning to reverse decades of steady progress in child survival (UNAIDS/WHO 2005).

The rate of MTCT in the absence of preventive interventions is about 15-25% among HIV-positive women who do not breastfeed (Thorne and Newell 2004) and 25-45% among HIV-positive women who practice customary breastfeeding which involves breastfeeding combined with other fluids or solids (WHO 2001). Data from different studies indicate that breastfeeding for up to two years may be responsible for one-third to half of HIV infections in infants and young children in African countries (DeCock et al. 2000). Table 1 summarises the different overall transmission rates.

Table 1: Estimated risk and timing of mother-to-child transmission of HIV in the absence of intervention

Time	Transmission rates
During pregnancy	5 – 10%
During labour and delivery	10 – 15%
During breastfeeding	5 – 20%
Overall without breastfeeding	15 – 25%
Overall with breastfeeding to six months	20 – 35%
Overall with breastfeeding to 18 to 24 months	30 – 45%

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

In Africa 30–50% of all untreated HIV-positive children die prematurely before their first birthday, and fewer than 30% survive beyond five years of age (Dray-Spira et al. 2000). In the first 20 years of the HIV/AIDS pandemic, up to 1.7 million children had contracted HIV through breastfeeding, but, most importantly, during this same period 30 million children were estimated to have died because they were not breastfed (Jansson 1990). The leading causes of the annual 10.9 million deaths in children under five throughout the world are pneumonia (19%) and diarrhoea (17%) (Bryce et al. 2005). However, malnutrition is an underlying cause of 53% of all mortality for children under five, against which breastfeeding is protective (Bryce et al. 2005). In countries hardest hit by HIV, the risk of dying from infectious diseases in the first two months of life has been estimated as six times greater for infants who are not breastfed (WHO 2000).

1.2 Risk factors for MTCT through breastfeeding

Several factors have been found to be associated with an increased risk of MTCT through breastfeeding. These include;

Maternal viral load and CD4-CD8 counts – High maternal viral load measured during pregnancy (John et al. 2001) or after delivery (Semba and Neville 1999) and a low

CD4/CD8 ratio (Semba and Neville 1999) have been associated with an increased rate of MTCT through breastfeeding.

Duration of breastfeeding – The risk of HIV transmission through breastfeeding is greatest in early infancy (before six months of age) and persists as long as breastfeeding continues (Miotti et al. 1999; Nduati et al. 2000). Studies found that a longer duration of breastfeeding is associated with increased risk of MTCT (Leroy et al. 1998; Embree et al. 2000; John et al. 2001).

Breast milk infectivity – A randomised clinical trial in Nairobi suggests that the volume of milk ingested is an important factor in breast milk transmission of HIV (Richardson and Fairbank 2000). Another study also found that infant oral thrush before six months of age is a risk factor for post-natal infection of children (Embree et al. 2000). Some studies found that inflammatory conditions such as mastitis, assessed clinically (Ekpini et al. 1997; John et al. 2001) or biologically by measuring the sodium level in breast milk (Semba and Neville 1999), fissures (Ekpini et al. 1997) and breast abscesses increase the risk of MTCT through breastfeeding.

Infant feeding patterns and MTCT – A carefully designed study conducted in KwaZulu Natal in South Africa recently provided crucial confirmatory evidence that when HIV-positive mothers breastfeed exclusively their babies have a significantly lower risk of infection from HIV. Mixed feeding before or after 14 weeks nearly doubled the transmission risk, and the addition of solids increased the risk 11-fold. The same study reported that mortality by three months of age for replacement-fed babies was more than double (15%) that of those who were exclusively breastfed (6%) (Coovadia et al. 2007). These findings added to the previous cumulated evidence about the additional risk of HIV transmission for non-exclusive breastfed babies (Coutsoudis et al. 1999; Coutsooudis 2001; Iliff et al. 2005).

1.3 Prevention of mother to child transmission of HIV (PMTCT)

PMTCT is the global intervention aimed at preventing mother-to-child transmission of HIV. Effective pMTCT requires a three-fold strategy (Duerr et al. 2005; UNAIDS/WHO 2005) that consists of:

- Preventing HIV infection among prospective parents

- Avoiding unwanted pregnancies among HIV-positive women
- Preventing the transmission of HIV from HIV-positive mothers to their infants during pregnancy, labour, delivery and breastfeeding

The third of these three strategies/pillars can be achieved through (1) effective voluntary counselling and testing, (2) the use of antiretroviral drugs, (3) safer delivery practices and (4) the implementation of safer feeding practices. The later point is the main focus of this thesis.

1.4 International guidelines on HIV and infant feeding

There have been various attempts at developing policies and guidelines in the search for the safest feeding options for infants of HIV-positive mothers. Internationally, the World Health Organization (WHO), the United Nations International Children's Emergency Fund (UNICEF) and the joint United Nations Programme on HIV/AIDS (UNAIDS) issued a series of revised guidelines on infant feeding for HIV-positive women in resource-poor settings over the time period 1992–2000 (see **appendix 1**). The preliminary infant feeding guidelines (1992) recommended that HIV-positive women should breastfeed in countries with a high infant mortality rate due to infection. This was based on the epidemiological argument that the risk of death from replacement feeding could be greater than the risk of acquiring HIV through breastfeeding in resource-poor countries. However, the guidelines were later criticised for creating a double-standard policy for the poor and for the rich, and were revised.

Further revisions were made throughout the 1990s based on the human rights perspective. The emphasis was for all women to make their own informed decision about feeding their infants according to their individual situation and to be fully supported in their feeding choice. The revision of the current HIV and infant feeding guidelines (WHO 2001) was based on the published data that quantified the risk of HIV infection through breastfeeding, and established that replacement feeding reduced the risk of HIV transmission significantly compared to exclusive breastfeeding (Nduati et al. 2000). Avoiding breastfeeding at that time was acknowledged as the only effective way of avoiding HIV transmission to the baby. Based on these publications the following statement was made:

“When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding by HIV-positive mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life. To minimize HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman’s situation and the risks of replacement feeding.” (WHO 2001).

According to the WHO (2001) guidelines, AFASS refers to five conditions that should be in place before any consideration is given to feeding the baby with breast milk substitutes (Box 1).

1.5 International recommended infant feeding options for HIV-positive women

The current international infant feeding guide for HIV-positive women is made up of the following options (WHO (2001):

Exclusive commercial infant formula: Feeding only formulated powdered milk made specifically for infants food.

Exclusive home-modified animal milk: Feeding only fresh or processed animal milk that is modified by adding water, sugar and micronutrients.

Exclusive breastfeeding: Feeding only breast milk and prescribed medicine but no water, other liquids or foods to the infants for the first six months of life.

Wet-nursing by an HIV-negative woman: Having another woman breastfeed the baby (the woman should be HIV-negative throughout the period of breastfeeding).

Expressing and heat-treating breast milk (pasteurised breast milk): Removing the milk from the breasts manually or with a pump, then heating it to kill HIV.

Breast milk banks: Places where donor breast milk is pasteurised and made available for infants.

After the release of the international guidelines and infant feeding recommendations, most national programmes focused their efforts on the implementation of safer infant feeding practices. Based on the cumulative research evidence and programmatic experience that i) mixed feeding increases the risk of HIV transmission compared with exclusive breastfeeding, ii) higher mortality occurs in infants who are formula fed compared to exclusive breastfed infants, and iii) exclusive breastfeeding could be supported in HIV-positive women, a need to balance the benefits and risks was recognised. This instigated a different focus in which child survival is regarded as a greater goal than merely the avoidance of HIV infection. The findings warranted recent updates (2006) for infant feeding guidelines (WHO 2001), which recommended replacement feeding to the infants of HIV-positive women when the AFASS conditions are met.

Box 1. The AFASS conditions

- ◆ **Acceptable:** lack of barriers, pressure and discrimination attached to formula feeding.
- ◆ **Feasible:** adequate time, knowledge and skills to prepare and feed formula up to 12 times in 24 hours despite other domestic or work disruptions.
- ◆ **Affordable:** parents can pay all the costs of formula feeding, including medical care for the increased number of infections suffered by a formula-fed baby.
- ◆ **Sustainable:** a continuous and uninterrupted supply of all ingredients and products needed for safe replacement feeding for as long as the infant needs it.
- ◆ **Safe:** replacement foods and liquids are hygienically prepared, stored and fed in nutritionally adequate quantities, preferably by cup, and there is a reliable supply of safe water, which can be boiled for at least ten minutes for preparing feeds and sterilising utensils.

1.5.1 Exclusive replacement feeding

The only way to achieve a zero-risk of postnatal HIV-transmission is by exclusive replacement feeding (WHO 2001). Nevertheless, parents need to consider their environments and the AFASS conditions before the decision to use replacement feeding is made. Safety is the most critical criterion among the AFASS conditions for replacement feeding. Several studies have tried to identify which type of infant feeding would result in the highest rate of HIV-free survival or a decreased death rate. A randomised trial in Kenya

conducted in 2001 concluded that infants assigned to be formula fed or breastfed had similar mortality rates during the first two years of life. However, HIV-free survival at the age of two was significantly higher in the formula arm (Mbori-Ngacha et al. 2001). A pooled analysis of African studies conducted in 2004 also found that mortality did not differ significantly between ever-breastfed and never-breastfed children born to HIV-positive mothers (Newell et al. 2004).

A mathematical simulation based on previously reported rates of HIV transmission and infant death indicated that in comparison with replacement feeding, breastfeeding during the first six months by HIV-positive mother increases HIV-free survival by 32 per 1000 live births. However, replacement feeding appears to be safer after six months (Ross and Labbok, 2004). The randomised Mashai study in Botswana suggested that breastfeeding with zidovudine prophylaxis was not as effective as formula feeding in preventing postnatal HIV transmission but was associated with a lower mortality rate at seven months. Both methods had comparable HIV-free survival at 18 months (Thior et al. 2005). A non-randomised DITRAME Plus study in Cote d'Ivoire found no difference in two-year rates of adverse health outcomes between early weaned breastfed and formula-fed children, and the mortality rates did not differ significantly between these two groups (Becquet et al. 2005).

Another study has also documented that stigma and secrecy surrounding HIV/AIDS make the choice of replacement feeding more difficult, particularly in the strong breastfeeding cultures of Africa, and bottle-feeding may amount to an inadvertent disclosure of the mother's HIV infection (Didan, 2003). Preparing formula is difficult and time-consuming, especially without refrigeration, running water or a ready supply of fuel for boiling water. These factors may contribute to HIV-positive mothers choosing to breastfeed or to practise mixed feeding even if they have access to formula (Didan, 2003).

The UNICEF programme that distributed free formula to pMTCT clinics found that most counsellors advised mothers not to breastfeed and that little time was spent considering the mothers' personal circumstances. Formula distribution was however sometimes delayed and quantities were inadequate, leading mothers to supplement with inappropriate weaning foods. Poor mothers who lacked fuel, running water or refrigeration were often unable to prepare the formula safely (Wilson 2001).

1.5.2 Exclusive breastfeeding in the context of HIV

The social, psychological, nutritional and health benefits of breastfeeding are widely documented (Cesar et al. 1999; Latham and Preble 2000; WHO 2000). Exclusive breastfeeding for the first months of life has been established as the best way to feed infants (Cohen et al. 2000; Dewey et al. 2001; Kramer et al. 2003), and could prevent 13–15% of child deaths in low-income countries (Arifeen et al. 2001; Jones et al. 2003). However, the discovery in 1985 that the HIV virus could be transmitted through breast milk created a major dilemma for the promotion of breastfeeding, particularly in areas where a large proportion of the population are HIV-infected and where breastfeeding is the cultural norm (UNAIDS/WHO 2004).

Given the risk of HIV transmission associated with breastfeeding, it would appear that the simplest and most straightforward approach to prevention is to avoid breastfeeding when mothers are infected (Nduati et al. 2000; Magoni and Giuliano 2005). However, in most parts of Africa replacement feeding is associated with an increased risk of morbidity and mortality (Bahl et al. 2005; Creek 2006; Wilfert and Fowler 2007). Although breastfeeding is common in most African settings, exclusive breastfeeding is rarely practised (DeCock et al. 2000). Whether a lower risk of MTCT through replacement feeding warrants the risk of damaging the life-saving cultural practice of breastfeeding in resource-poor countries is a major question. Most operational challenges have been how to make breastfeeding safer in communities with a high HIV prevalence and where breastfeeding is the traditional acceptable way of feeding the babies.

The finding that exclusive breastfeeding carries a lower risk of transmission compared to mixed feeding (Coutsoudis et al. 1999; Iliff et al. 2005; Coovadia et al. 2007) gave new hope and set new challenges for promoting exclusive breastfeeding. It has stimulated increasing attention to the social and cultural factors that affect HIV-positive mothers' decisions and practices of infant feeding (Bland et al. 2002; Thairu et al. 2005). Coutsooudis and colleagues suggest that exclusive breastfeeding reduce the risk of HIV transmission to the baby because the infants become exposed to fewer bacterial contaminants and food antigens that can damage the gut lining and cause inflammation. Additional liquids and foods may compromise intestinal integrity, resulting in small lesions in the immature gut through which the HIV virus can pass to infect the infant (Coutsoudis et al. 1999).

However, several studies have shown some challenges to exclusive breastfeeding. For example, a study from South Africa found that women of unknown HIV status who started out exclusive breastfeeding introduced light foods or formula from first month of life (Chopra 2000). Other studies reported that fluids were commonly introduced within the first 48 hours of life (de Paoli et al. 2001; Bland et al. 2002). It was also reported that infant formula was given to the baby from six to eight weeks after birth because mothers tended to view breastfeeding not enough food for the baby's growth (Bland et al. 2002). Another study in Uganda indicated that HIV-positive mothers who started exclusive breastfeeding switched to mixed feeding by the time the babies were three months old (Bakaki 2002).

1.5.3 Early breastfeeding cessation to reduce postnatal transmission of HIV

Early cessation of breastfeeding was identified as one of the infant feeding options for HIV-positive mothers who find it difficult to avoid breastfeeding completely, or who develop symptoms of AIDS during breastfeeding, or who are able to provide adequate replacement feeds after a few months of breastfeeding (WHO 1998). The risk of HIV transmission increases over time, and shorter periods of breastfeeding carry a smaller risk of HIV transmission. The transmission rate for babies over six months of age has been reported to carry a 5% risk (Coutsoudis et al. 2001), and this risk can be reduced even further if exclusive breastfeeding is practised. Indirect evidence from observational studies and mathematical modelling exercises suggests that exclusive breastfeeding followed by a rapid transition to exclusive replacement feeding may be one of the safest feeding options for HIV-positive mothers (WHO 2000). Several studies from various settings in Africa (Coutsoudis 2001; Fawzi et al. 2002; Leroy et al. 2003; Iliff et al. 2005) have provided strong justification for supporting early breastfeeding cessation among HIV-positive women. These studies have revealed that more than two-thirds of all postnatal HIV transmission occurred after the baby reached the age of six months. To minimise the HIV transmission risk, breastfeeding should therefore be discontinued as soon as feasible, taking into account the individual woman's situation as indicated in the guidelines (WHO 2003).

Most African women breastfeed for more than one year but rarely practise exclusive breastfeeding since they gradually introduce other liquids and foods while continuing breastfeeding into the second year of life (Piwoz and Humphrey 2005). Abrupt weaning does

occur, but it is most frequently practised in the second year of life once the child has had time to become accustomed to solid foods (Millard and Graham 1985).

The major challenge associated with this ‘modified breastfeeding’ option (early breastfeeding cessation) is that it conflicts directly with traditional infant feeding patterns in Africa. How to wean safely and whether abrupt weaning is feasible was one of the significant and hotly-debated infant feeding topics at the international AIDS conference (2006) in Toronto, Canada. Some studies from South Africa and Eastern Africa (Almedom and de Waal 1990; Bland et al. 2007) have shown that most mothers who tried abrupt cessation of breastfeeding re-introduce breastfeeding again in order to comfort their crying babies. The major reason given was the baby was crying in public beyond the mother’s tolerance. Such re-introduction of mothers milk has been found to increase the risk of postnatal HIV transmission. However, there are a few studies, for example in West Africa (Leroy et al. 2007) and in Zimbabwe (Iliff et al. 2005), that have reported the feasibility of early cessation of breastfeeding especially when women are socially supported to do so as safely as possible and when safe nutritionally adequate alternatives are available.

1.5.4 Expressing and heat-treating breast milk (pasteurised breast milk)

Manually expressed heat-treated breast milk is among the WHO recommended breastfeeding modifications to reduce the risk of postnatal HIV transmission while providing breast milk’s immune properties to protect the infant against other common childhood infections (UNAIDS/WHO 2004). Some studies have shown that HIV in breast milk could be inactivated by Holder pasteurisation (heating to 62.5 degrees C for 30 minutes) while retaining most of the breast milk’s protective elements (Eglin and Wilkinson 1987; Orloff et al. 1993; Giles and Mijch 2005). However, the method requires temperature gauges and timing devices that are not available in most at-risk communities (Israel-Ballard et al. 2005). A recent published study (Israel-Ballard et al. 2007) has confirmed that flash-heat can inactivate HIV in naturally infected breast milk from HIV-positive mothers. The previous pilot data had suggested that the flash-heat method was capable of inactivating HIV in ‘spiked’ breast milk samples from healthy mothers while retaining most of the milk’s nutritional and antimicrobial properties (Israel-Ballard et al. 2005; Israel-Ballard et al. 2006). It has been recommended as a simple pasteurisation method that a mother in a developing country could implement in her kitchen.

In 2000 and 2001 a study in Pretoria researched another method of home pasteurisation that could be employed using very simple implements available in the homes of ordinary women living in resource-poor settings (Jeffery and Mercer 2000). However, there is still limited knowledge about the safety of this method, and its acceptability is poorly understood (Coutsoudis 2000). Kiersten and colleagues conducted focus group discussions among mothers, grandmothers, midwives and husbands in various regions of Zimbabwe. Initially the topic was received with hesitation because of the potential obstacles, including time constraints and social stigma. But at the end of discussions, participants expressed that, given its affordability and its potential protection of HIV transmission to infants, the method may be a feasible infant feeding option for HIV-positive mothers in Zimbabwe (Kiersten et al. 2006).

The responses from the UNICEF exploratory studies conducted in Tanzania, Kenya, South Africa and Zambia suggest that the method is known but would be poorly accepted (UNICEF, 2000). In Uganda there is a strong cultural prohibition against expressing breast milk and feeding it to the baby (Steel and Sserunjogi, 1993). In Rwanda mothers also were found to consider the idea of expressing breast milk and feeding it to their babies as strange and unnatural (Rwanda Ministry of Health, 1994). In general very little is documented on the acceptability, feasibility or consequences of this approach in practice, and such studies are essential in informing policy before it is widely recommended as a public health strategy.

1.5.5 Wet-nursing / Surrogate breastfeeding

Wet-nursing has been a long established practice in most African cultures (Riordan 1993) for a variety of reasons, including feeding the baby after the death of the mother or in the case of very sick mother. The babies were breastfed by close female relatives such as aunts or female friends who were nursing their own babies (Agnarsson 2001). The WHO recommended guidelines (1998) state that the wet-nurse should be offered voluntary counselling and testing; she should have serial HIV-testing and regular counselling to remain negative; she should be able to practise safe sex in order to remain HIV-negative during the breastfeeding period; she should breastfeed the baby on demand, and no payment should be involved in the arrangement. But also this method has been met with uncertainty due to the increasing knowledge of the presence of the HIV virus in the mothers' milk. Studies have pointed out various concerns and beliefs related to wet-nursing in Africa. For

example in Zimbabwe women were highly concerned about having someone else breastfeeding a woman's baby due to the potential chance that the wet-nurse might also be HIV-positive or have another chronic disease (Gavin et al. 1999).

1.6 Recent (2006) updates for international HIV and infant feeding guidelines

Organised by WHO, the international HIV and infant feeding technical consultation meeting was held in Geneva on behalf of the Inter-Agency Task Team (IATT) on the prevention of HIV infections in pregnant women, mothers and their infants, October 25-27, 2006. The recommendations from this meeting (Box 2) were intended to supplement, clarify and update the 2001 UN guidance but not to replace it (WHO 2007).

Box 2. Updates (2006) of the infant feeding guidelines:

- *“Exclusive breastfeeding is recommended for HIV-positive women for the first 6 months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time.”*
- *“When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-positive women is recommended.”*

Exclusive home-modified animal milk was also discussed at this meeting, and it was concluded that the method should not be recommended as a feasible and safe long-term replacement option because of the technical difficulties of formulating and preparing a nutritionally adequate recipe. Data regarding its safety is also lacking. Only in situations where access to commercial infant formula has been temporarily interrupted should this method be considered for short-term feeding to a baby below six months of age.

1.7 Antiretroviral drugs and infant feeding in PMTCT

The most effective way to prevent MTCT of HIV is the use of a combination of several antiretroviral drugs (Carpenter et al. 1997) and the avoidance of breastfeeding, which reduces the risk to below 2% (European Study 2001). Several studies are underway to explore the impact of antiretroviral therapy (ART) given to the mother who is breastfeeding and/or to the infant during the breastfeeding period. The aim is to reduce the transmission of the infection by reducing the viral load in the breast milk and/or providing antiretroviral prophylaxis to infants to reduce sero-conversion (Gaillard et al. 2004).

1.7.1 Single-dose nevirapine PMTCT regimens

The HIVNET 012¹ study conducted in Uganda in 2003 found that single-dose nevirapine given to the mother and the new-born, combined with short duration breastfeeding for six months could reduce HIV transmission to 16% (Jackson et al., 2003). The SAINT² study, which used single-dose nevirapine to the mother and new-born combined with replacement feeding, reduced HIV transmission to 11% (Moodley et al. 2003). “DITRAME plus”, which used AZT (Zidovudine and Retrovir) for a long duration from 28 weeks and single-dose nevirapine to the mothers and infants combined with a short duration of breastfeeding for six months, reduced transmission to 10% (Leroy et al. 2002). The Thai PHPT³-2 study used AZT for a long duration from 28 weeks and single-dose nevirapine to the mothers and infants combined with replacement feeding, and reduced HIV transmission to 2% (Jourdain et al. 2004).

1.7.2 Combined ARVs PMTCT regimens

The important findings from the PETRA⁴ study were that short-term treatment of mothers and children with a combination of two antiretroviral drugs reduced the rate of infection transmission up to six weeks of age by more than 60%. However, after 18 months transmission was comparable with the rate in a group that received no treatment (PETRA 2002). This discouraging finding is important because it showed the significance of infection transmission through breast milk. On the basis of the PETRA findings, the MITRA and *MITRA Plus* studies were initiated in Tanzania. The MITRA study is a non-randomised study where HIV-positive mothers are given Combivir (ZDV/3TC) from 36 weeks of pregnancy to one week after delivery, and infants are given Combivir for one week and daily 3TC throughout the breastfeeding period. Mothers are advised to stop breastfeeding by six months. The study is still being conducted but the preliminary result shows that at six

¹ HIVNET 012 is the International HIV Network for Prevention Trials 012.

² The SAINT HIV study is the multicentre randomised controlled trial of NVP versus ZDV and 3TC to reduce MTCT.

³ Thai PHPT is the perinatal HIV transmission controlled trial in Thailand.

⁴ The PETRA study is a randomised, double-blind, placebo-controlled trial conducted under the auspices of UNAIDS in South Africa, Tanzania and Uganda between June 1996 and January 2000. The goal was to assess the efficacy of short-course regimens with Zidovudine (ZDV) and Lamivudine (3TC) in a predominantly breastfeeding population.

months 4.9% of infants were HIV-positive compared to 11.9% in the PETRA group (Kilewo et al. 2005).

However certain ARV drugs, e.g. Nevirapine, may be better than others at suppressing viral loads in breast milk. A recent study of viral load in breast milk conducted in Kenya found that at two to three weeks after childbirth women receiving single-dose Nevirapine had a lower viral load and lower MTCT rates than those who had received ZDV from week 34 of pregnancy and during labour (Chung et al. 2005). Given that most women in sub-Saharan Africa report to the health facility late for delivery and with an unknown HIV-status, the clinical trial in Malawi aimed to determine whether post exposure prophylaxis of nevirapine plus zidovudine given to babies could reduce transmission of HIV. The overall rate of mother-to-child transmission at six to eight weeks was 15.3% in babies who received nevirapine and zidovudine and 20.9% in babies who received nevirapine only (Taha et al. 2004).

Recognising that the majority of pMTCT research is focused on saving infants from HIV infection and that little attention is paid to the mother's health needs and those of the family, another multi-country study supported by WHO is underway in five countries (Burkina-Faso, South Africa, Kenya, Rwanda and Tanzania). The study is called "Kesho Bora"⁵. The aim is to assess the impact of maternal HAART used during ante-partum, intra-partum and post-partum periods to prevent MTCT of HIV, as well as preserving maternal health while breastfeeding is continued (WHO, 2004).

1.8 Barriers to PMTCT – common infant feeding patterns in sub-Saharan Africa

The findings that the pattern of infant feeding may influence rates of MTCT of HIV through breast milk has provided additional incentives for consistent and strict definitions of infant feeding patterns (Greiner 2002). In 2003, the World Health Organization and its partner agencies UNICEF and UNAIDS developed a definitional schema for use in research, training and education on breastfeeding (see Table 2, Appendix 2).

⁵ "Kesho Bora" in Swahili means "Better-Future -Tomorrow"

Some ethnographic studies from different countries, for example Nigeria and Tanzania, have indicated that the benefits of exclusive breastfeeding argued biomedically lack local credibility as they conflict with local understandings of the best strategies to increase the growth of a healthy child (Mabilia 1996; Davies-Adetugbo 1997). It has been shown that within sub-Saharan Africa it is common to give infants '*prelacteal*' – other substances to drink within the first few days of life before lactation is well established. These include water, herbal teas, cow's milk, honey, infant formula and other local fluids (Agnarsson 2001; de Paoli et al. 2001; Semega-Janneh et al. 2001; Akuse and Obinya 2002; Sellen 2002).

Certain beliefs had been found to motivate this feeding practice – for example in Dodoma, Tanzania Sellen described the belief that “colostrum was perceived as too heavy for the stomach of the infant” and would therefore cause problems of indigestion in the baby (Sellen 2002). It was also perceived to be “dirty and rotten” and not healthy for the baby (Sellen 2002). In Nigeria, Akuse and his colleague expressed the same perception that “colostrum was too strong for the baby” and that breast milk was “insufficient and could lead to hypoglycaemia and dehydration” in the infant (Akuse and Obinya 2002). However, it is scientifically recognised that giving prelacteal feeds to newborns may inhibit or delay the onset of lactation that is dependent on suckling and may increase the risk of breast engorgement due to infrequent emptying. The practice may also lead to nipple confusion, especially when using bottles with rubber teats (WHO 2000), as implies risks of morbidity and mortality for the babies – especially when the feeds are given from contaminated bottles.

It has been noted that infants in most African contexts are '*supplemented with foods and liquids*' before they are six months of age. Liquids are introduced into infants' diets quite early (Agnarsson 2001; de Paoli et al. 2001; Shirima et al. 2001). The pressure from significant others and the demand for mothers to return to work were the major reasons given. The particular types of fluids or foods given to infants depend on local availability, the baby's age and the family's economic status. For example, in urban areas the babies were more likely to be fed commercial infant formula or commercially prepared cereals, while those in the rural areas were more likely to have animal milk and porridge (Semega-Janneh et al. 2001).

Most infants sleep with their mothers during the night and are given *frequent night breastfeeds*, and they continue to breastfeed at night well into their second year of life (Piwoz 2000).

1.9 HIV and infant feeding counselling

PMTCT counsellors are advised to individualise infant feeding counselling, describe the risks and benefits of each method, and encourage the mother to choose the infant feeding option that is ‘most Acceptable, Feasible, Affordable, Sustainable and Safe’ in her particular situation (WHO 2003). However, some studies have reported that the quality of the infant feeding counselling for HIV-positive women is poor and that counselling messages are inconsistent (de Paoli et al. 2002; Rollins et al. 2002; Chopra et al. 2005). In Côte d'Ivoire, healthcare workers reported that they had difficulty counselling HIV-positive women and that the long-term infant feeding options for these women seem inadequate (Becquet et al. 2005).

The evaluation report from UNICEF pMTCT programmes from some African countries indicated that the infant feeding component was still weak (Rutenberg et al. 2004). Some studies have shown that counsellors were not aware of the existence of the guidelines on HIV and infant feeding (Latham and Preble 2000). It has been also documented that not all pMTCT counsellors are trained in infant feeding counselling (WHO 2005). In addition to the documented breach in updated knowledge on HIV and infant feeding, the counsellors’ practices as care providers have been heavily criticised (Buskens 2005). Counsellors are frequently pressed for time and have too little insight into the mother’s personal circumstances to offer appropriate comment and recommendations on the basis of the AFASS criteria (WHO 2005).

A study in South Africa that observed and interviewed counsellors about how they informed mothers about infant feeding found that the HIV-positive women had been informed about the advantages of exclusive breastfeeding, but only a minority of them had been told about the risk of breast milk transmission when complementary food was added (Chopra et al. 2005). None of the mothers had been properly informed about the advantages and disadvantages of replacement feeding (Chopra et al. 2005). In a study of the differences between the international recommendations on breastfeeding and counselling messages of

health workers in Malawi, Piwoz and colleagues found that misconceptions were common and that counsellors were strongly influenced by cultural beliefs about infant feeding (Piwoz et al. 2006).

1.10 Rationale for the present study

Breast milk remains the best and safest source of nutrition for the vast majority of infants worldwide (WHO 2006). However, there is continued concern that up to 20% of infants born to HIV-positive mothers may acquire HIV through breastfeeding, depending on the duration of breastfeeding and exposure to other risk factors (DeCock et al. 2000; Gaillard et al. 2004). In sub-Saharan Africa where the HIV prevalence is very high and where breastfeeding is essential for child health and culturally normative, this fact represents one of the most serious public health dilemmas today and represents an obstacle for the promotion of breastfeeding (Bland et al., 2002; de Paoli et al., 2002; Piwoz and Humphrey, 2005).

The National and International HIV and infant feeding guidelines recommend that HIV-positive women should either breastfeed exclusively their babies or use replacement feeding, and strongly discouraged mixed feeding (WHO, 2000). Mixed feeding has been found to increase the HIV transmission risk substantially more than exclusive breastfeeding (Coovadia et al., 2007; Iliff et al., 2005; Coutsoydis et al., 1999). However, exclusive breastfeeding has been found rarely practiced while early mixed feeding is common in most African countries (Becquet et al., 2005; Coutsoydis et al., 2005). In Kilimanjaro region, the setting of the current study, a mixed feeding pattern where the baby is partly breastfed and partly fed with water, cows' milk or porridge is common irrespective of the mother's intention to adhere to one feeding method (de Paoli et al., 2002).

The guidelines for HIV and infant feeding recommend feeding methods to reduce the risk of HIV transmission to the babies of HIV-positive women (WHO 2000). However, the recommendations are not adapted to the local context, and the feasibility and the social acceptability of the recommended methods are not well documented. There is limited knowledge about individual women's experiences trying to adhere to the recommendations and about determinants of poor adherence, although several studies in diverse contexts have revealed poor adherence to the recommended feeding methods (de Paoli et al., 2002; Omari et al., 2003; Kiarie et al., 2004). Little is known about the social and cultural dimensions of

breastfeeding and the meanings attached to it in particular local contexts. There is also limited knowledge about how these meanings change in the context of HIV, or the local interpretation of the risk of HIV through breastfeeding and the judgement of a mother who do not breastfeed. Furthermore, these recommendations give little attention to the decision making process and it seems that the choice and decision on how a woman feeds her baby is taken for granted and left to the individual woman's decision. There is little knowledge of what happens when a woman is presented with a choice of infant feeding method; about the decision making process; about decision making power and social pressures. Moreover, HIV-positive women's own concerns and experiences with the recommended infant feeding options have not received sufficient attention in the pMTCT research efforts, although this information could yield empirically-based knowledge on the potential barriers to safer infant feeding practices. Such potential barriers and their impact need to be assessed to improve the quality of pMTCT services. The first aim of this study was to explore this gap by investigating the barriers to the recommended infant feeding methods from HIV-positive mothers' own experience and perspectives.

Quality counselling is central to successful infant feeding practices (de Paoli et al. 2002; Rollins et al. 2002). The HIV and infant feeding guidelines emphasize that counselling should be based on the principle of informed choice, and HIV-positive women should be given the best available information on the risks and benefits of each feeding method, with specific guidance in selecting the option most likely to be suitable for individual woman's situation (WHO, 2003).

Nurse-counsellors being the major group counselling women at the pMTCT programmes in Tanzania, carry the heavy burden of informing women about HIV status and about the various precautions on prevention of HIV transmission. However, several studies have documented the shortcomings of infant feeding counselling particularly in terms of counsellors' knowledge about pMTCT and counselling skills (de Paoli et al., 2002; Rollins et al., 2002; Chopra et al., 2005). Inaccurate and inconsistent information and lack of adequate support from pMTCT counsellors has also been documented as a major obstacle to HIV and infant feeding counselling (Chopra et al., 2005; de Paoli et al., 2002). But, little attention has been paid to the nurse-counsellors' work situation and structural barriers including emotional strains. The experiences of counsellors in infant feeding counselling and their perception of the infant feeding recommendations have not been sufficiently explored.

The second aim of this study was to investigate the nurse-counsellors' own perspectives linked to the quality of the services they provided and the obstacles they experienced in their every day work situation.

Several studies have documented inadequacy in infant feeding counselling (de Paoli et al., 2002; Rollins et al., 2002; Chopra et al., 2005), but little have been done to strengthen counselling services or to ease the work of the counsellors when guiding women to make an informed choice. The guidelines do not represent an adequate tool for counselling as they are meant to provide universal infant feeding recommendations and may not be relevant or appropriate on the local level unless they are adapted to the particular social and cultural context in which women make their choices of infant feeding method (WHO 2003). Earlier studies have documented that written instructions as well as personal encouragement by the service provider exerted a favourable influence on feeding practices (Hoyer and Horvat 2000). But, not much is known about its effectiveness in improving both mothers' and counsellors knowledge and practices of infant feeding. The third and fourth aim of this study was to respond to this call; trying to increase local relevance of the global guidelines and strengthening counsellors' ability to guide mothers to make an informed choice and adherence to the chosen feeding method by developing and evaluating counselling tools (job aids).

2. Objectives of the study

The overall aim of the study is to generate knowledge on infant feeding and infant feeding counselling that can strengthen pMTCT programme implementation and policy development in Tanzania. The purpose of the study was to document infant feeding and counselling experiences in the context of HIV infection, and to design a culturally appropriate intervention to improve the quality of infant feeding counselling. More specifically, this study was designed to examine HIV-positive mothers' experiences linked to infant feeding choice and adherence to choice and the practices and experiences of nurse-counsellors in pMTCT programmes. Furthermore the study represents an effort to assess the relevance of the international infant feeding guidelines in the particular social and cultural context of the Kilimanjaro region and to develop material that could strengthen the relevance and applicability of the guidelines in the local context.

The thesis is composed of two parts with two papers in each. The first part is formative research and is reported in paper I and II. The second part is intervention research and is reported in paper III and IV. Each of the objectives below relates to one of the papers.

Objectives and research questions:

Paper I

Objective: To explore HIV-positive mothers' experiences connected to choice of and adherence to the particular infant feeding methods recommended in pMTCT programmes

The study aimed to answer the following four research questions:

1. Cultural significance: What is the cultural significance of breastfeeding and other infant feeding methods in the Kilimanjaro region?
2. Transmission of knowledge: How is medical knowledge on HIV transmission through breastfeeding interpreted and handled in the social and cultural context of the Chagga community?

3. Decision making: Who are involved in decision making processes related to infant feeding?
4. Mothers' experiences: How do HIV-positive women enrolled in pMTCT programmes experience choice and adherence to choice of infant feeding method?

Paper II

Objective: To explore the challenges experienced by nurses as counsellors in pMTCT programmes

The study aimed to answer the following three research questions:

1. Counsellors' perception: How do counsellors in pMTCT programmes perceive the recommended infant feeding options in terms of acceptability, feasibility, affordability, sustainability and safety in the particular social and cultural context of the Kilimanjaro region?
2. Confidence and skills: How do counsellors perceive their work and to what extent do they feel confident and skilled as infant feeding counsellors?
3. Health system support: How are counsellors supported in implementing their role as pMTCT counsellors?

Paper III

Objective: To develop counselling tools to strengthen the knowledge and performance of counsellors and the adherence to infant feeding choices among mothers in the Kilimanjaro region.

The study aimed to answer the following four research questions:

1. Culturally-sensitive counselling tools: How can the counselling messages be developed in a way that strengthens their relevance and applicability in the particular social and cultural context of the Kilimanjaro region?

2. Recommended infant feeding methods: What knowledge is relevant and applicable for the development of counselling messages related to exclusive breastfeeding and exclusive replacement feeding?
3. Care of the breasts: What knowledge is relevant and applicable for the development of counselling messages related to breast care?
4. Replacement feeding: What knowledge is relevant and applicable for the development of counselling messages related to safe preparation of replacement feeds?

Paper IV

Objective: To evaluate the effectiveness of the counselling tools in strengthening the quality of counselling and the adherence to infant feeding choice among mothers in Kilimanjaro region.

The study aimed to answer the following research questions:

1. Counsellor performance: How does introduction of counsellor job aids, mother's take-home brochures, and specific counsellor's training in pMTCT programmes affect the quality and relevance of infant feeding counselling to HIV-positive and HIV-negative mothers in the Kilimanjaro region?
2. Mothers' knowledge and practices: How does the use of 'job aids' during infant feeding counselling and the provided take home material affect the choice of infant feeding method and adherence to this method among HIV- positive and HIV-negative mothers?

3. The theoretical framework

The study is a cross disciplinary endeavour drawing on theory from the social sciences and psychology. The dual focus on formative- and intervention research made it necessary to apply different theoretical approaches and tools. Sociological/anthropological theories and approaches were employed to gain knowledge of the complexity of experiences related to HIV and infant feeding practices and counselling. Although not explicitly discussed in any of the four papers that make up this thesis, the work draws upon phenomenology, social constructivism and critical theory. The conceptual framework proposed by Scheper Hughes & Lock (1987) which applies these broader approaches to the analysis of the dynamics between individual body experiences, body symbolism and body politics has been a great inspiration in planning the present study, and in understanding and contextualising the study findings related to breastfeeding / infant feeding choice and experiences among HIV-positive women. Social cognitive theory, developed by Bandura (1986) with the aim to analyse and to motivate change in human behaviour taking into account both individual and social factors, was used in planning the intervention.

Below the theory of “the three bodies” with a few comments on the underlying theories / epistemologies, and social cognitive theory will be briefly presented.

3.1 “The three bodies”

In an article from 1987, Nancy Scheper-Hughes and Margaret Lock (1987) introduced a framework that analysed the body using three different theoretical approaches and epistemologies. The initiative was a reaction against “the biological fallacy” which they characterise as paradigmatic in biomedicine, and which in this study is seen as basic also to the conditions underlying the pMTCT concept (Sheper-Hughes and Lock 1987). Fundamental to Scheper Hughes’ and Lock’s understanding of the body is “an assumption of the body as simultaneously a physical and symbolic artefact, as both naturally and culturally produced, and as securely anchored in a particular historical moment” (Scheper Hughes’ and Lock, 1998:208). Inspired by phenomenology, symbolic anthropology and

post-structuralism, the authors developed the theory of “the three bodies” representing three levels of analysis. The first level is described as ‘the individual body’, understood in the phenomenological sense of the lived experience of the body-self. The second level is described as ‘the social body’, referring to the body as a natural symbol with which to think about nature, society, and culture. The third level is described as ‘the body politic’ referring to the regulation, surveillance, and control of bodies (individual and collective) (Scheper Hughes and Lock 1998:209). In their criticism of biomedicine and the comprehensive medicalisation processes that characterise modernisation, Scheper Hughes and Lock argue that “[m]edicalisation inevitably entails a missed identification between the individual and the social bodies, and a tendency to transform the social into the biological” (1998:208).

The three bodies as presented by Scheper Hughes and Lock represent analytical categories with which to explore human experiences in health and sickness. It is however important to emphasise that the one level or the one ‘body’ cannot be understood in isolation from the others. Each body presupposes the other and it is the anticipated interconnection and the dynamics between ‘the three bodies’ that makes the framework powerful.

The insights of Mary Douglas lie at the heart of Scheper-Hughes’ and Lock’s theory of ‘the three bodies’. Basic in her theory of the body as a natural symbol (Douglas 1973) is the view of the physical body and its products like blood and breast milk as rich sources of symbol production. Mary Douglas argued that in symbolic term human beings have two bodies; the individual body which is the physical body we are born with and the social body that is developed through being a member of a particular social or cultural group (Douglas 1973). The social body provides a framework with which to perceive and interpret experiences (Douglas 1973; Helman 2000). But as Scheper Hughes and Lock have asserted, the relationship between individual and social bodies is also about power and control (1998:217). The social body is the means by which the physical functioning of individuals is influenced and controlled by the society they live in. The powerful control exerted by the larger society over the individual body in sexual and reproductive life, in health and sickness etc. is what Scheper Hughes and Lock have called ‘the body politic’. (Scheper Huges and Lock 1987; Helman 2000: 14). Power and control can be exerted over individual bodies on both micro and macro levels. The present study concerns the control exerted over

childbearing women on the family and community level as well as the control exerted by government and global actors through the health care system.

The framework developed by Scheper Hughes and Lock which recognises the social and political dimensions of the body as well as the complexity of human experiences was found to be a useful entry point for a study of the pMTCT programme and the problem of infant feeding. It was seen as invaluable in providing insights into the symbolism and meaning making processes surrounding the body and body functions, like breastfeeding and to understand the various ways in which control is exerted over women's bodies in reproductive life both on the family, community and health care levels. In this study the individual experiences and the social meanings attached to the body and to the body functions as well as the control exerted over women on the micro level are described on a detailed and experiential level in the four papers. How macro processes and global policy and power impact on local women's experiences remain a major concern and the backdrop of the study. However this issue has not been dealt with in a similarly comprehensive and systematic manner in the papers making up this thesis.

Before proceeding to the presentation of Social Cognitive Theory some of the basic theoretical positions and assumptions that underlie the framework of 'the three bodies' and how they have informed the present study deserve some additional comments.

3.1.1 Phenomenology

Phenomenology is concerned with human experience and with providing a direct description of this experience, commonly referred to as 'the lived experience'. It is the study of the ways in which we, as human beings, experience the world, and the meanings we attach to these experiences. Knowledge and understanding are seen as embedded in our everyday world, and the only way to understand social reality is through the meanings that people give to that reality (see e.g. Locke 1939). The concept of 'life world' is located at the centre of this tradition suggesting that the social world and what is perceived as "reality" is a projection of individual consciousness (Husserl, 1962; 1965).

Merleau-Ponty (1962) who is known for his phenomenology of ‘the lived body’ sees phenomenology as a method of describing the nature of our perceptions of the world. In opposition to the body-mind duality which has permeated Western thinking since Descartes, and the associated objectification of the body inherent in biomedical science, Merleau-Ponty saw the body as a permanent condition of experience. He held that it was only through the body that perception of the world is possible (Merleau-Ponty 1962).

Hence, in a phenomenological study the researcher tries to see reality through an informant’s eyes (Gordon and Tamari 2004), and it is the subjective point of view that is of interest.

In the present study, the phenomenological tradition was drawn upon through the qualitative approach in the attempt to grasp the multiplicity of “the individually experienced body” particularly as it was expressed through HIV-positive mothers’ perceptions of and experience with infant feeding. Through an analysis of personal accounts, the study describes the meaning and essence of ‘the lived experience’ of being an HIV-positive mother struggling with infant feeding dilemmas in northern Tanzania today.

3.1.2 Social constructivism

A basic assumption in the present study is that reality is socially constructed and that social order is an ongoing human production (Berger and Luckmann 1967). Furthermore there is no one objective reality, but many since reality is constructed in time and space; produced and experienced in different historical, social and cultural contexts. Realities then, are subjective and multiple (Douglas 1970; Berger and Luckman 1967).

A central concept in social construction theory is ‘knowledge’. According to Berger and Luckman (1967) “social construction theory seeks to explain the process by which knowledge is created and assumed as reality” (Berger and Luckman 1967). The basic condition in this school of thought is that meaning is created through social interaction. It is through social interaction that people learn how to see the world (Taylor and Bogdan, 1984:9). In this process they internalise established meanings which in turn become confirmed as social reality.

Meaning then, is developed, conveyed and maintained in a given social context (Douglas 1970). Different people say and do different things because people have had different

experiences and have learned different social meanings (Taylor and Bogdan, 1984:10). Hence, as Taylor and Bogdan argued, “[it] is the interpretation and definitions of the situation that determine action” (Taylor and Bogdan 1984).

In this line of thought every human phenomenon is socially and culturally constructed. Even if the phenomenon or the action in question is rooted in biology or is a function of the body, like breastfeeding, it is subject to meaning-making processes that transform it from a biological function to a social practice. This process is what Berger and Luckman have called ‘habitualisation’ (1966), and describes how the meanings of actions become embedded as routines. An important aspect of ‘habitualisation’ is that it serves to narrow down choice which is clearly illustrated in this work.

The point of departure here then is that the problem of breastfeeding in pMTCT programmes cannot be understood without an appreciation of the way in which it is socially constructed in particular social and cultural contexts – in this case in the Kilimanjaro region. Hence, the basic notion guiding this study is that relevant policy guidelines and interventions cannot be developed without a comprehension of local knowledge and meanings attached to a particular phenomenon; in other words, of the ways in which local reality is constructed.

3.1.3 Critical theory

Critical theory is often used as an umbrella term for social theories that fundamentally critique existing social structures and that aim to change these structures. Among others these are Marxism, post structuralism and feminism. Hence, in contrast to descriptive theories, critical theory has a double aim; to explain and to transform the structures that oppress and enslave human beings (Horkheimer 1982). This combination of a descriptive and a normative approach to social inquiry makes up an inherent tension in critical theory.

Critical theories are based in a social constructivist tradition, and share the assumption that ‘versions of reality can be used to conceal complex political, economic and social relationships’ (Brown 1998). In line with Michel Foucault, Scheper Hughes and Lock argue that biomedicine often has served the interest of the state with respect to control over sexuality, reproduction, women and sexual deviants (1998:219). Furthermore critical

perspectives also concern how ‘large-scale political, economic and cognitive structures constrain individuals’ decisions, shape their social behaviour and even increase their risk of disease’ (Brown 1998:16). In a pMTCT context, where the safety of breastfeeding is questioned in large-scale global programmes, critical perspectives emerge and are reflected in the many politicized dilemmas and controversies described in the four papers.

In critical theory gender has emerged as a most central concept and may be defined as ‘the ascribed normative aspect, generally focused around the human concept of sex, a biological, physical division, that extends to a broad social construction, informing, shaping, limiting ways of being, both masculinism and feminism’ (Spence 1993). Janeth Spence describes gender theory as a more comprehensive feminism; one that includes man, woman and child. She explains that gender theory seeks to understand both the roles, implications, impacts and potential of male/female interaction. Thus, gender theory is the sum total of three dimension: 1) women’s lives, 2) men’s lives, and 3) the interactions and the products of male/female, feminine/masculine converge (Spence, 1993:3-16).

The general assumption and understanding in this study is that all aspects of human interaction are gendered. Interaction which concerns reproductive issues is no exception. Indeed, sexuality and reproduction are areas where gender domination becomes particularly visible and acute. In an HIV context in general and in a pMTCT context in particular the gender dimension emerges continuously. To understand infant feeding dilemmas in an HIV context we need a gendered perspective, a perspective that asks how gender domination and discrimination shape women’s lives, their perceptions and their experiences. But domination and power is not limited to men’s power over women. In pMTCT it also involves inter-generational dynamics. The ways in which the dynamics of gender, age and power work to undermine women’s decision-making power in pMTCT efforts is a major concern of this thesis.

3.2 Social cognitive theory

The planning of the intervention to strengthen infant feeding and infant feeding counselling to HIV positive mothers was guided by Bandura’s social cognitive theory (Bandura 1997).

Social cognitive theory provides a framework that specifies a set of core determinants for health behaviour, the mechanism through which they work and the way to translate this knowledge into better health behaviour / practices (Bandura, 1997). The core determinants include *knowledge* of health risks and benefits of different health practices, perceived *self-efficacy* that one can exercise control over ones health habits, *outcome expectations* about the expected costs and benefits of different health habits, the *health goals* that people set for themselves and the concrete plans and strategies for realising them, and the *perceived facilitators* and social and structural *impediments* to the changes they seek (Bandura 2004).

Knowledge of health risks and benefits provides the preconditions for change, but knowledge in itself is not sufficient to overcome the impediments to adapting and maintaining new behaviour / practices. Beliefs of personal efficacy play a vital role in behaviour change. According to Bandura (1986), self-efficacy is the belief people hold in their own ability to accomplish a task. The theory maintains that self-efficacy influences the choices people make, and how they feel about facing a challenge. It holds that the higher self-efficacy, the more likely people are to exert effort and persevere to succeed. If people do not believe that they have the power to change the outcome of a particular issue, their motivation to persevere when they encounter problems (including the social costs involved,) will be negatively affected.

Bandura suggests that there are four sources or modes that influence self-efficacy: performance accomplishment, vicarious learning, social/verbal persuasion, and emotional/physiological arousal (Bandura 1994; Bandura 1997). These four influential sources of self-efficacy were applied in this intervention to establish successful infant feeding practices. *Performance accomplishment*, or role mastery, would mean that as a woman is successful with the act of feeding the child, she builds her confidence in her ability to feed the child well. *Vicarious experience*, or learning from others, requires that a woman gets support from the counsellor and/or significant others. *Social or verbal persuasion* from a credible source such as a nurse-counsellor can help increase a woman's confidence in her ability to feed the child.

In planning an intervention to decrease MTCT, it was important also to strengthen the knowledge and practices of nurse-counsellors to ensure that specific standardized knowledge

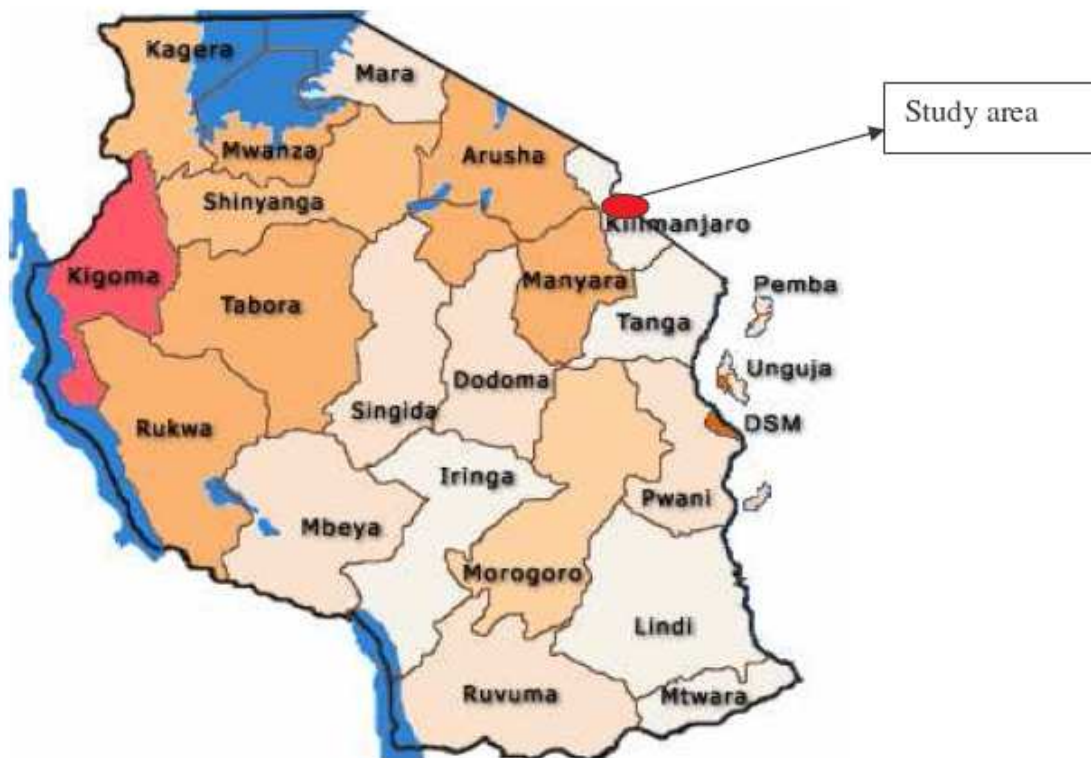
and skills are communicated to the mothers. The intention was to address commonly held myths and misconceptions about exclusive breastfeeding and replacement feeding; to foster positive attitudes towards the feeding methods and enhance women's self efficacy to implement safer infant feeding practices.

Although the theories outlined above have not been discussed in a comprehensive and systematic way in any of the four papers, they have made up an important backdrop for this research venture both in terms of design/methodology and analysis/discussion.

4. Study setting

This study was conducted in Tanzania at the pMTCT site attached to Kilimanjaro Christian Medical Centre in Kilimanjaro region, from August 2003 to June 2004.

Fig. 1. Map of Tanzania showing the Kilimanjaro region



4.1 The national context

Tanzanians have a strong sense of national identity that is influenced by several factors – including the Tanzania socialism or ‘Ujamaa’ developed under the years of Julius Nyerere, the first President of the independent nation. The core of Ujamaa is the traditional extended family and clan structure of most ethnic groups, which provides a framework for mutual support and social collectivity. It has an area of 363,950 square miles and 120 ethnic groups.

4.1.1 Health and development indicators

Tanzania struggles with most of the challenges observed in low-income or ‘developing’ countries on the African continent. Access to health care is constrained by the distance to the facility, poor road infrastructure and lack of vehicles for transportation, and most public health facilities do not have proper services (TDHS 2005).

Tanzania has an estimated population of 34.6 million (Tanzania Census 2002) with an overall life expectancy of 51 years. The total fertility rate is 5.7 children per women, and the maternal mortality rate, which is a critical indicator of human development, is alarmingly high with an estimated 578 deaths per 100,000 live births (TDHS 2005). The high mortality rate is not only an indication of poor reproductive health, but also of women’s low status and poor access to basic health services. The population is predominantly rural (77%), but the urban population is rapidly increasing (23%). Thirty five per cent have access to piped water – mostly in urban areas (TDHS 2005). About 88% of Tanzanians use firewood as fuel for cooking, and only 1% of the rural population have access to electricity (Johnsen 1999).

4.1.2 The HIV epidemic in Tanzania

The HIV prevalence in the general population was according to the Tanzania HIV Indicator Survey in 2003-4 just below 8% (THIS 2005). The Kilimanjaro region, where the present study was carried out, was among the three regions with highest number of AIDS cases in 2004 (Ministry of Health, 2006). The first HIV infection was confirmed in Tanzania in 1985, and by 1986 HIV/AIDS had been reported from all the 20 regions of the country. The National HIV/AIDS Control Programme (NACP) was formed in 1986 under the Ministry of Health (Ministry of Health 2004). It formulated strategies to prevent and control the effect of the epidemic. In 2001, the Tanzania Commission for AIDS (TACAIDS) was established to provide strategic leadership and to coordinate the multisectoral response against HIV/AIDS that includes monitoring and evaluation, research, resource mobilization, and advocacy. The National Policy on HIV/AIDS and the National Multisectoral Strategic Framework are tools to guide the implementation of national multisectoral responses.

4.1.3 PMTCT in Tanzania

Mother-to-child transmission of HIV contributes to about 5% of the HIV prevalence in Tanzania. Through the Ministry of Health, UNICEF initiated a national pilot programme of pMTCT sites in 2002 in four referral hospitals and one regional hospital: Muhimbili National Hospital, Kilimanjaro Christian Medical Centre (KCMC), Mbeya hospital, Bugando hospital and Bukoba hospital. The Ministry of Health planned to expand pMTCT services from five regions in 2004 to 21 regions by 2006 (NACP, 2006). However, observations indicate that there has been a slow increase of pMTCT sites, and AMREF reported that only 10.1% of the 5,379 total facilities in Tanzania provide pMTCT services routinely through antenatal services (AMREF, 2006).

PMTCT interventions include voluntary counselling and testing, antiretroviral treatment, modified delivery practices and infant feeding counselling. Infant feeding guidelines related to pMTCT in Tanzania recommend that HIV-positive mothers be counselled about the benefits of breastfeeding, including the risks of breast milk transmission of HIV. They are to be given three options for feeding: (a) exclusive breastfeeding for six months or early cessation any time convenient to the individual woman's situation, (b) replacement feeding with commercial infant formula, and (c) replacement/home modified formula (cow's or goat's milk) (United Republic of Tanzania 2003). It is stated that HIV-positive mothers who choose not to breastfeed should receive education and support on how to prepare and give their infant replacement food. The programme does not provide free formula feeding. It is also emphasized that the mother should make the final choice about the feeding method and should be supported to ensure optimal nutrition for mother and child (United Republic of Tanzania 2003).

4.2 Kilimanjaro region

4.2.1 Economic adaptation, gender relations and family structure

Kilimanjaro is one of 26 regions in Tanzania. It is located in the north-eastern part of the country (see map in Fig. 1). The region is administratively divided into six districts: Rombo,

Hai, Moshi rural, Moshi urban, Mwanga and Same. The regional altitude varies significantly between the two economic and culturally distinct areas, namely the mountainous areas (Mt. Kilimanjaro and Mt. Pare) and the plain. Those who live in the mountains are involved in agriculture and cultivate coffee and bananas. The drier, plain area is traditionally the habitat of the Masai who are cattle herders/pastoralists. Recently an increasing number of peasants from the fertile mountainous areas have moved to the savannah/plains due to overpopulation and land shortage in the mountains (Klepp et al. 1995).

The majority of the populations in Kilimanjaro are peasants who produce crops primarily for subsistence. The population is multi-ethnic, the major group being the cultivating Christian Chagga peasants who are known for their relatively high educational level and their development-oriented attitude (Klepp et al. 1995). Pare is another major ethnic group in the area, with other and smaller ethnic groups being the Kahe, Masai and a few others migrating from the neighbouring regions. The Chagga inhabit the most fertile slopes of Mount Kilimanjaro while the Pare Mountains in the south east are inhabited by Pare.

Clan- or kinship systems of social organisation are still of great significance in the daily lives of the Chagga. Kinship systems provide networks for support, which indirectly allow men to have several sexual partners. The family structure is extended, although significant pressures due to market economy have increasingly led to nuclear family units, particularly in urban areas. Children are commonly raised with the strong influence of parents as well as close relatives, friends, and neighbours. The majority of women (Chagga) in the Kilimanjaro region belong to patrilineal groups in which men and boys are favoured over women and girls regarding access to property and land which is secured mainly through men (Setel 1999). When women marry they tend to live with or near their husband's family. Traditionally, mothers-in-law exert significant influence on the daily life of their sons' families. They are honoured and respected by the rest of the community because of their role as care-givers for their daughters-in-law during the postnatal period. With few exceptions, women have a lower status than men, and few women enjoy privileges equal to those of men. Although women perform the bulk of agricultural labour, the customary laws have not permitted them to own land. In most cases, the husband is the supreme head of the household. A woman is not considered a fully mature woman until she has given birth to a healthy child, and earns respect mostly through her children.

Customs advocate a gender division of labour: women and girls take care of the household chores, small children and livestock, and plant and weed the agricultural fields while men prepare the land for cultivation, market produce, and make the important financial and political decisions for the family. At present the access of women and girls to formal education challenges the customary division of labour. However, with increasing land scarcity and high living expenses, men commonly leave the village in search of work in the town, leaving their wives behind in charge of their children, their land and their aging parents (Moland 2002). Separation from families may place men in high-risk sexual networks, while concurrently may also lead to women's reliance on sex to supplement their incomes while their male partners are away for long periods.

4.2.2 Health and development indicators

According to the Tanzania National Census (2002), the population of the Kilimanjaro region was 1,381,149. In this region the infant mortality rate is 46 deaths per 1,000 live births, i.e. considerably lower than the national infant mortality rate of 68. The under-five mortality rate is 67 per 1,000 live births, again much lower than the national rate of 112. Almost all pregnant women (98%) in this region attend antenatal clinic at least once during pregnancy, i.e. slightly higher compared to 94% nationally. The majority of women (71%) in the Kilimanjaro region deliver at health facilities compared to 47% at the national level. Most women in Kilimanjaro (74%) are assisted by trained personnel during delivery, which is again slightly higher than the nationally percentage (51%). Most of the antenatal services are provided by nurses and midwives throughout the country. While biomedical services have become increasingly important in pregnancy and delivery, the postnatal period including breastfeeding has been largely non-medicalised. Post-delivery care is largely taken over by mothers-in-law (Moland 2002).

4.2.3 The HIV epidemic

Although data show a general decline in HIV from 1995, the figures are still high. The HIV prevalence in the antenatal population in the Kilimanjaro region was in 1995 estimated to 13.5%, which was higher than the national level in 2003. The rate has however dropped

drastically to a present 5.7%, which is significantly lower than the national prevalence estimates of 9.6% among pregnant women (Ministry of Health 2005). One of the factors for the observed HIV prevalence reduction could be the high literacy rate in the region which is estimated at 92% for female and 94% for males (TDHS 2005). This is substantially higher than the national literacy rate of 70% (World Bank, 2006).

4.2.4 Infant feeding

Breastfeeding is universal for all communities in Tanzania and almost all children are breastfed (96%) (TDHS 2005). The median duration of breastfeeding in the Kilimanjaro region was reported to be 22.6 months, slightly higher than the 21 months for the whole country (TDHS 2005). Prolonged breastfeeding and early supplementation with water and other fluids is widely practised (Ministry of Health 2004). Howard (1994) reports that in the Kilimanjaro region it is considered healthy to breastfeed for one to three years, to stop breastfeeding as soon as a woman finds she is pregnant, and to avoid sexual intercourse postpartum. However, the prolonged breastfeeding duration camouflages a sub-optimal breastfeeding pattern: according to the previous surveys (TDHS, 1996), the median duration of exclusive breastfeeding was only about one month as most new-born receive water in addition to breast milk. In many areas, the water given is symbolically charged as a metaphor for growth. De Paoli and colleagues have indicated that 46% of the babies in Kilimanjaro have been given additional fluids to breast milk after only a few days after delivery (de Paoli et al., 2001).

4.2.5 Kilimanjaro Christian Medical Centre (KCMC)

KCMC is a referral hospital for over 11 million people in northern Tanzania and is among the national teaching medical centres (Kilimanjaro Christian Medical College). It also conducts hospital-based activities, outreach activities, training and research. Since 2000 the pMTCT pilot site at KCMC has offered VCT to all women enrolled in the antenatal clinic as well as antiretroviral prophylactics and infant feeding counselling to HIV-positive women (Ministry of Health 2004). Mothers were recruited from the antenatal clinic after the routine antenatal examinations. The HIV test result was disclosed on the same day as the test was made in a one-to-one post-counselling session followed by “healthy living” information

including infant feeding counselling. The infant feeding counselling follows the national guidelines, where HIV-positive women were encouraged to bring their husbands/sexual partners for VCT free of charge. Sixteen nurses were recruited as part-time pMTCT counsellors from different sections of maternity care within the hospital, including the antenatal clinic, labour ward, postnatal and neonatal ward. In general the refusal rate for VCT at KCMC is about 10%, and 7 to 12 women per day were counselled at the pMTCT clinic during the study period.

5. Research methods

The first part of this chapter briefly describes the research design and the rationale for the choice of research methods. The second part gives an overview of the methods employed in the different sub-studies making up this thesis, while the last part discusses ethical issues involved in the research.

5.1 Study design and rationale

The study has an explorative qualitative research design employing qualitative triangulation. It is composed of two parts: a formative research part and an intervention part.

The formative research focuses on:

- 1) The customary infant feeding concepts and practices in the Kilimanjaro region
- 2) Mothers' and counsellors' experiences with infant feeding recommendations in pMTCT programmes.

The intervention study focuses on:

- 1) The development of culturally-sensitive counselling tools ('job aids') to be employed by nurse-counsellors during the counselling of women linked to pMTCT programmes, as well as by HIV-positive mothers for reference on how to perform safer infant feeding. The formative research findings contributed to the identification of the key messages to be communicated and illustrated in relation to infant feeding method.
- 2) Evaluation of the counselling tools, assessing the impact on mothers' infant feeding knowledge and practice.

5.1.1 Qualitative research

John Creswell has defined qualitative research as "an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting" (Creswell 1998). In the well known works of Herbert Blumer (1969), the authors write that qualitative researchers attempt to make sense of or interpret social phenomena in terms of the *meanings* people bring to them. They underline that qualitative researchers do not study a phenomenon in and of itself. Their

actual target can only be the meaning the phenomenon has for those experiencing it (Blumer 1969). The aim is to gain in-depth knowledge of people's life experiences through people's representations of these experiences. In the present study it is hence not HIV transmission through breastfeeding in and of itself that constitutes the object of study, but the way in which this phenomenon is interpreted or given meaning and handled in the particular cultural and social context of the pMTCT programme in the Kilimanjaro region. Qualitative approaches are furthermore particularly appropriate when information is sought on complex phenomena and on concepts and notions, thoughts, opinions, beliefs, perceptions, and experiences (Miles and Hubert 1994). The issue of infant feeding in the context of the HIV epidemic is a highly complex phenomenon that involves deep-seated local cultural ideas, in contexts of biomedical knowledge, power relations and global policies. In order to grasp this complexity and the way it is experienced, it was deemed necessary to employ an open and explorative approach that allowed questioning and probing. A basic characterizing feature of such explorative approaches is that the research encounter starts out without any priori clearly defined hypotheses, and follows an inductive (rather than a deductive) line of reasoning that facilitates flexibility and an ability to adjust to new and unexpected findings see for example (Taylor and Bogdan 1984). The flexibility and potential for adjustment was particularly important in the formative part of the study which had an explicit explorative ambition, while the intervention/evaluation part had a semi-structured approach drawing strongly on the experience and findings in the formative part of the research.

5.1.2 Qualitative triangulation

The methods of data collection employed in the present study were in-depth interviews, focus group discussions and participant observation. The in-depth interview was considered an appropriate data collection tool because of its ability to effectively address complex and sensitive topics and to persuade people to talk about personal feelings, opinions and experiences (see for example Kvale, 1996). A recognised weakness of the individual interview is researcher impact and the lack of possibility to generalise the findings beyond the group of study informants – the latter being a general weakness of qualitative research ventures.

The focus group discussion was another important tool and complemented the in-depth interview with its ability to identify group norms, to elicit opinions about group norms and to discover diversity within a population (Finch and Lewis 2003). In the present study, focus group discussions were primarily conducted to generate feedback on the findings from the individual interviews, thus increasing the confirmability, dependability, and credibility of the study findings. The major strength of the focus group discussion is that it tends to elicit fairly rich information in a relatively short time (Robinson, 1999). Well-functioning groups commonly consist of individuals who share certain characteristics such as age and gender or socio-economic characteristics. Lack of group dynamics is however a common problem that reduces its potential value. Another well recognised weakness is the potential change or modification of the perceptions that take place in group contexts – either because of the ‘Hawthorne effect’ (the conduct of persons who know themselves to be under observation changes) or because their interaction with other participants gives them new insights and perspectives (Krueger 1994).

Dahlgren and colleagues stress the compatible nature of observation and interview and argue that observation guides researchers to some of the important questions they want to ask and interviewing helps to interpret the significance of what researchers are observing (Dahlgren et al., 2004:73). In the present study, participant observation was limited to particular situations in the hospital and home visits. It was seen as a complementary method that would serve to prepare the interview situation both in terms of establishing rapport with study participants and in terms of discovering issues to follow up during the interview. As Kvale has argued: “The endurance in close relationships provides the researcher with opportunities of establishing confidence and rapport with informants, thus reducing the likelihood of eliciting socially acceptable responses that may not be accurate” (Kvale, 1996:43). It also allows the researcher to witness people’s conduct, recognizing the fact that people do not always do what they say they do. Words and practice are basically nowhere exactly the same.

5.2 Methods employed in the four sub-studies

5.2.1 An overview of the methods

1. The formative research

Paper I – Hospital- and community-based study

- Participant observation (recording: hand-written notes)
- Recruitment talks with 22 HIV-positive women study participants (recording: hand-written notes)
- Individual in-depth interviews with 20 of the 22 study participants (tape recorded & transcribed)
- Focus group discussions with community members, four groups (tape recorded & transcribed)

Paper II – Hospital-based study

- Individual in-depth interviews with 25 nurse-counsellors (recording: hand-written notes)
- Focus group discussions with nurse-counsellors, three groups (tape recorded & Transcribed)

2. The intervention study

Paper III – Development of counselling tools:

- Analysis of formative research findings
- Identification of behavioural change objectives
- Development of key messages

Paper IV – Evaluation study

- Training of nurse-counsellors
- Individual in-depth interviews – 59 women (30 intervention and 29 control group + 20 follow-up (recording: interview guide)
- Focus group talks – one group with four intervention counsellors (recording: hand-written notes)

To provide an overview, the presentation of the research methods below follows the four papers that make up this thesis. To a large extent this also gives a sense of how the actual fieldwork process took place over time, although there was substantial overlap between the different sub-studies.

5.2.2 The formative study

The formative study is reported in Papers I and II.

Paper I: Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania

The study aimed to investigate women's experiences related to the infant feeding recommendations given during infant feeding counselling in the pMTCT programme, as well as community perceptions about infant feeding. It was partly conducted at the hospital and partly in the local community. While the antenatal clinic provided an entry point for establishing contact with HIV-positive pregnant women, the follow-up during the first six months of infant feeding was first carried out in the maternity ward and later in individual homes or at other convenient locations.

The hospital-based part

The hospital-based part of the study aimed to recruit and become familiar with the study participants, including getting their early feedback on counselling experiences, and to gather information about the experiences of nurse-counsellors on infant feeding counselling. A contact nurse-counsellor was recruited among the 16 nurses who were working as counsellors at the KCMC pMTCT site. Considerable time was spent informing and discussing the project in detail with the nurse-counsellor, as she was of vital importance for the recruitment of the study participants. The recruitment demanded particular attention – not the least because of the sensitivity of the subject. This implied informing the contact nurse in detail about the focus of the project and the ethical principles guiding the study. She was cautioned not to put pressure of any kind on the individual women (direct or indirect) and was not to recruit informants she knew on beforehand. The contact nurse established a good rapport with the clients and had very good communication skills. Beyond the important

role of recruiting study participants, the contact nurse-counsellor also provided valuable assistance during focus group discussions in the hospital as well as in local communities.

Exit interviews/recruitment talks with study participants (HI- positive pregnant woman)

Exit interviews in the form of recruitment talks were conducted by the researcher with each prospective study participant (see **appendix 4a**). Twenty-two HIV-positive pregnant women (around 36 weeks pregnant) attending the KCMC antenatal clinic were recruited by the contact nurse-counsellor after pre- and post-test counselling during the first two months of the study (August and September, 2003). Two study participants were later excluded as they travelled to stay with relatives outside the Kilimanjaro region after delivery. The women who voluntarily consented to participate in the study were brought by the contact nurse-counsellor to a private room close to the counselling room where the initial talks were held by the researcher, the so-called 'exit interviews'. The aim of this talk was to confirm the participants' sustained informed voluntary consent to participate in the study and to provide information about the coming follow-up talks in the hospital and community settings.

The researcher moreover used this opportunity to gather early feedback on how the woman experienced the information given on infant feeding and her comprehension of the information. These talks took place at a very critical time in the women's lives as they had just received their HIV test results. It was in a hospital room just next to the post-counselling room, where the nurse-counsellor brought the woman who consented to participate in the study just after the post-test. Great care was therefore taken not to worsen their condition. For some (two of them) this situation necessitated postponement of the talks, which meant that the researcher merely had the home addresses for further follow-up or potential meetings at the ANC before delivery depending on the individual situation. For others, the talk emerged as an opportunity to talk to someone interested in their lives at a most critical point in time. These early meetings with the study participants provided an opportunity for the researcher to get to know the participants and to plan for follow-up meetings. As for all the subsequent interviews and discussions, the recruitment talks were mainly conducted in Swahili and at times in Chagga depending on the preference of participants.

The key information gathered during the recruitment talks was recorded in hand-written notes during or after the meetings. The notes taken during these talks were used as background information for the follow-up talks and the in-depth interviews that were to take place at later points with each mother. The same 20 HIV-positive women (study participants) were followed by the researcher in connection with the antenatal visits during the last part of pregnancy, during delivery and during the postnatal phase in hospital and later in the community.

Familiarisation with clinic staff

During the initial periods of the fieldwork, the researcher spent time becoming familiar with the hospital staff, and having informal meetings and discussions in order to gain an understanding of the daily implementation of the pMTCT services, as well as staff perspectives on the utilisation of the services. At this time the researcher moreover, reviewed the existing training/service materials for pMTCT including guidelines, training manuals, monitoring forms and reports.

She also attended relevant on-going activities. The researcher started by participating and observing the routine health education sessions given to a group of women (commonly more than 50 women) attending antenatal and under-five MCH clinics that take place for 30 to 45 minutes every working day in the morning before the commencement of clinics. The major question the researcher asked during this study period was: What are women/mothers told or what do they learn about MTCT through breastfeeding in the context of the high HIV seroprevalence in Kilimanjaro region? The researcher participated in health education sessions that were conducted by a public health nurse at the out-patient clinic, and also observed talks on the postnatal wards at the time when mothers were being discharged. The major focus was the interaction between the counsellor and the mothers with regard to infant feeding. Hand-written notes were taken simultaneously during this period.

The community-based part

The community-based part of the study had two major aims. The first of which was to perform home-based follow-up of the 20 HIV-positive mothers (recruited during the hospital-based part of the study) after discharge from the hospital and through the critical six first months of the infant feeding period in their homes. The idea was to collect information

about their views and experiences related to the infant feeding option chosen, as well as any potential change of the infant feeding methods the mother had opted for. The second major aim for the community based part was to collect socio-cultural data on existing infant feeding practices in Kilimanjaro, norms and attitudes related to breastfeeding and other modalities of infant feeding, experiences with infant feeding decisions, as well as knowledge of HIV transmission through breastfeeding and how this particular challenge was interpreted and handled within the social and cultural context of the Kilimanjaro communities.

Home visits

The majority of the study participants (11 out of 20) were living in one village in Moshi district. This particular village was therefore chosen as the major field site. The village is located close to KCMC hospital which is a likely reason why many women came from this area. The remaining nine participants were dispersed throughout the Kilimanjaro region. These women were also followed up at home⁶. The researcher lived in a house that was located between the field study and KCMC (two to three km's in each direction), which facilitated easy movement between the various research settings for both the researcher and the research participants.

The entry point to the field study was through the ward leader, a retired primary school teacher and a person knowledgeable about current health issues. He spent most of his time during the first week of fieldwork introducing the researcher to key individuals in the community and to the various families in the community, including study participants (anonymous to the ward leader). The researcher was introduced as one who is studying infant feeding practices in that community. As time passed the researcher made home visits without assistance from the ward leader.

All 20 study participants were visited at home more than once during the first two weeks after delivery. The first two weeks of the baby's life were of special interest because of the usual early challenges linked to infant feeding. It is a time when breastfeeding is not always well established, and the mother and infant may not have completely recovered after the

⁶ The researcher had a permission from the regional and district administrators to allow for such movements within the larger area.

delivery. This sometimes encourages prelacteal feeding. The fundamental issue was to assess whether the woman managed to follow the feeding option she had decided upon. The researcher spent some time on home visiting and participated in the mother's daily activities, chatted with the mother and observed and discussed her infant feeding practices. No strict time limits were followed during this part of the fieldwork, the researcher sometimes performing follow-up in one and the same household for three to four days in a row. Informal talk alternated with unstructured interviews and participant observation during this part of the research.

The stay in the village also included visits to other households with and without breastfeeding women in order not to raise suspicion and cause involuntary disclosure of the HIV-positive status of the study participants. Also with these women the researcher discussed infant feeding experiences. Visits were also made to central community members/leaders, schools, local village markets and trading centres, including various drinking areas. This included attendance at local community meetings, marriage ceremonies, church services, funeral rites and women's group activities. People were very kind and welcoming, and discussion about infant feeding – whether in groups or with individuals – commonly initiated substantial engaged discussions as infant feeding emerged as a topic of great concern and interest to people.

The talks were linked to many of the prevailing diseases in the community such as typhoid, tuberculosis, HIV infection etc. Some had had direct experience with the study topic by either having breastfeeding women in their family or by having observed the changing nutritional status of children in their community – not the least when mothers were sick or dying. Unstructured interviews were also conducted with central individuals in the community such as teachers, traditional birth attendants, traditional healers, community elders, and members of the community health committees. The main issues covered in these interviews were knowledge, beliefs and experiences related to breastfeeding, replacement feeding, mixed feeding, mother-to-child transmission of HIV, safe sex etc. These interviews were conducted as either home visits or as visits to workplaces or other agreed meeting place. The researcher used an interview guide during these discussions (**see Appendix 3**). This part of the study generated a broad knowledge base which proved immensely important in understanding the intricacies of the research topic.

All the talks and in-depth interviews and informal chatting were recorded through hand-written notes, commonly at the same time as the talk took place. The records were also kept in the form of detailed hand-written ‘memos’ of important observations made. Informants were sometimes asked to repeat important statements to enable proper recording. At some points the researcher repeated what had been noted as well as her interpretation of the information for clarification. This method of data collection generated materials around the study topic that provided the basis for the subsequent more focused data collection. The insights gained were used to modify the questions/themes for the semi-structured in-depth interview guides and generated topics for the focus group discussions.

Individual in-depth interviews with HIV-positive mothers

Individual in-depth interviews were conducted with all 20 study participants using an interview guide. These interviews took place when the babies were around three months old and thus when the mother had already been employing her feeding method for a considerable time. Most of the mothers chose to come to the researcher’s house for the interview. For most of the women the house was considered a more neutral place than their own homes, and it was easily reached by all. The few interviews (three) that were conducted in the mothers’ homes were carried out at a time when there was nobody else at home apart from the mother and the baby. If unplanned visitors arrived the interview was re-scheduled for another day.

At the beginning of the interview most of the mothers were somewhat hesitant to talking much about their experiences, but during the course of the interview most of the informants spoke freely and seemingly honestly about their situation. Some of them stated that it was a relief for them to have someone they could talk to freely to and air their painful experiences and feelings to without fear of disclosure. The fact that the researcher was by now known to the women eased the process of discussing the difficult infant feeding and HIV theme. The questions explored experiences and probed into mothers’ thoughts, feelings, and concerns about their infant feeding decisions before and after delivery. An interview guide was employed as it was perceived as important to stick to the general topic while simultaneously recording thorough and detailed narratives from the informants. The questions in the guide were arranged from simple to complex (see **interview guide–Appendix 4b**). The interviews

were commonly conducted for more or less 60 to 70 minutes, varying slightly with the mothers' other priority activities and interruptions such as the baby crying etc. All the 20 individual in-depth interviews were tape recorded with the mothers' permission and were transcribed word by word by the researcher during or after the fieldwork.

Focus group discussions with community informants

Four focus group discussions were conducted with diverse community groups of informants at the field site with 8-12 participants in each group. The aim was to explore views and opinions (uniform or conflicting) on infant feeding, motherhood, fatherhood and general knowledge about infant feeding with and without a focus on HIV (with caution). Another aim was to acquire a broader understanding of the context of infant feeding, decision making regarding breast feeding, local concepts of breastfeeding, as well as potential culturally constituted dilemmas of breastfeeding. Division by age and gender were the criteria employed in attempts to create well-functioning and articulate groups. The group's participants were ordinary villagers and consisted of 'young women', 'old women', and 'young men' and 'old men' respectively. The difference by age provided an opportunity to grasp potential continuity or change in infant feeding perceptions and practices over time.

The focus group discussions were conducted in an open place on the premises of the village ruling-party (Chama Cha Mapinduzi) office. The venue had adequate privacy and protection from the sun by shade from trees. The participants were encouraged to respond directly to remarks that other group participants were making. The majority of the informants spoke freely during the discussions, and efforts were made to encourage the few informants who were silent to express their views. Most informants showed considerable interest in the discussions, and they expressed appreciation for being given the chance to discuss a topic of great concern to them. The researcher acted as moderator in the groups and guided the discussion while a research assistant (the contact nurse-counsellor) took notes on additional observations and tape recording.

The discussions started with self introduction. The moderator employed a semi-structured interview guide (see **Appendix 5**) containing open-ended questions on the main themes to be discussed. At the end of the discussion the moderator reviewed the major issues that had

been raised and the main inputs to them. The discussions lasted for approximately one and a half to two hours. The four group interviews were tape recorded with permission from the participants. All tapes were transcribed by the researcher although not all sections were transcribed word by word. Some of the focus group discussions contained sections that did not seem relevant to the topic of interest and were thus not transcribed.

Data analysis

Data analysis began at the start of the very first conversation and interview and continued concurrently with data collection through the data collection period and through the write-up period (implying continuous clarifications, feedback, revisions). At the end of the data collection, a more thorough analysis was made within and across the various sets of material. The data collected in the individual interviews, the focus group discussions and during participant observation were analyzed in the following way:

- Field notes, memos and transcriptions from the interviews were carefully read sentence by sentence. The researcher re-read all the material several times to become familiar with its content as presented by the informants.
- Then followed manual coding in the margins of all field notes and transcribed texts (using central concepts, sometimes central Chagga concepts, at other times the researcher's concept of what was being dealt with). Several rounds of coding were necessary in order to find ways of eliciting the meaning expressed by the study participants. (For example 'mother-in-law' and infant feeding, customary mixed feeding, initiation of breast feeding, discontinuation of breast feeding, thoughts about exclusive breast feeding, experiences with exclusive breast feeding etc.). Whenever possible culture-specific label/labels that were closely related to the way the statement was expressed were included employing Chagga terms.
- The material was after coding re-read again and surplus, non-relevant material that did not appear to be related to the research topic was removed to make the material more manageable. This took place in a process in which gradually more information was deleted.
- The first condensed and detailed texts from the field notes and transcripts were read again, the researcher now dealing with the second 'draft' in which all the collected information

deemed relevant to the study topic was included and in which all the information was eventually coded. - A detailed list of the various concepts related to the study topic was then generated. The researcher went through the text repeatedly to check if any important information was left without coding. More information was at this point eliminated.

- Then followed the step of organising / synthesising / grouping / categorising the coded material under broader themes with a large number of sub-themes to allow for multiple views, contradiction etc. Ensuring the multiplicity or complexity of meaning was a key concern. At this point the researcher worked back and forth moving pieces of detailed notes and lists of concepts to derive at clusters/categories of coded themes covering the relevant meanings on a particular topic that had emerged. Sometimes consistent meaning throughout emerged, while at other times an overlap of meaning emerged or the meaning emerged as ambiguous or contradictory.

- Then followed a move of the similar piles together into different documents so as to get documents that were dealing with a particular topic separately.

- Throughout the process of analysis, the detailed notes and transcripts from the interviews and field observations were repeatedly reviewed and compared with the final list of codes and themes to check that the central topics brought up by the participants were included.

- The researcher compared coded/categorised data both within the different sets of data (for example a focus group of villagers) as well as across the different data sources (within different focus groups of villagers and between focus group discussion with villagers and individual interviews with the mothers) drawing upon interviews, notes from observations, transcribed texts and memos to extract the complexity of meaning and opinions on the main themes.

- After all the material had been categorised under appropriate broader headings, the researcher had to move pieces of categorized material into documents where everything was dealing with a particular topic, and the writing process started.

The originals of all interview notes, including all the notebooks and fieldwork tapes, were locked safely for reference so that they could be reviewed again whenever the need arose.

Paper II: HIV and infant feeding counselling: Challenges faced by nurse-counsellors in northern Tanzania

The second paper is primarily based on individual in-depth interviews as well as on focus group discussions with nurse-counsellors. The aim was to explore nurse-counsellors' experience of counselling HIV-positive women on the recommended infant feeding methods.

Individual in-depth interviews with 25 pMTCT counsellors

The researcher conducted 25 individual in-depth interviews with nurse-counsellors using an interview guide (see **Appendix 6**). The nurse-counsellors were working at the pMTCT site at KCMC as well as at three other pMTCT sites in the Moshi district. The nurse-counsellors voluntarily consented to participate in the study.

The interview guide was made up of questions that were partly adapted from the WHO recommended sample questions for formative research on HIV and infant feeding (UNAIDS/WHO 2004). The major goal for these interviews was to answer the question: 'What are the experiences of nurses working as infant feeding counsellors to HIV-positive mothers enrolled on pMTCT programmes in the Kilimanjaro region?' The interviews were conducted in private rooms in the health facility where the counsellors were working, and usually took place after working hours so as not to disturb the work. Four of the interviews took place in the nurses' homes during the weekend. The interviews were all conducted by the researcher herself, and the information was recorded in hand-written notes during the interview.

At the beginning of the interviews a few counsellors did not seem to respond freely to some of the questions, but after assurance of anonymity and after learning that the researcher was also a nurse with the aim of contributing to the future improvement of the pMTCT programme most of them expressed their views very openly and apparently honestly. The interviews took approximately 70 to 80 minutes; some took a bit less or a bit longer but within this approximation. The counsellors' descriptions provided important perspectives on the many challenges they faced in their daily practice. Each interview was followed by a

preliminary analysis before the next one was undertaken so that insights gained were used to inform, modify or develop the questions for the next interview. The pre-service training curriculum for nurse/midwives was also reviewed in order to get a sense of how well prepared the nurses were for their roles as counsellors in general and as infant feeding counsellors in particular.

Focus group discussions with nurse-counsellors

Three focus group discussions (eight participants in each group) were conducted with the same study participants who were interviewed individually. The discussions aimed to explore collective norms, ideas, experiences and possible divergent views related to their role as infant feeding counsellors. The discussions also aimed to add to and validate the information that had emerged in the individual interview sessions. Each group discussion built on the previous one with only slight modification. The counsellors' supervisor was purposely excluded during FGDs to allow a free-flowing discussion. A neutral place outside the hospital was chosen as venue. The topic and objectives for the discussion were introduced by the moderator who used a discussion guide (see **Appendix 7**). This topic guide was also partly adapted from the WHO recommended questions on HIV and infant feeding (UNAIDS/WHO 2004). The discussion was characterised by lively, free and engaged expression on experience of infant feeding counselling. The discussions were tape recorded, and the tapes were transcribed by the researcher.

Data analysis

The effort required to analyze the substantial data material collected from the mothers and the community informants (reported in Paper I) instigated a search for alternative ways handling the information collected from nurse-counsellors. The researcher decided to employ a qualitative software programme called 'Open code'. A computer program can however obviously not code or classify a material, but can only assist in organising already coded material. Once the document was imported it was stored as lines with line numbers that provided broad margins for the coding. The researcher coded the document in the margin sentence by sentence. Now, followed a search for single or combined codes in the document (one statement being given several codes as the content has different meanings). A detailed list of various codes related to the study topic was then generated and moved pieces

of coded material into documents dealing with a particular topic. Thereafter, followed synthesising / grouping / categorising the coded material under broader themes using the same steps as those employed in analysing Paper I. After the material had been coded and categorised under appropriate broader headings, the topical lists were printed out to get overview of the collected material. The writing process started. Again the originals of all interview and discussion notes, including fieldwork tapes, were locked safely for reference so that they could be reviewed again whenever the need arose.

5.2.3 The intervention study

The intervention study is reported in Paper III and Paper IV. It needs to be mentioned that the intervention research was not planned as part of the present PhD study. The initial plan was for a solely descriptive study. The intervention study emerged as an opportunity after the researcher's encounter with an expert in material development from the Quality Assurance Project (QAP)/URC in the USA who suggested collaborating on an intervention to strengthen pMTCT counselling. This idea was greatly supported by both the local (KCMC authority) and national stakeholders (Ministry of Health) who agreed to participate in the development of the intervention. The rationale behind the adding of the intervention component was the challenges experienced by pMTCT programmes in promoting the infant feeding methods proposed by WHO, and the stated need to improve the counseling services. A substantial part of the data collection in connection with the intervention component was carried out by a research assistant.

The intervention became an attempt to transfer the knowledge generated in the formative study to practical counselling tools (job aids) to be employed by counsellors as well as by HIV-positive women. Hence the formative research findings that mapped existing practices, perceptions and attitudes related to HIV and infant feeding, preceded and informed the intervention (infant feeding counselling tools). The intervention as a whole was carried out in a participatory manner between all major stakeholders at all levels (local, national and international) in close collaboration with all members of the research team. (Please refer to Paper III for a more detailed description.)

The study aimed at translating theory-based intervention methods into practical strategies that could be organised into a logical series of learning activities that would instigate changes in infant feeding practices.

The intervention was developed as a stepwise process:

1. Learning objectives were developed from the formative research and the existing international infant feeding guidelines.
2. Methods and practical strategies to influence infant feeding behaviour were selected.
3. The intervention programme was designed
4. The programme was adopted and implemented.
5. The programme was evaluated.

These steps corresponded well with the steps suggested in the Intervention Mapping Protocol (Bartholomew et al., 2001) which was later used in the process of systemising and reporting on the process. Steps 1, 2 and 3 are reported in Paper III, and step 5 is reported in Paper IV. Step 4 is only partly reported in both papers.

Recruitment of a research assistant

The research assistant recruited for the intervention study was chosen because of her previous substantial experience in fieldwork and community surveys in the Kilimanjaro region. She had a background in community development, and had vast knowledge of the villages, health facilities, community leaders and other influential people in the research area. Moreover she was a Chagga by ethnic origin, and could read, write and speak English, Swahili and Chagga. She was able to take very good notes in Swahili. As important as her scholarly skills was her ability to develop rapport and conduct interviews in an excellent atmosphere with both rural and urban women. The research assistant was involved in the process of developing and refining the interview guides together with the researcher. This research assistant became vital in the intervention study, and carried out a major part of the data collection.

Paper III: Translating global recommendations on HIV and infant feeding to the local context: the development of culturally-sensitive counselling tools in the Kilimanjaro region

Step 1: Identification of learning objectives

The researchers postulated that mothers who have inadequate *knowledge* about mother-to-child transmission of HIV would not change their infant feeding practice. Therefore the specific learning objective was to teach HIV-positive mothers the importance of exclusive breastfeeding and exclusive replacement feeding and of avoiding mixed feeding patterns in preventing MTCT of HIV. The substantial ‘individual’ and ‘environmental’ determinants of international/national recommended safer infant feeding practices were now identified from the formative research findings as well as from literature reviews of relevant empirical studies and reviews of theoretical models such as Social Cognitive Theory (Bandura, 1986).

According to the Social Cognitive Theory, in order for the mothers to accomplish behavioural change related to infant feeding, it was vital to:

- recognise the importance of existing attitudes and practices
- utilise external sources (social support available, either at family or community level)
- draw upon personal skills to cope with barriers (self-efficacy)

A few glimpses of knowledge drawn upon from the formative research:

- Mothers were not positioning and attaching the baby well to the breast, which caused breast problems
- Mothers were not sure how to prepare, mix and feed the formula or cow’s milk
- The customary aspects of mixed feeding practices (breastfeeding plus other feeds)
- Mothers were counselled on infant feeding only once during ANC (just after being given the HIV test results at a point in time when they were confused. Thus difficulties of remembering the information discussed)
- Mothers could read and comprehend Swahili information from a written document
- Nurses are trusted health educators in the area
- Most counsellors were not trained in infant feeding counselling, nor did they know the content of the infant feeding guidelines, and were in need of counselling tools and algorithms that could standardise counselling messages and provide some structure and guidance when counselling on infant feeding.
- Local dressing and resources that could be employed to illustrate the preparation of replacement feeding

Step 2: Development of key messages and graphics

The key messages to be communicated to the mothers on how to safely execute infant feeding were not least developed by drawing upon knowledge gained about the substantial gaps identified in the formative research. Social Cognitive Theory (Bandura, 1986) informed the researchers about widely applied techniques to instigate behavioural change. The theory holds that particular techniques ‘enhance one’s self-efficacy in practices’, e.g. in information transfer, and enhance ‘skills building’, ‘role modelling’, and ‘reinforcement from trusted people’. On the basis of the formative research and the knowledge gained from Social Cognitive Theory, the researchers developed reading materials in Swahili with visual illustrations reflecting locality. The text in the developed material was to be discussed by nurse-counsellors (trusted advisors) during counselling sessions at pMTCT sites.

Step 3: Development of the counselling tools

The researchers then developed counselling tools with key messages on how to properly execute the recommended infant feeding methods. The graphics aimed to reflect culturally appropriate norms of the Kilimanjaro community. The copies were first developed in English for technical experts’ review, and then translated into Swahili. The materials were pre-tested in four FGDs among key users (counsellors and mothers) and the layout and content were subsequently modified according to the feedback given.

Step 4: Programme adoption and implementation

Strategic participation and consensus building between all major stakeholders were considered from the beginning and throughout the process of developing the intervention in order to ensure its social and cultural relevance and potential for scale-up. Policy makers, technical experts, service providers and clients were involved in various phases of the process. HIV-positive mothers, local community members and nurse-counsellors responsible for the day-to-day running of the pMTCT programme, and individuals who had participated in the formative research now took part in the testing of the draft materials. Members of the national consultative group responsible for developing guidelines on infant feeding as well as other national and international technical experts provided guidance during the planning process and during the adaptation or design of the technical content for the images taken from existing generic materials.

Paper IV: Counselling tools in the promotion of safer infant feeding practices in the context of HIV: An evaluation study from the Kilimanjaro region, northern Tanzania

The evaluation study employed a qualitative design using individual in-depth interviews and focus group discussions. However, parts of the findings were transformed to numerical figures during the analysis phase to ease the comparative aspects between the intervention group and comparison group (*see below*). The role of the researcher was very different in the evaluation study compared to the other parts of the study: she acted as a supervisor for the research assistant who carried out most of the interviews. The researcher did carry out the first ten interviews together with the research assistant at the start-up of the study. She also assured the follow-up.

Training of nurse-counsellors

A one-day training session was conducted at KCMC hospital for all 16 KCMC counsellors who were working at pMTCT at the time of the fieldwork. The aim was to provide a technical update on HIV and infant feeding and to teach the essential characteristics of good interpersonal communication and counselling and the effective use of the developed counselling tools. The trainers included the research team and a national trainer from the Tanzania Food and Nutrition Centre (TFNC). Copies of the materials, in English and Swahili, were given to all nurse-counsellors. Participants were divided into groups (five to six nurse-counsellors) to review and discuss the content of each item in order to ensure that everyone was familiar with the technical recommendations. Role plays using the various counselling materials were conducted to reinforce the interpersonal communication and counselling skills and to provide an opportunity for participants to discuss different case scenarios.

Four of the 16 counsellors who participated in the one-day training course were recruited as participants in the intervention study. The criteria used for recruitment were reports of good rapport with clients and an expressed interest in the study.

The evaluation design

The evaluation study employed a qualitative design that compared an ‘intervention group’ to a ‘comparison group’. The intervention group consisted of 30 mothers (20 HIV-positive and 10 HIV-negative) from the pMTCT programme at KCMC. These mothers were recruited and served by four counsellors who had participated in the one-day training session at KCMC and who received the counselling and take-home materials. The comparison group consisted of 29 mothers (19 HIV-positive and 10 HIV-negative) from two pMTCT programmes within the same district. These pMTCT programmes were run by government health centres offering a standard package of VCT, ART prophylaxis and infant feeding counselling, and were not part of the intervention.

In order to gain access to women who would form a comparative group for the study, the research team established collaboration with an on-going pMTCT cohort study in Moshi. The only two trained counsellors who were working on this project were recruited as research assistants for the present study. These two counsellors received individual orientation about the general purpose of the study and their role in recruiting the mothers. Neither of them received additional training, nor were they exposed to any of the counselling materials or to the WHO guidelines. All six counsellors were given a small honorarium to help defray the communication and transportation costs associated with the recruitment of the mothers. No additional payment or incentives were offered.

Recruitment of mothers

The intervention group were counselled, tested and recruited to the study by the four counsellors selected for the intervention. The criteria for selection were willingness to participate and to be interviewed at home after delivery. Similarly, the comparison group was identified and consulted by the two counsellors at the comparison pMTCT sites, and the members were subsequently recruited into the study. One HIV-positive mother selected for the comparison group was excluded from the study after she travelled to the intervention site for a postpartum follow-up visit and received the take-home materials there. Hence, the comparison group was left with 29 participants.

The mothers in the comparison group recruited from the cohort study were the only feasible comparison group that could be accessed outside the intervention site. The challenge employing this group was however that they had been monitored for some time, and the majority of the mothers had already completed the first critical phase of the infant feeding. Hence the infants in the comparison group were older than the infants in the intervention group at the time of interview, and the study team had to depend on recall of infant feeding among the mothers in the comparison group. The possible effect of this discrepancy is discussed in the section on methodological reflections.

Individual in-depth interviews

A semi-structured interview guide with a set of questions developed in Swahili was employed during the study (see **appendix 8a**). The questions focused on the mother's knowledge and beliefs about HIV and infant feeding, intended infant feeding practices, problems encountered with infant feeding, the nature of the infant feeding counselling they received, and feedback from the intervention mothers on the counselling and take-home materials. All the 59 mothers in the two groups were interviewed at home by the research assistant using this same interview guide (10 interviews together with the main researcher). Whenever possible, additional observations related to infant feeding were noted on the interview form.

Follow-up interviews were carried out with 13 mothers in the intervention group and with 7 mothers in the comparison group between four and six weeks after the first interview. It was not possible to follow up all the mothers given the limited time and resources. The criteria for the selection of these mothers were feeding method practised, counselling site and willingness to be home-visited a second time. The follow-up interviews were conducted by the same research assistant. These interviews investigated potential changes in knowledge and practice related to infant feeding since the first interview, as well as thoughts and experiences related to the take-home materials. The responses were all hand-written in the interview guide form (see **appendix 8b**).

At the end of the study, the four intervention nurse-counsellors participated in a group discussion with the research team focusing on their experiences of using the counselling tools. They also presented recommendations for improving the counselling tools.

Data analysis

All the information collected was translated from Swahili into English by the researcher. The collected narratives were reviewed by the three research members (SL, PKB, and Bart) who independently read through the entire set of narratives several times. Each one coded/sought for the emerging themes from the text. Thereafter the themes were presented and discussed in the group. The authors then condensed part of the material by defining the research questions that the themes were attempting to answer. The next step transformed the unstructured responses to structured data by defining categories of answers to each question in both the first and the second interviews. The answers were then coded under each research question and entered into an electronic file and analysed.

6. Ethical consideration

The study received ethical clearance from Muhimbili University College of Health Sciences (MUCHS) (see **appendix 9**), the KCMC Ethical Committee (see **appendix 10**), and the Norwegian Committee on Ethics in research (see **appendix 11**). The intervention proposal was written after agreement with the KCMC administration on the priority need of such an intervention, and was thereafter re-submitted to the Ethical Committee at KCMC. Permission was granted (see **appendix 12**) and MUCHS ethical committee was informed in writing about the additional intervention component in the study. The regional and district local authorities granted approval for the study to be conducted in the communities (letters were presented to the concerned ward leaders).

The extreme sensitivity of the research topic and the personal, conversational nature of the discussion and interviews in this study highlighted many fundamental ethical research issues. Voluntary participation, free right of withdrawal at any time and assurance of anonymity and confidentiality were emphasized throughout the study. A review of this central point is given below.

Informed consent: The aim and purpose of the study were explained to all potential study participants (HIV-positive mothers, counsellors and community key informants). The study participants gave verbal or written informed consent to participate in the study. The study opted for oral consent from the HIV-positive mothers and written informed consent from all other categories of informants. Signing a contract between a researcher and oneself which in 'Western countries' gives reassurance that one's rights as a study participants are ensured/protected is not necessarily experienced in the same manner in many 'non-Western context'. In this particular research setting most people will be quite willing to contribute to research, but many will be highly sceptical to research to which their signature is required due to the fear that it might be used against him/her. In the context of the present study, the fear would not the least involve a fear of disclosure of one's HIV- status. On this basis the researcher opted for oral consents from the HIV-positive mothers. All other informants (counsellors and key community informants) gave their written consent to participate in the study. The consent forms (see **appendix 13**) were carefully stored. It was also emphasized

that the informants could decline from answering particular questions or could withdraw from the study at any point without any consequences.

Confidentiality: The right of confidentiality and privacy of the study participants was in this study taken into great consideration, not least due to the stigma related to HIV infection at both individual and community levels. The participants in this study were concerned about the risks of disclosure. The research team thus emphasized to the research participants that their confidentiality and anonymity would be taken most seriously and would be ensured to the extent possible and quite rigorous measures were followed to ensure that this premise was fulfilled. For example this meant that the time and location for interviews were chosen according to the preferences of the study participants. A few of the informants did not wish to be visited at home. In such cases other neutral ground was found – for example for the in-depth interviews with the HIV-positive mothers – at the time of the community-based study. During the community-based study, visits were made to a number of households with both HIV-positive and HIV-negative women, to breastfeeding mothers of unknown HIV-status, as well as to households with no breastfeeding women so as not to risk identifying the HIV-positive study participants. Great care was taken in similar ways with regards to the amount of time spent in the various households to avoid potential identification of the study participants in those communities.

Ensuring confidentiality also required caution when details were noted down concerning the experiences of particular research participants so as to ensure that no identifiable parts of interviews or discussions would be lost or published. Each participant's name was changed into a number or a fictitious name in the write-up. The material collected – including handwritten notes, transcripts, checklists and tapes – was locked into a cabinet to which only the main research had access. Those who made up the intervention research team signed an agreement regarding confidentiality.

Potential risk assessment: It was clear to the researcher that HIV-positive women who had recently received their diagnosis were extremely vulnerable. As mentioned above, the study implied risk in the sense of potential revelation of the participants' HIV-status. Moreover, it was unlikely that these research participants would experience psychological stress during or after the discussion of the situation they were in. Theoretically one could also envisage that the research participants could face ostracism by peers or staff who believed that the

participant had made unflattering remarks about them to the interviewer. To minimize this risk, the researcher did try to be as sensitive as possible to potential reactions from the research participants. The sensitivity and risk implied by the interview were also discussed thoroughly with the research assistant in the intervention part of the study. All interviews were carried out in complete privacy. The study was presented as research on “infant feeding practices” in the communities and was not linked to HIV except to the actual study participants (mothers, nurse-counsellors and few key hospital administrators) in the private setting of the study.

Promises and reciprocity: It was emphasized from the onset of the study that the research findings were part of a PhD study, and that no personal benefit was linked to participation in the study. Only in cases where the participant spent her/his money on transport was the money refunded by the researcher. However, there were some few gift-giving especially when the researcher visited the family of the new-born baby for the first time. This was according to the traditional norms that seeing a newborn empty handed without giving something is not normal, but this was not part of the contract.

Interviewer psychological experiences: The contact with HIV-positive women in an extremely vulnerable position also implied intense personal experiences for the interviewers involved in the research. The numerous stories of suffering that were shared with the researchers could potentially lead to situations where the researchers become overwhelmed by what they hear. Within the intervention research group so-called ‘debriefing’ was practised after some of the interviews to review the experiences of the researchers.

7. Study Findings

The findings of the study are presented in four papers, three of them published and one submitted for publication. The content of the papers is briefly summed up in the section below.

Paper I

“Difficult Choices: Infant feeding experiences among HIV-positive mothers in northern Tanzania”.

This descriptive qualitative study explores HIV-positive mothers' experiences connected to choice of - and adherence to the infant feeding methods recommended in prevention of mother to child transmission of HIV programmes (pMTCT). The main study was conducted between August 2003 to June 2004 with periods of follow up in 2005 and 2006. The study is based on in-depth interviews and follow-up talks with 20 HIV-positive mothers during the last part of their pregnancies, at the time of delivery and during the critical first six months of the infant feeding period. The study participants were between 20 and 32 years of age, 16 of the women were married, 19 had primary school education and they came from both rural and urban areas within the Kilimanjaro region in Tanzania.

The study findings reveal breastfeeding as the only culturally acceptable infant feeding method, and the only way to fulfil ideals of being a good mother. After being given infant feeding counselling 13 of the 20 mothers opted for exclusive breastfeeding while the rest opted for replacement feeding. In the latter group some chose to feed their infants infant formula while others chose cow milk. The category that opted for breastfeeding would express their choice through statements such as: *“Babies grow well on breast milk.”*; *“It is the only acceptable way of feeding babies”*; *“All good mothers breastfeed their babies, what reason will I give for not breastfeeding?”*; *“It is the only way of avoiding people suspecting my HIV status.”*; *“My husband and in-laws will not understand me if I don't breastfeed my baby.”*; *“Buying formula is too expensive, I cannot afford it.”*

A substantial majority of the study participants had not disclosed their HIV-positive status to anyone, and HIV-related stigma and fear of rejection emerged as a major condition when HIV-positive mothers made their decisions on how to feed their infants. In addition to fear of disclosure of HIV-positive status, poor purchasing power and social pressure emerged as

factors with substantial impact on choice of infant feeding method. Among the seven women who chose replacement feeding (formula or cow's milk), five had disclosed their HIV status to their partner. The same five were employed and had a regular income. For these women the risk of HIV transmission to the baby through breastfeeding, maintenance of the mother's health and access to replacement milk provided important conditions of choice. The rationality behind their choice emerged in statements such as: *"It is the only way to prevent transmitting the HIV infection to the baby."*; *"I'm worried about my health, - if I breastfeed I would become very weak and it would shorten my life."*; *"I chose cow's milk because my neighbour sells cow's milk at a cheaper price and I want my baby to be healthy."*

The presentation of the study findings details four of the informant's cases. They bring up the major challenges linked to choice of and attempts to adhere to exclusive breastfeeding, feeding with modified cow milk and formula feeding respectively. The findings demonstrate that the recommended feeding options were extremely difficult to adhere to, whether the choice is exclusive breastfeeding or exclusive replacement feeding. Indeed, all of the 20 study participants experienced severe hardship implementing their infant feeding choice, and only one of the mothers managed to stick firmly to the feeding method she had opted for, a woman uncommonly positioned in the community. All mothers who opted for exclusive breastfeeding contrary to their intentions ended up practicing mixed feeding, either giving water in early infancy, supplementation with other types of milk or soup or both. The major reasons given by the mothers were experiences of social pressure, work outside the home, lack of sufficient mothers' milk, and mothers' weight loss. The paper discusses the substantial difficulties women have in relating to the WHO infant feeding recommendations.

Paper II

"HIV and infant feeding counselling: Challenges faced by nurse-counsellors in northern Tanzania"

This article is based on a study that intended to investigate the content of infant feeding counselling, potential shortcomings in infant feeding counselling and reasons for potential challenges from a nurse-counsellor's perspectives. Particular emphasis is placed on nurse-counsellors' perceptions of the relevance of the WHO infant feeding guidelines in the cultural and social setting of the Kilimanjaro region, and the challenges that face nurse-

counsellors in their work in pMTCT programmes. A qualitative study was conducted using in-depth interviews and focus group discussions with 25 nurse-counsellors working on a part-time basis at four pMTCT sites within the Kilimanjaro region, Tanzania. Six nurse-counsellors were recruited from each of the four sites and from different sections of maternity care within each site, including from the antenatal clinic, the labour ward, and the postnatal- and neonatal wards. The overall pMTCT supervisor was also included in the study. The four pMTCT sites encompass the two largest health centres, the regional hospital and the referral hospital. The sites were characterised by heavy patient load and targeted both rural and urban populations. The counsellors were all nursing officers holding diplomas in nursing and midwifery. Only two of the counsellors - including the supervisor - had been trained specifically in HIV and infant feeding.

The findings demonstrate that the counsellors experienced great difficulties in their attempts to give relevant and qualified advice to HIV-positive women on how best to feed their infants. Most expressed confusion regarding the appropriateness of the feeding options they were to present for the women. They perceived both exclusive breastfeeding and exclusive replacement feeding as culturally and socially challenging violating cultural norms and practices, and were hence difficult to both promote and to implement. Some international recommended infant feeding methods – in particular wet nursing and expression and heat treatment of breast milk - were found to be so culturally unacceptable that the counsellors expressed strong reluctance in promoting them. The majority of the counsellors perceived that replacement feeding, and in particular infant formula, was the best option for an HIV positive woman. The counsellors' recommendations to the HIV-positive women was as such in line with WHO's recommendations putting replacement feeding as the first choice. Most of the counsellors placed particular emphasis on and recommended this feeding method even though they were sceptical about its overall feasibility, affordability, acceptability or safety. That is they were sceptical to whether the women would fulfil the so-called AFASS criteria that lie at the heart of the WHO charter. They did, for example, recognize the substantial economic constraints implied in securing sufficient tins of milk, as well as the practical problems involved in preparing and storing formula or cow milk, and acknowledged that it was an option that was extremely difficult to adhere to exclusively.

The fact that nurse-counsellors did not believe in the infant feeding methods they were supposed to counsel mothers on led to frustration, exhaustion and burn-out. Most of the counsellors expressed a lack of confidence in their own knowledge on HIV and infant feeding, as well as in their own skills in assessing a woman's possibilities of adhering to a particular method of feeding. They moreover expressed that they were overwhelmed by a constantly increasing workload which pressured them to compromise the quality of their work. They reported having very limited opportunity to keep updated, and complained about the lack of accessible reference material for review. The counsellors also expressed great dissatisfaction by the fact that they had no support that enabled them to make follow up visits of their clients at home during the crucial postnatal period after birth.

The findings bring attention to the major transitions for the nurses' assignments and the shift in the nursing role from health-educators to nurse-counsellors that are brought about by the handling of the HIV pandemic. The findings suggest that nursing education and socialization imply that patients are expected to be told what is right and wrong, and what they should do to prevent illness or to heal disease. The nurse-counsellors expressed that their roles as educated individuals with particular trusted skills and knowledge is threatened with their newly gained roles as advisors operating within an atmosphere of patient self determination and health-related decisions resting with the patient (counselling). The mothers/clients on their side feel betrayed by nurses who appear to lack the necessary authoritative knowledge that can assist them in the counselling context.

Paper III

“Translating global recommendations on HIV and infant feeding to the local context: The development of culturally sensitive counselling tools in the Kilimanjaro region, Tanzania”

The paper describes and discusses the process of developing a set of culturally-sensitive counselling tools ('job aids') with a focus on HIV and infant feeding to be employed by nurse-counsellors during the pMTCT counselling sessions and by HIV positive mothers for reference on how to perform safer infant feeding at home. The process entailed the translation of theory-based intervention methods into practical strategies that could be organised into a series of 'learning activities' that would ease modification in infant feeding

practices. The overall aim was to contribute to improving infant feeding counselling services for HIV-positive women in the Kilimanjaro region of Tanzania with potential impact on infant feeding in the context of HIV also in other areas in Africa. Formative research based on qualitative research tools preceded the development of the intervention. This first phase of the research mapped existing practices, perceptions and attitudes towards infant feeding and HIV among mothers, nurse-counsellors and community members (main findings are reported in paper I and II). The formative research was drawn upon to assess how infant feeding messages could be presented in a culturally appropriate and relevant manner through key messages and visual illustrations.

The intervention was developed as a stepwise process. These steps bear resemblance to the five steps in the framework 'Intervention Mapping Protocol', a health promotion framework that emphasizes and promotes close collaboration among stakeholders who are developing health related interventions. The performance and learning objectives were defined, and communication messages and corresponding visual graphic were designed by drawing upon knowledge generated in the formative research, theories of behaviour and attitude change, and the international and national infant feeding guidelines. The development of the 'job aids' was carried out in a highly participatory manner in a process where all major stakeholders at diverse bureaucratic levels (local-, national- and international) were working closely together with the members of the research team. Strategic participation and consensus building between stakeholders was seen as critical in the process of developing the counselling tools to ensure their political, social and cultural acceptability. Policy makers, technical experts, service providers and service users were thus all involved in all phases of the process. The national consultative group responsible for developing guidelines on HIV and infant feeding provided guidance on the content while the national and international technical experts provided technical advice and assistance in designing the material and in creating the images. HIV-positive mothers, other local community members and nurse-counsellors responsible for the day-to-day running of the pMTCT programmes participated both in generating knowledge for the formative research and in the pre-testing of the drafted materials.

The process led to the development of an integrated set of infant feeding counselling tools, referred to as 'job aids' consisting of the following components;

- i) Three counselling/take-home brochures on the infant feeding methods that were deemed to be the most socially and culturally acceptable. The three brochures focus on exclusive breastfeeding, formula feeding and cow's milk feeding respectively, and describe the steps to safe infant feeding. They employ local language, and are illustrated with images based on local ideas, dressing and resources. The brochures are to serve as reference material during infant feeding counselling sessions in the pMTCT programmes as well as take-home material for the mothers/parents.
- ii) A 'Question and Answer Guide' for counsellors on HIV and infant feeding including illustrated answers to 25 questions commonly asked by mothers, their families and community members. This guide aimed to provide counsellors with an easy-to-use guide for the counselling activities.
- iii) A counselling card that explains through illustrations the relative risk of MTCT during pregnancy, labour and breastfeeding when no preventive measure is taken.
- iv) An infant feeding counselling tool-kit for the demonstration of how to prepare replacement feeds.

The images and lay-out of the counselling tools were developed from those photographs taken at home, using state of the art process through computer graphics.

Paper IV:

“Counselling tools for the promotion of safer infant feeding practices in the context of HIV: An evaluation study from Kilimanjaro region, northern Tanzania

This paper aims at assessing how the employment of a set of counselling tools ('job aids') of infant feeding counselling for HIV positive women ('job aids') affect the quality of the infant feeding counselling as well as the infant feeding practices. The study used a qualitative design with assessment of an 'intervention group' and a 'comparison group'. The 'intervention group' consisted of 30 mothers (20 HIV-positive and 10 HIV-negative) recruited from the pMTCT programme at Kilimanjaro Christian Medical Centre (KCMC) in Tanzania. The comparison group consisted of 29 mothers (19 HIV-positive and 10 HIV-negative) who were recruited from two pMTCT programmes in the same district, but who were not exposed to the 'job aids' related intervention. The programmes where the 'comparison group' was recruited from were run by government health centres that offered a

‘standard package’ of Voluntary Counselling and Testing, antiretroviral prophylaxis and infant feeding counselling. Semi-structured qualitative interviews employing an interview guide were conducted with all study participants within the first nine months after delivery to elicit their knowledge, beliefs and experiences related to HIV and infant feeding.

Key findings reveal that the employment of the counselling tools during infant feeding counselling increased knowledge about infant feeding among mothers, and strengthen certain aspects of the infant feeding counselling as compared with the counselling offered in the standard pMTCT programmes. For example, the mothers in the ‘intervention group’ had more knowledge on the definition of and benefits of exclusive breastfeeding, and demonstrated greater knowledge on the relative risk of HIV transmission, on safe preparation techniques of infant milk and on safe sex practices. Proper breastfeeding practices as well as proper positioning were reported to have been demonstrated to almost all the mothers in the ‘intervention group’ compared to none in the ‘comparison group’. Moreover, the women in the ‘intervention group’ were able to cite more ways of protecting their babies from HIV infection, and were more knowledgeable about breast care as an infant feeding protection measure than the women in the ‘comparison group’. The counsellors in the ‘intervention group’ indicate that the counselling tools and the training in how to use them during counselling sessions enabled them to follow a logical, sequential flow in the presentation of the key counselling messages.

However, some clear limitations and challenges were revealed in the course of the study. The risks associated with failing to breastfeed exclusively or to replacement-feed exclusively, with mixed breast-feeding as a consequence – the least desirable in an HIV context -were not paid much attention during the counselling sessions in either category. Indeed, counselling advice on mixed feeding did not seem to differ strongly between the ‘intervention group’ and the ‘comparison group’. Replacement feeding was favoured by more mothers in the ‘intervention group’ than in the ‘comparison group’, and most of the mothers in the ‘intervention group’ reported that the counsellors had advised them to replacement feed their babies. The mothers in both groups on their side expressed little or no understanding of the many risks associated with replacement feeding. Even though the counsellors for the ‘intervention group’ had recommended replacement feeding, nearly all

the mothers decided to breastfeed because they could not afford replacement milk and/or feared disclosing their HIV status if they didn't breastfeed. It was revealed that the quality of the infant feeding counselling was strongly compromised by the counsellors' poor judgement of the so-called AFASS criteria (the 'acceptability, feasibility, affordability, sustainability and safety' criteria) that are to be assessed in order to inform and guide mothers regarding the diverse infant feeding options for women in varying infant feeding situations. The discussion reflects on how a lack of active assessment of the AFASS criteria in pMTCT counselling undermines the relevance of the WHO guidelines, and promotes misguided counselling including illusions of choice of safe infant feeding alternatives for innumerable vulnerable and marginalized HIV-positive women. The paper thus indicates the enormous challenges the international infant feeding guidelines for HIV-positive women are confronted with even in contexts where efforts are made to adjust them to local settings.

8. Discussions

The first section (8.1) of this chapter briefly describes methodological reflections for the study. The second section (8.2) of this chapter will provide a discussion of the study findings and of the implications of these findings.

8.1 Methodological reflections

8.1.1 Study design: Qualitative triangulation

As described in the justification for the choice of study design, a qualitative approach was chosen due to the perceived complexity of the topic to be studied and the fundamental need to acquire contextually grounded knowledge. The sensitivity of the research topic that required substantial flexibility in approach added to the reasoning behind the choice of study design. A triangulation design was chosen due to the perceived shortcomings of any one of the qualitative methods on its own, and to enable the strengths of different methods to be drawn upon. A few comments on the experiences of each of the methods employed in the study are given below before more overarching reflections on the study as a whole are presented in the latter part of this section.

Participant observation

The choice of participant observation was made with the reasoning that to gain knowledge on a complex and sensitive topic informal long-term presence makes it easier to capture the ‘insider’ view. The opportunity participant observation provides to gain knowledge from observation, from narratives of personal experiences and from discussions and interviews with varying degrees of formality cannot be matched by any other method, which was also the experience in the present research endeavor. The researcher’s knowledge of the local language and culture as well as her former training and experience of this ‘data collection technique’ from her courses of sociology and public health and prior research experiences were extremely important in this case. Most of the comments in the present section pertain to the community-based fieldwork.

A main challenge was the well known dilemma linked to the balance between interviewing as well as participating and to still remaining detached or avoiding to 'go native'. This was particularly difficult due to the researchers' heritage as well as to her being female and a mother with a substantial engagement in the theme studied. However, the continuous need to record, write and reflect helped to retain the outsider's perspective and worked against 'going native'.

Another prime challenge for the researcher was found to be the ability to combine participation and note-taking. When, where and the amount of information to be noted down was a continuous dilemma. In fact, writing field notes was drudgery and required a tremendous amount of self-discipline to carry through in a thorough and systematic way. The process can be described as one of continuous trial and error.

A third major challenge linked to the fieldwork period was the degree to which this part of the study was unstructured. This rarely went as planned despite thorough preparation before going out into the field. The flexibility principle of qualitative methods was learned the hard way.

Another continuous challenge that emerged particularly during the phase of participant observation was deciding how the families could be recompensed for their time and the continuous meals offered to the researcher during the numerous follow-up visits. The challenge was to find appropriate compensation while avoiding this being misinterpreted as payment for research participation or for the breakfast, lunch or dinner offered. The researcher avoided giving money in cash, but small amounts of sugar, tea leaves, ripe bananas, small gifts for the babies etc. were taken on the visits.

As experienced in this study the main strength of participant observation was that it lay grounds for and facilitated the other parts of the data collection in particular ways. One aspect was that the community became used to the presence of the researcher. A second aspect was the manner in which the participatory research approach assisted the researcher in gaining comprehensive and complex knowledge of the experiences and practices related to infant feeding. The knowledge gained during the long-term stay thus eased the process of formulating culturally appropriate questions. This method was hence perceived as giving the researcher a unique opportunity to explore the study topic from the target population's point

of view, to learn the lay language employed to talk about the study topic, and to observe the practices within the context of people's daily lives. This knowledge assisted in identifying the motivations that underlie particular infant feeding choices and practices.

Individual interviews

The possibility of a more focused discussion using an interview guide and tape recording and transcribing the interviews gave the researcher an opportunity to thicken descriptions on experiences and perception related to the theme. One challenge experienced was that many informants were less willing to share information openly with the awareness of being tape recorded. Although they had agreed to the taping of the interview, the researcher nonetheless had to continuously weigh the advantages of tape recording against rich and open discussions, and often had to make some quick decisions on what to opt for. Sometimes it was even difficult to write during the interview, as the discussion required the full attention of the researcher. The content was then as carefully as possible written down afterwards in attempts to cover the main aspects dealt with in the interview. This was an extremely difficult and time-consuming process as many of the informants had a lot to talk about and the researcher would not stop until she felt that the discussion was relatively exhausted.

A particularly valuable aspect of this method was the manner in which it facilitated closeness and 'private' talks with the informants. The confidential nature of the research topic and the ways in which the informants lived with the fear of transmitting HIV to their children in contexts of non-disclosure meant that the individual interviews became an arena for voicing experiences, fear, worries and questions. This interview method thus became extremely rewarding albeit emotionally very taxing.

Focus group discussions

The ease with which one can gain knowledge through group discussions was drawn upon to provide feedback to the researcher on the early findings. The group interaction facilitated a discussion on the infant feeding decisions and choices. For groups to be well functioning and active, similarity in main characteristics is important. That was not always easy to achieve.

One example was the wish to stratify the groups of counsellors according to facilities and years of experience in counselling. This turned out to be impossible in practice for logistic reasons as it simply became difficult to find a suitable time for them to meet. The researcher therefore had to let the nurse-counsellors register in the groups according to each participant's convenient time. The overall experience is however that the group discussions added valuable information to the study and played a particularly important role in discussing, confirming, questioning major study findings.

8.1.2 The intervention study

The intervention study consisted of various parts including individual interviews, focus group discussions, intervention, training, evaluation. The choice of the intervention strategy presented a major dilemma. It was clear from the formative study findings that the infant feeding decision is a social rather than an individual decision. Yet, the study team agreed to work on an intervention (i.e. the development of the counselling tools) that targeted the individual mother's decision at the health facility. This decision was made since the pMTCT programme was already well established at KCMC, since a relatively high level of trust was enjoyed by the pMTCT nurse-counsellors, and since the government planned to scale up its pMTCT programme. Although the study team recognised that a health system approach may potentially have limited impact in a context where infant feeding decisions are customarily made at home, the formative research confirmed that ideas emanating from the healthcare system generally reach the larger population. Thus the idea of strengthening pMTCT counselling services was determined to be an appropriate focus.

The study team fully realised however that not all aspects of this multidimensional problem could be addressed through this intervention. The pMTCT programme was acknowledged as the major arena for information exchange related to infant feeding in the context of HIV counselling and testing. However, these counselling tools (job aids) would only make up one 'behaviour change communication tool'. Complementary behaviour change communication materials and other interventions would be needed to address factors external to mothers and counsellors such as the utilisation of mass media like radio, or home visits, follow-up support, programmes to promote male involvement, materials and messages directed to the family etc.

The scope of the intervention research and the evaluation research study may emerge as enormous, and indeed the overall design of the study, the training of the pMTCT counsellors prior to the start of evaluation research, the development of the interview guides, the daily discussions and reviews of data collection experiences with the interviewer (the research assistant), as well as feedback comments from the counsellors constituted a very laborious and time-consuming venture. It is however important to note that the researcher had a different role in the intervention/evaluation study than in the formative study in the sense of being more of a research supervisor. The fact that the interviewer had substantial experience with interviewing and community-based research at the time of the intervention/evaluation study also eased the process, and made it possible to foresee and discuss how potential challenges could be met.

A major challenge in the training of the counsellors was linked to time: the training was simply too condensed. In the evaluation of the intervention it was identified as leading to a fear of mothers' milk and an awkward emphasis on replacement feeding in the counselling sessions.

A serious limitation that arose from the intervention/evaluation study was that the physician and the counsellors who were recruiting study participants from comparison sites had to recruit them from their ongoing study, and thus had to recruit much older babies than those in the intervention group. This group therefore had to recall how they fed their infants, while the other group would present their current experiences. What was more, the fact that the mothers in the control group were recruited from within the project implied that it is likely that the selected mothers had a particularly positive relationship with the physician or counsellor.

In addition the timeframe for the research was short: a duration of only four months. Although the findings shed some light on the improvement in the knowledge and practices for both counsellors and mothers, many of the findings point to questionable aspects of the intervention.

Despite these limitations, the study has contributed to the start-up of a nationally approved way of approaching HIV and infant feeding in Tanzania and to international debates on the issue and has also enhanced knowledge of pMTCT in global health policy fora. The intervention study was, however, very time-consuming and resulted in a very complex overall study design.

Transcription and analysis

The study collected a vast amount of information that required considerable time to be properly collected, transcribe and analysed. The interviews and hand-written notes were compiled concurrently each day. Preliminary analysis took place continuously at the close of each interview. This job was indeed so substantial that it led to the researcher extending the time period for the PhD programme. It turned out to be impossible to transcribe all the collected material and the researcher had to be pragmatic during transcription. Some interviews were partially transcribed focusing merely on the parts that emerged as relevant for the study. Particularly the focus group discussions contained sections that did not seem relevant to the topic of interest and were not transcribed. This process of omitting parts of the taped material might however have left out pieces of information of potential importance for the study even though the researcher exercised the utmost care not to do so.

Analysis of the data was also extremely time-consuming as the entire data set was read and re-read over and over again before it was manually coded and categorised. Organising the large coded data-set into condensed and meaningful themes was an enormous process that took long time to complete.

The challenges learnt from analysing and making sense of / organising the first set of collected data (from the mothers and community informants) reported in Paper 1 caused the researcher to look for alternative ways of approaching the data analysis process in the second round of a data collection (from the nurse-counsellors). This time the researcher decided to use a qualitative software programme ('Open code') for sorting and classifying the material. However, the experience was still tedious and not as easy as envisaged. The difference experienced by using the computer program was that it was much easier to store the text files and to move back and forth between the files, hence gaining an overview of

how the data was organised and structured. A major challenge of the study was linked to maintaining focus, tolerance, perseverance and self-discipline in ensuring proper systematic analysis of the large amount of data.

Although some parts of the material would have deserved even more attention, it is the researcher's belief that the rigorous manner in which the material was reviewed, coded, synthesised, grouped and categorised under broader themes has ensured that the complexity and multi-faceted character of the study topic has emerged.

Summing up experiences with the study design

Despite the challenges encountered both during data collection and analysis, the overall experience of the methodological approach opted for in the study is very positive. The design facilitated a substantial enhancement of the understanding of the study phenomenon, and provided the researcher with a unique opportunity to gain a thorough understanding of the study topic that could hardly have been gained with a less complex study design. Staying in the area for a long period of time and having discussions with and observing a large number of individuals differently situated with regard to the study topic generated invaluable in-depth knowledge. A number of unexpected but relevant facts were learnt from the discussions and observations – themes that would not have emerged if the researcher had not been there with the mothers in their daily lives for an extended period of time. Indeed, during the period of fieldwork she realized that her prior knowledge on the study topic had been surprisingly limited and somewhat naive. New knowledge was gained through varied interaction with the study informants – knowledge that emerged as quite different from the researcher's earlier somewhat simplistic conceptions of breastfeeding and HIV.

8.1.3 Credibility of the study findings

In this study the credibility of the study findings is primarily linked to the manner in which the researcher sought to address the study topic by making sure that the multiple realities of those studied were captured. Major efforts were made to ensure a proper understanding and description of the informants' subjective realities. The closeness of the researcher to the informants and the long-term nature of the field periods eased this process. However, there is

no value-free or bias-free research, and awareness of interaction between the informants' perspectives and the researcher's pre-understanding is vital for any consideration of credibility. This knowledge is not least important in qualitative research in which the human being is the primary instrument for data collection and is used as a tool in the interpretation process (Bernard, 1995:145). The pre-understanding is not easy to make explicit and capture as it is commonly unconsciously adopted and taken for granted.

In this thesis the researcher was a woman, a mother, a nurse, and a person originating from the study area and the major ethnic group (Chagga) in the Moshi district where the study was conducted. One should hence ask how these 'statuses' may influence or bias the study results. On a general level the researcher experienced it as highly beneficial to be a researcher in an area where she knows the language, verbal and non-verbal gestures, local customs and norms. The researcher believes that her understanding of the local language and culture brought her closer to the informants and enabled her to easily pick up the meanings of informal comments or signs. Knowing how and when to approach different groups of people in this community surely increased acceptance, and the informants' level of trust and closeness. This fact was also revealed in the talks and introductions where they would use such words such as "huyu ni wakwetu" ("she belongs to our community").

The researcher was very much aware that the methods were dependent on interpersonal exchanges with informants and was very careful in her dress, language and expressed behaviour. Moreover she tried to set aside her own beliefs, perspectives and predispositions, and attempted to learn as much as possible. As in principle everything was a subject matter of inquiry, it also turned out that she learnt a lot, and substantial amounts of pre-knowledge had to be reconsidered.

Despite the fact that the researcher was born in the Moshi district, talked with them in both Chagga and Swahili, and dressed like any other woman in the community, she was still regarded as a visitor. Being introduced as a nurse and a researcher from Muhimbili University implies that you are treated as a somewhat more 'knowledgeable' person. People who teach at the university are believed to be particularly knowledgeable, and nurses are taken as role models and advisors on health issues. This 'distance' could be recognised from the informal greetings and common talks – "niko na mgeni wangu hapa" ("I'm with my

visitor here”). Being introduced to this community by a highly respected community leader might also have placed the researcher in a position of certain respect to most village women. She became aware that some informants would at times behave in ways considered to be suitable for a person positioned differently in the hierarchy – for example they would express views that were consistent with the general social standards, and would try not to present them negatively to disassociate themselves from them. As a researcher she was aware that a social desirability bias might lead informants to self-censor their actual views, especially when they were in a group setting.

The researcher would particularly sense this special treatment during the first days of home visits. She would observe the unusual cleanliness of the house and home environment. Some mothers would rush to borrow a chair from a neighbour for her to sit on if there were no chairs in the home, and sometimes the mother would try to clean it using her own ‘khangas’ (a local piece of cloth worn by women) or with her hands. But as the visits continued these special efforts became fewer, and gradually they let me use the local low wooden chairs known as ‘vigoda’.

To counteract some of these challenges, the researcher spent around eleven months in the community for fieldwork, dressing locally, attending usual women’s activities and participating in the daily chores and familiarisation process and maintaining a relaxed relationship with the people in their homes before conducting interviews and group discussions. As Dahlgren and colleagues said, “The longer time the researcher spends in the field, the greater the likelihood that the researcher will grasp the reality of those studied, because it will allow the researcher to build trust with the study participants” (Dahlgren et al., 2004:48).

During the interviews the researcher was actively probing to counter-check the responses and to ‘validate’ findings from the informal talks. She employed a mixture of indirect questions to compare with the responses given to the direct questions – for example by asking questions like ‘*What would a woman like you do?*’ cross-checking with the responses to ‘*What would you do?*’ Although surely losing many chances of interesting probing, the research was guided by an open mind that tried to keep various possibilities open. Continuous modification of the interview guides enhanced the relevance and hence the

credibility of the findings. The data for the thesis were collected from different individuals and categories of individuals from within the same community. The flexible nature of the approach facilitated inquiries about the same issue from the various categories of informants in the same as well as in different study settings and allowed a deep exploration of the study topic, hence strengthening the credibility and truth value of the findings. The in-depth expressions and the emotions attached to the daily experiences and challenges facing both mothers and counsellors in relation to the topic moreover made it possible to get a sense of the women's main concerns.

Different strategies were used in the research process to help the researcher evaluate her own role including receiving inputs and critical comments from different people outside the research process. There were several rounds of discussing the study protocol between the researcher and her supervisors. The study protocol was presented twice at the University of Bergen to colleagues and academic staff members. It was also discussed with academic members of the Kilimanjaro Christian Medical (KCM) University before the actual fieldwork. This provided substantial inputs that were used in refining the research design and process.

The continuous discussion of the field experiences and findings with stakeholders both at the local and national level helped in the interpretation of the findings. Moreover, the involvement of different stakeholders at different levels in the decision making and the development of the counselling tools substantially improved the study process. The continuous discussions of the fieldwork experiences with academic staff at Muhimbili University also produced substantial feedback and contributed greatly. Furthermore, various presentations and discussions of the study findings at different national and international conferences such as the Tanzania AIDS Conference in Arusha (2004), the International AIDS Conference in Bangkok (2004) and Canada (2006), the International Students Conference in Oslo (2004), the International Congress of Midwives in Australia (2005), the World Alliance for Breastfeeding Action (WABA) Conference in Toronto (2006), a panel discussion at the Global Health Conference (2006) and at the WHO meetings in Geneva (2004) provided feedback that was incorporated into the final writing of the findings of this thesis. The presentation of the preliminary study findings towards the end of the fieldwork period to the stakeholders at different levels – including stakeholders at KCMC, Muhimbili

University and the officials responsible for ‘Programme and policy planning for infant and young child nutrition’ in the Ministry of Health Tanzania – provided the opportunity to gain early reactions and interpretations of the findings of this thesis.

The applicability/transferability of the study findings

Albeit fairly high levels of education, Kilimanjaro cannot be said to be a highly untypical research setting in a low-income country. The contextual information provided in this thesis will moreover further allow readers to judge the extent to which the study findings are applicable to other contexts.

As for any qualitative research study, the number of participants in this study is too small to be representative of the population and cannot therefore be subjected to statistical analysis to estimate how opinions expressed by informants reflect the opinions of the general population. The mothers were recruited purposefully from those attending the antenatal clinic, and only those who were willing participated. They were not selected randomly. However, the high coverage (94%) of first-time antenatal clinic attendance in Tanzania (TDHS, 2004-5) implies that sampling through the antenatal clinic can give a fairly representative sample of pregnant women. All those consulted consented to participate, indicating that the views reflected among the study participants might be similar to those of other pregnant women in this population. Although in principle the researcher of this thesis cannot draw any conclusions about the prevalence of specific concerns, attitudes or beliefs among the target audience, the qualitative triangulation design with its long-term checking and cross-checking of findings (validation) produces a strong in-depth knowledge base of issues that have been explored qualitatively/in-depth in the present study.

Dependability/Consistency

The extent to which the results are likely to be repeated if the study was to be replicated is reflected in all the papers. The researcher in this study made great efforts to give a detailed description of the methodological process that was followed when conducting the study. Detailed field notes, field tapes, transcripts, notes on the preliminary and later analyses have been kept throughout the research process. Memos of general views and impressions including detailed daily notes entries based on observations, discussions and interviews were moreover recorded and used during analysis.

Confirmability/neutrality

The details relating to confirmability/neutrality are reflected in the credibility of the findings above. However, in addition the researcher tried to limit established assumptions as much as possible during the design stage, when collecting data, and when analysing data and reporting. By observing people in their everyday lives, listening to them talk about what is on their minds and questioning the meaning behind their talk, the researcher obtained first-hand knowledge of the social life pertaining to infant feeding in the era of HIV.

Moral challenges

The nature of the study was very challenging also for the researcher. Some stories were so intolerable that the researcher cried together with the informants during interviews. The physical and health conditions of some informants were at times very poor, and made her constantly wonder whether it was morally right to collect data from these women without having anything to offer in return. The stories of the study participants, the references to their own approaching deaths, talks of no hope, of the miseries of their HIV-infected babies, of children with dying parents, of being stigmatised by the community members because of a shameful disease etc. characterised the talks with the women. The mothers had innumerable sensitive and appropriate questions that the researcher had to answer genuinely even when she knew the answers would increase the emotional pain. She was disappointed with herself because of her inability to provide any immediate help for the mothers' survival. She remained open, and explained to every informant that she was assessing the situation in connection with her study, but would share their experiences within various kinds of meetings for potential impact on future relevant programmes. She explained that their views would be used in the development of the counselling tools that would help mothers improve their knowledge and skill in feeding the babies in a safer way. But the researcher's major emphasis was that she was not in a position to provide them with an immediate solution to their many challenges. As a researcher, she was acutely aware of the fact that she was supposed to separate her own feelings from those of the study participants, but this was surely easier in theory than in practice. She remained with the recognition that the discussions at least were a way of giving voice to HIV-positive mothers and nurse-counsellors, a category of uncommonly hard pressed women who are rarely heard in the global health discourse.

8.2 Discussion of main findings

A more detailed discussion of the findings related to the specific study objectives is found in the individual papers. The discussion in this section will focus on the issue of choice which is an issue that cuts across the four sub-studies making up this thesis. The following discussion seeks to illuminate two questions: Firstly, how can we understand choice of infant feeding method among HIV-positive mothers? Secondly, how can counselling improve HIV-positive women's possibilities to make an appropriate choice of infant feeding method? The first question involves a discussion of the meanings attached to breastfeeding in the context of HIV and of power and control over infant feeding on the family and community level. The second question will be illuminated through a discussion of the problems involved in infant feeding counselling, the intervention to strengthen infant feeding counselling and the local relevance of the global infant feeding guidelines including the concept of informed choice.

8.2.1 Understanding choice of infant feeding method

The issue of choice is located in the very core of the infant feeding in pMTCT, but as demonstrated in the papers making up this thesis, choice of infant feeding method in pMTCT is no simple matter. In the present study most of the study participants ended up breastfeeding irrespective of counselling advice (paper IV). Considering the fact that both ordinary community members and nurse counsellors had a tendency to overestimate the risk of HIV transmission through breastfeeding (paper III), and that counsellors in fact did tend to advise HIV-positive women to replacement feed (paper IV), this finding is very interesting. Why did the vast majority of the HIV-positive women end up breastfeeding despite counsellors' advice and common knowledge of the risk of HIV transmission through breastfeeding?

To understand choice as well as mothers' experiences implementing their choice we need to understand what is at stake. We also need to understand what social relationships that surround infant feeding and the control structures or mechanisms that women are subjected to during the period of infant feeding. In other words, following Schepher-Hughes and Lock's conceptual framework of the three bodies, we need to understand individual

women's concerns and experiences and the social meanings that shape these experiences and that are attached to infant feeding in general and breastfeeding in particular. Furthermore we need to understand how society exerts control over infant feeding on family and community level as well as on the health care level through infant feeding counselling in the pMTCT programme.

The meanings attached to breastfeeding

In the following section we will discuss choice of infant feeding method in view of local interpretation of the medical risk of infecting the baby through breastfeeding on the one hand and the social risk of being judged as a bad mother on the other. These concerns are based in two different knowledge systems with different representations of the childbearing body and with different mechanisms of power and control attached to them. How the two concerns articulate in individual cases is important for infant feeding choice and practice.

The risk rationality in the local context

The international guidelines on HIV and infant feeding are based on medical evidence of the risk of HIV transmission from mother to child through breastfeeding. The suggested safer infant feeding methods recommended to the HIV-positive mother aim to reduce the risk of MTCT and secure an HIV-negative baby. Hence, the pMTCT programme is based in a risk rationality that links the health behaviour of the individual mother to the concrete health outcome of the baby. As long as the mother is the only one who by taking certain precautions may be able to influence the health status of the baby, she is the one who is held responsible also for a bad outcome. Risk in postnatal MTCT has primarily been linked to the risks of breastfeeding while the risks of not breastfeeding (which, as a number of studies have shown, involves a greater risk to child survival than being breastfed by an HIV-positive mother) have not attained the same attention (paper II and IV).

This risk rationality has been spread in HIV campaigns run through health care channels including the pMTCT programmes and mass media. In the Kilimanjaro region the awareness of the risk of HIV transmission through breastfeeding is widespread in the population at

large, also in peripheral rural areas (paper III). The radio in particular has been effective in disseminating HIV information and with the high radio density in the Kilimanjaro region; many people otherwise missed in information campaigns are reached, including women farmers in rural areas. However, the information disseminated through mass media is sometimes rudimentary and the actual risk of infection (about 30%) often not properly explained. The ordinary man and woman are often left with an impression of a one to one relationship between exposure and infection. Furthermore the medical knowledge of the risk of HIV transmission is interpreted locally on the basis of local epistemologies / knowledge of the body. In the Kilimanjaro region, it is commonly believed that mother and child share blood during pregnancy and that mother's milk is produced directly from mother's blood (see e.g. Moland 2004). Hence, the child of an HIV-positive woman can hardly avoid getting infected through pregnancy, birth and through breastfeeding. On the basis of this understanding, a common concept has developed that an HIV-positive mother should not breastfeed because she will infect her child (paper III). In addition to this perception which greatly exaggerates the risk of MTCT, the various ways of modifying the risk of HIV transmission for instance through avoidance of mixed feeding, early and rapid cessation of breastfeeding and through breast care and proper positioning during breastfeeding, are not commonly known.

Although the risk rationality underlying the pMTCT concept is a very powerful one which fundamentally questions the safety of breastfeeding in terms of HIV infection pulling towards replacement feeding, it is not the only concern of importance in the decision-making process. On the contrary, it is the competing concerns represented by the local ideology on motherhood that produces the infant feeding dilemma for the individual mother.

Motherhood concerns

There is a common concept in the Kilimanjaro region that an infant will not survive without being breastfed. Breastfeeding is seen as vital to child survival. This is an experience which has long historical roots. The most important role of a woman is to nurture her offspring. The mother is responsible to make the child grow. Failure to thrive raises questions about infant feeding and the mother's ability to care for the child. Hence, breastfeeding is located at the very centre of motherhood. A very telling quote in this context is: "A good mother is a mother who breastfeeds her child" (paper 1). In the Kilimanjaro region breastfeeding has a

strong hold and is the only acceptable way of feeding a new-born baby. In their study of child malnutrition in Kilimanjaro, Howard and Millard describe the failure of a mother to breastfeed as 'a significant failure' (Howard and Millard 1997), pointing to the substantial failure to live up to practices deeply embedded in a culturally constituted moral universe.

There is no doubt that breastfeeding is seen as a condition for child survival, and hence, it is seen as the duty of the mother to breastfeed her child. In the patrilineal kinship system of the Chagga, the child belongs to the patriclan and the duty to breastfeed must be understood as a duty not only to the child, but also to the clan. Howard and Millard claim that denying breast milk to the baby is seen as an evil act and met with sanctions. Failure to breastfeed and secure the health of the new born member of the clan and hence, failure to be a good mother may be met with withdrawal of the rights and the privileges normally given to the mother by the in-laws during the confinement period (*as reported in paper I and III*). Non-breastfeeding mothers were in the present study described as irresponsible, and were not considered deserving of the customary privileges of a new mother. To abstain from breastfeeding and feed the child only cow's milk or infant formula in early infancy, thus implied going against the rules of good motherhood.

The concept of breastfeeding as a mother's duty is not unique to this region. According to traditional Christian thought, a woman's sacred duty is to breastfeed her child and this duty should take precedence over all other obligations (Baumslag and Michels 1995). The strong influence of Christianity through missionaries in the Kilimanjaro region in the 19th and 20th century (see e.g. Setel 1999) may further have strengthened the view of breastfeeding as fundamental to motherhood (Moland 2004).

Local control and surveillance

Fear of disclosure and the problem of adherence to one feeding method

In the Kilimanjaro region and especially among the Chagga, how the mother feeds the baby is subjected to close social scrutiny and surveillance (see also Moland 2004). A key finding that runs through all four papers is that the recommended methods, be it exclusive breastfeeding or exclusive replacement feeding (infant formula or animal milk), are hard to live by in the every day life of women in the Kilimanjaro region. While adherence to

exclusive replacement feeding was experienced as critically dependent on the woman's disclosure of HIV status to partner and to her economic independence (paper 1), failure to exclusively replacement feed was related to economic constraints, social pressure to breastfeed, own feeling of guilt for not breastfeeding and fear of HIV disclosure. As demonstrated in paper one, women who chose replacement feeding often went to a lot of trouble hiding their feeding method and they commonly excused themselves saying that they had too little milk so they breastfed at night only. Similar findings were documented in a study in South Africa where Doherty and colleagues (2006) reported that fear of disclosure of HIV status and stigma had weakened the ability of mothers to resist family and community norms that question not breastfeeding. The effect of fear of stigma is also described in a number of other studies (Thairu et al., 2005, Pool et al., 2001; Kilewo et al., 2001; Gaillard et al., 2000).

In the wake of the HIV epidemic and the knowledge about the risk of HIV transmission through breastfeeding, women who do not breastfeed their infants may be suspected of HIV-positive status. But although exclusive breastfeeding obviously was a much more socially acceptable choice in the Kilimanjaro region, where breastfeeding is normative, the demands not to give supplements of any kind including water during the entire breastfeeding period involved going against what was considered normal infant feeding behaviour and could cause conflicts and suspicion. Likewise, early and rapid cessation of breastfeeding at four to six months was perceived as unacceptable and gave rise to suspicion of adultery or of an undue preoccupation with the shape of the body.

The social relationships surrounding infant feeding

Whether a mother was able to adhere to her choice of infant feeding method or not basically depended upon the individual mother's control over the feeding situation and hence; in other words, to her decision making power. Breastfeeding in the Kilimanjaro region as discussed above is intimately associated with ideas about fertility and procreation, and as such concerns not only the mother and her infant, but also her kin, in particular her affinal kin (Moland 2004). In addition to putting the life of the child at risk and violating the rules of good motherhood, not breastfeeding an infant is thus interpreted as an act of disrespect to the lineage and to the mother-in-law.

The social relations surrounding infant feeding are therefore of utmost importance for the mother's initial choice and her possibilities to adhere to that choice. Although a woman makes a decision on how to feed her infant during or after counselling, she may not be able to execute that decision in practice because her mother or mother-in-law wishes it otherwise. In traditional households with an extended family structure still common in rural areas, women often have limited control over the feeding situation. Although it varies between the different ethnic and socio-economic groups in the region, women commonly stay with their mothers in law or with their mothers during the period of confinement when breastfeeding is established. As grandmothers, the elder women have an important role to play in this process securing the survival of their grandchild. This involves both cooking nutritious and rich food for the mother and advising and assisting her with infant feeding and child care. The grandmother is often the one who insists on giving the child certain customary foods and drinks which may compromise adherence to exclusive breastfeeding. The role of mother-in-law as a complicating factor to achieving safer infant feeding through exclusive breastfeeding and early cessation has also been reported in a study in Abidjan, Cote d'Ivoire, where HIV-positive women who failed to cease breastfeeding early or before introducing supplements reported to be under social pressure from their mothers-in-law (Becquet et al. 2005) .

The traditional way of organising confinement is often not strictly adhered to in more urban and modern contexts where the mother may be able to attain a higher level of control over infant feeding whether she chooses exclusive breastfeeding or exclusive replacement feeding. Furthermore, not surprisingly women in paid jobs who can afford to pay for instance infant formula themselves gains control over choice and adherence to choice in a different manner than women who have to depend on uncertain support from partner or other.

What is at stake?

Hence, the observation that the majority of the study participants ended up breastfeeding cannot be understood primarily as lack of knowledge of the risk of HIV transmission involved in breastfeeding. Neither can it be understood merely on the basis of alternative

feeding options being too costly and technically complicated. Rather, it is linked to a series of other concerns.

Infant feeding is imbued with meaning beyond the purely nutritional aspects and the physical feeding of a baby. This study strongly demonstrates the power of breastfeeding as a culturally anchored practice that is vital to child survival and hence, as a moral commitment on the part of the mother. As such infant feeding is monitored and controlled by others, primarily kin who have an interest in the survival of the baby. In Kilimanjaro this control is primarily vested in the role of mother in law during the postnatal phase when breastfeeding is established. No doubt, the social relations surrounding infant feeding are of utmost importance for the HIV-positive mother's initial choice and her potential to adhere to that choice. But, as the findings clearly show, HIV-positive women in the present pMTCT programme generally did not make a choice of infant feeding in collaboration with close kin. Rather choice of feeding method seemed to evolve as a product of a series of concerns related to being considered as a good mother, to avoid HIV disclosure and subsequent stigmatization and ostracism by family members and neighbours.

In an HIV context not breastfeeding tend to fuel local diagnostic processes where kin and neighbours may stamp women as HIV-positive (see also Moland 2004). For HIV-positive mothers the risk of being involuntarily disclosed through not breastfeeding was experienced as a threat not only to the privileges of confinement, but as a threat to the marriage and to social life in the local community. Hence, in addition to pressing concerns about the survival of the baby, the HIV-positive mother found her social survival at stake.

In view of the risk of HIV infection on the one hand and social expectations to breastfeed and the perceived social implications of not breastfeeding on the other, the experience of internal conflicts connected to choice of infant feeding method was common-place among the HIV-positive women in the present study. The expressions of HIV-positive mothers across all papers demonstrated a feeling of insecurity and fear of disclosure of HIV status whether choosing exclusive breastfeeding with early cessation or replacement feeding. Infant feeding counselling did not always seem to make the choice any easier for the individual woman.

8.2.2 Infant feeding counselling and the implementation of AFASS and informed choice

A major concern expressed in the international guidelines on HIV and infant feeding (WHO, 2001) is that the HIV-positive mother should be enabled to make an informed choice of infant feeding method. The choice should be done in consideration of the risks and benefits of each feeding method and the AFASS criteria which seek to establish the acceptability, feasibility, affordability, sustainability and safety of the feeding methods, given the particular life situation of the individual mother. If a method that is not culturally acceptable, or affordable or feasible is chosen, adherence to that method will become difficult. Hence, in addition to information about the risks and benefits of each of the recommended feeding methods, consideration of AFASS is fundamental in reaching an informed choice. The AFASS conditions will vary between individuals, but also between populations living in different socio-economic and cultural contexts. This will obviously have an impact on what choices are available to the individual mother and possible to live by (see paper 1). Furthermore counselling may not always be experienced as empowering (see paper IV).

Counsellors' influence over choice

PMTCT counselling involves the exchange of information between the HIV-positive mother and her counsellor. Considering the social and cultural inequalities between the trained nurse-counsellor and the HIV-positive often poor and uneducated mother, the counsellor may be expected to exert considerable power over infant feeding decisions. The data presented here indeed confirm that the nurse counsellors do have considerable influence over the intention to practice the one method or the other (see paper I, II and IV). But infant feeding is practiced at home and, as has been shown across all papers as well as in the discussion above, it is the social situation and the social relationships at home that seem to be critical for adherence to the infant feeding choice made and hence to the success of the prevention efforts. Even so there is little doubt that the impact of the pMTCT programme in shaping women's concerns related to choice of infant feeding method is substantial. Therefore it is essential that the counsellors are well informed not only about pMTCT, but also about the conditions provided by the social and cultural context of the programme.

Professional knowledge and confidence

However it was clearly documented across all four papers that the knowledge of the counsellors could be strengthened. In fact, the findings of this thesis revealed that it is not only the HIV-positive mothers that felt uncertain about how to feed their infants (*paper I*). To a surprisingly large extent, the counsellors shared this uncertainty (*paper II*) and their recommendations are not always experienced as relevant (*paper I and IV*).

Counselling is a highly complex relational process which requires both knowledge and professional confidence and skills on the part of the counsellor, as well as trust on the part of the client. It requires a very different approach to patient interaction from traditional nursing. Skills in infant feeding counselling are not yet covered in the nursing curriculum, and the nurses do not feel that they have sufficient competence in their new roles as counsellors (*paper II*).

A basic condition for successful pMTCT counselling is that the counsellor not only has confidence in her own professional knowledge, but also in the relevance and applicability of this knowledge for the individual woman in her particular situation. The findings in this study show that the nurse-counsellors do not have this kind of confidence. They did not feel well enough informed or skilled about MTCT to be able to present the message well enough to enable mothers to make an informed choice. In fact as pointed out in paper II, the counsellors did not really know how big the risk of MTCT was, but as the general population, they had a tendency to overestimate it and hence, were reluctant to recommend exclusive breastfeeding to HIV-positive women. Conversely, very little attention was paid to the risks involved in not breastfeeding or in replacement feeding. In this respect the general understanding of the risk of MTCT in the general population seemed to some extent to mirror the understanding of the counsellors, or the other way around. As nurses and midwives are part of the community in which they live, and share a number of features with other community members they are subject to the same norms, values and social pressures, and their risk perception may be as influenced by local ideas as by medical facts (Grinstead and van der Straten 2000). What appears as even more serious however, is that the nurses in the study simply did not believe that any of the alternative infant feeding methods they were proposing to the mothers – including exclusive breastfeeding, cow's milk feeding or formula feeding – were acceptable or feasible in the social and cultural context of the Kilimanjaro

region. Wet-nursing emerged as so farfetched in the present context that they were not introduced as options for the mothers to consider. The nurse-counsellors did not believe that most of the mothers would be able to adhere to either exclusive breast feeding, formula feeding or other replacement feeding, as these methods violated cultural norms or were too impractical. Consequently the nurses did not believe in the very health-promoting concept they were set to work with.

An assessment of the AFASS criteria may be a challenging exercise, but is undoubtedly fundamental to infant feeding counselling. Without a proper AFASS assessment, counsellors may as we have seen in paper II and IV, end up guiding women according to their own preferences and beliefs rather than according to the individual woman's possibilities to succeed exclusively replacement feeding or exclusively breastfeeding.

The high level of uncertainty experienced both on the part of the mothers and the counsellors was closely associated with a lack of attention to the AFASS criteria. The counsellors tended to believe that the best way for an HIV-positive mother to feed her baby was replacement feeding. They therefore forwarded exclusive replacement feeding as the first choice to all irrespective of the AFASS conditions. But, as the findings of this thesis indicate (paper I and IV), most women did not adhere to the advice of the counsellors.

The HIV epidemic has brought about major transitions in terms of nurses' assignments, not least manifested in the major shift in the nursing role from health educators to counsellors. As discussed in paper II, nurse- counsellors commonly experience that their roles as educated individuals with particular trusted skills and knowledge have become threatened by their newly gained roles as counsellors operating within an atmosphere of patient self-determination and health-related decisions resting with the patient. Both nurses and clients expressed that the counselling role leaves nurses with a diffuse guiding role which in fact works to undermine the trust that they used to enjoy.

All in all, the role performance of the counsellors was for a number of reasons (associated with time, overwork and inadequate access to updated knowledge) rather weak. Their capacity to convey research based knowledge to the mothers, and hence impact on their possibilities to make an informed choice of infant feeding method had a considerable potential for improvement.

8.2.3 The counselling tools

The development process

Two major problems were identified during the formative research. Firstly it was observed that in general HIV-positive mothers for various reasons did not manage to adhere to the infant feeding recommendations issued during counselling, and ended up mixed feeding. The second important observation was the great uncertainty about infant feeding and HIV transmission and the local relevance of the recommended feeding methods among nurse-counsellors in the study area. On the basis of the formative research it was quite clear that informed choice was not achieved in the pMTCT programme at KCMC at the time of research. It was also quite clear that the reason for this failure was not either economic, social and cultural issues, or issues related to the health systems and the counselling services offered. Rather the formative research strongly demonstrated the complexity of the issue of HIV and infant feeding choice. However, the weakness of the counselling services provided was by KCMC Hospital including the pMTCT programme and the involved counsellors, considered an appropriate entry point to address some of the challenges identified. Considering the experience that some of the methods suggested in the international guidelines were culturally inappropriate and that the counsellors requested reference material that would guide them during the counselling and help them standardise the information given to each woman, the development of culturally appropriate counselling material was chosen as a strategy to strengthen women's possibilities to make an informed choice.

The intervention was made possible through collaboration with Quality Assurance Project (QAP), a USAID centrally funded project managed by University Research Co., LLC which assisted in developing the counselling tools (the so-called 'job aids'). The intervention represented an effort to translate the international guidelines on HIV and infant feeding to the local social and cultural context. It selected the methods of infant feeding that were reported as socially and culturally acceptable (exclusive breastfeeding, formula feeding and cows milk feeding) in the context of the Kilimanjaro region and omitted the methods that were perceived locally as unacceptable (wet-nursing and expressed and heat treated breast-milk).

The study recognised the importance of self-efficacy for behavioural change. Hence, the material developed sought to influence the self-efficacy of the mothers through a combination of verbal information and demonstration during counselling and illustrative images and text in the local language to take home. The messages conveyed in the brochures were based on the international infant feeding guidelines on the one hand and the local barriers and facilitators to their use identified in the formative research preceding the intervention. A careful balance between local acceptability and global standards was sought in the development of the material.

With the set of counselling tools produced including the three infant feeding brochures, the question and answer guide, the risk chart and the demonstration toolbox (see paper III), it was assumed that the counsellors would guide the HIV-positive women through a series of steps, giving them personalised information (Kim et al, 2005; O'Connor, 2001), and clarification of the risk related to the infant feeding options.

The impact

However, in the evaluation study which compared an intervention group of mothers who had been counselled using the developed counselling tools and the comparison group, it was revealed that counselling on the dangers associated with mixed feeding was largely lacking. This is rather alarming considering the strong evidence of the increased risk of HIV transmission involved in combining breastfeeding with other fluids and solids (Coovadia et al., 2007; Iliff et al., 2005; Coutsooudis et al., 2001), which is customarily practiced in the Kilimanjaro region (de Paoli et al., 2001). Furthermore, the AFASS conditions were poorly or not at all assessed.

A major counselling dilemma as documented in this study is that most counsellors believed that formula feeding was the 'right way' for an HIV-positive woman to feed her infant (paper II). This perception was addressed during the training course for counsellors as well as in the package of counselling tools which promoted exclusive breastfeeding as safe way to feed an infant if practiced exclusively, and exclusive replacement feeding only if AFASS. Nevertheless, women who obviously did not satisfy the AFASS criteria claimed to have

been counselled to replacement feed. Hence, reflecting the attitudes of the counsellors, replacement feeding was found to be favoured more by mothers in the intervention group than in the comparison group.

The replacement feeding bias among the counsellors that participated in the intervention seriously questions the intervention methodology. Rather than increasing the counsellor's ability to counsel women to safely implement exclusive breastfeeding or exclusive formula feeding, the intervention seemed to strengthen the counsellors' beliefs that breastfeeding is risky and should be avoided. This indicates that the counsellors had a higher degree of awareness about the HIV transmission risk than about infant survival chances linked to the nutritional and immunological assets of breastfeeding and the risks associated with replacement feeding. Whether this is linked to fear of accountability for later HIV status of the child measured at 1 and a half years is only a matter of speculation. However, it is rather interesting that in her pMTCT study from the same area in 2001, Marina de Paoli found that counsellors at KCMC generally thought that exclusive breastfeeding was the only feasible option for HIV-positive mothers in the Kilimanjaro region (de Paoli et al. 2001). Meanwhile their exposure to the messages of infant feeding promoted in the international guidelines and disseminated through various channels including health care and mass-media, may gradually have changed their attitude towards replacement feeding as the only safe food for infants born to HIV-positive mothers. The training connected to the intervention in the present study seems to have reinforced this idea. After being trained in infant feeding counselling during the present study the counsellors may have felt prepared and motivated to promote replacement feeding because they now had tools, including counselling job aids, mothers' take-home materials, and the demonstration box of replacement feeding utensils. Alternatively, the counsellors did not believe that women could adhere to exclusive breastfeeding and that mixed feeding would be the inevitable outcome. The counsellors in the comparison group by contrast had not been trained for the intervention, and were probably less confident about promoting replacement feeding.

Hence, it seems that increased exposure to the infant feeding guidelines has created more uncertainty about breastfeeding and has increased confusion and uncertainty among counsellors which is in turn transferred to the mothers. This is not to say, of course, that the goal of the intervention was bad. Rather it is an indication that the training methods employed were not good enough. In connection with the intervention being scaled up to the

national level in Tanzania, it has been subjected to major revisions where particular tools to assess AFASS have been developed and training in the use of the counselling tools has been extended from one to five days.

Limitations

According to Bandura, knowledge of health risks and benefits provides the preconditions for change, but knowledge in itself is not sufficient to overcome the impediments to adapting and maintaining new behaviour / practices. If people do not believe that they have the power to change the outcome of a particular issue, their motivation to persevere when they encounter problems (including the social costs involved), will be negatively affected (Bandura, 1986).

To what extent the present intervention strengthened self-efficacy is not completely clear, but it was confirmed that some mothers managed to use the take-home material as references for themselves and for their kin (mostly husbands) in a way that was empowering. There is no doubt however that these women were also the ones with the highest degree of economic independence. All in all the job aids as an intervention strategy to strengthen infant feeding among HIV-positive mothers tried to address a very complex phenomenon with a rather limited “knowledge approach” to empowerment. Although increasing the level of knowledge, skills and confidence of the HIV-positive mothers as well as of the counsellors is a necessary condition for the achievement of better infant feeding practices, it is not a sufficient condition for change in as much as it does not address the social environment of choice. Hence it does not address the fundamental issues connected to the acceptability and feasibility of the infant feeding methods in the local community. As has been shown in the discussion above as well as in the papers, it is these conditions combined with the knowledge of risk that produce the infant feeding dilemma for the individual HIV-positive mother.

8.2.4 Global guidelines and local relevance

This study recognizes that infant feeding norms and practices are produced and reproduced or transformed in the encounter between local ideas and customs on the one hand and forces emanating from the larger national and international community on the other. A basic

understanding underlying this study is that reality, or the perception and knowledge of the reality is not an objective given, but is constructed in specific historical, social and cultural contexts. Furthermore, action and choice cannot be understood without an appreciation of this fact. The international infant feeding guidelines are based in a construction of reality which emphasises biomedical evidence of the risk of HIV transmission through breastfeeding. Other concerns related to breastfeeding are not fully integrated although the AFASS criteria certainly represent an attempt to do so. The present study clearly shows that the guidelines on infant feeding conflict with local knowledge and reality constructions. For an intervention to succeed it is of utmost importance that the intervention is designed in such a way that it is experienced as relevant for the targeted populations and the reality in which they live their lives.

Some ethnographic studies have argued that scientific claims about the benefits of safer feeding methods for babies lack local credibility because they conflict with local understandings of the best strategies to enhance child growth and survival (Davies-Adetugbo, 1997; Mabilla, 1996). The findings of this thesis very much strengthen this argument and support suggestions that strategies to increase safer infant feeding practices among HIV-positive women should be culturally relevant (Kuhn et al. 2004). However, the issue of cultural relevance in some cases stand in opposition to the basic requirement of informed choice and each individual's right to knowledge.

Informed choice

Not only in the study area, but to most women in sub-Saharan Africa, breastfeeding is the only way to feed an infant. PMTCT introduces alternative infant feeding methods and hence, subjects infant feeding to choice. PMTCT programmes with infant feeding counselling based on the international guidelines introduces alternatives to breastfeeding. But, to what extent do women in Kilimanjaro have a choice of infant feeding method? To what extent do the recommended feeding options create an illusion of choice?

The problem of assessing AFASS and guiding an HIV-positive mother to choose between the recommended infant feeding options may be linked to more fundamental problems associated with the principle of 'informed choice'. The idea of informed choice in PMTCT is based on the assumption that the mother is capable of making an autonomous decision about how to feed her infant if she is provided with sufficient information. However, this

assumption fails to recognise the fact that a pregnant woman lives her life in the middle of many social relationships which influence the decisions that she makes and indeed limits the choices that are available to her. As the examples in this thesis illustrate, infant feeding is an issue that is subject to social pressure and control. Hence, in a context where information is scarce (paper I), where breastfeeding is normative, the economic status of families is commonly very marginal, and where choice of infant feeding method commonly does not rest with the mother alone, the concept of informed choice may not be of much use. In light of the fact that mortality is much higher for replacement- and mix fed infants than among exclusively breastfed infants, and also higher than the rate of HIV transmission in exclusively breastfed infants of HIV-positive mothers, it may be tempting to question the entire AFASS recommendation and hence, to dismiss the issue of informed choice in pMTCT and promote exclusive breastfeeding to all.

However, limited choice means limiting information which is a doubtful practice seen from a human rights perspective. Hence, even though the concept of informed choice does not articulate well with the local ways in which breastfeeding is understood and controlled, it can hardly be dismissed. But for counsellors the task of presenting information so that the mother can reach an informed decision, and adhere to it requires skills, time and dedicated supervision (Rollins et al. 2002).

9. Conclusions and Recommendations

This thesis has illuminated the complexity of HIV and infant feeding counselling and practices from both counsellors' and HIV-positive mothers' perspectives. It has investigated norms of infant feeding and the potential for improving them in relation to current infant feeding guidelines. It has generated socio-cultural knowledge regarding practices, beliefs and norms related to infant feeding that may promote or hinder the implementation of PMTCT efforts. The study provides insight into the ways in which HIV-positive mothers conceptualized infant feeding and their experiences in implementing them. The methodology used in the study provided an opportunity to observe women's responses to infant feeding recommendations under their daily life circumstances. Several misconceptions concerning recommended safer infant feeding methods were identified and need to be targeted.

The social cost of not breastfeeding, including isolation and other expressions of social stigma, remain a major concern and most women need substantial support in confronting challenges that are beyond their control. The findings suggest that infant feeding support that extends beyond the antenatal period is important to enable mothers to cope with new challenges and pressures during the postpartum period at home. Finding ways to support women to make appropriate infant feeding choices and to adhere to that choice should be a priority for future efforts to enhance infant feeding practices among HIV-positive mothers in Kilimanjaro region and in Tanzania as a whole. The study underscores the complexity of promoting recommended infant feeding practices and clearly indicates the need for a multi-dimensional behaviour change strategy involving both mothers and counsellors and if possible significant others who influence choice and decision-making processes.

The study raises some important themes and issues related to HIV and infant feeding of which researchers and practitioners might take note. The recommendations involve practical, research and policy implications as follows:

9.1 Recommendations for practice

Promotion of exclusive breastfeeding to all mothers in the community

It was evident from the study findings that prolonged mixed breastfeeding is a cultural norm and the acceptable way of feeding an infant in the Kilimanjaro region. It was also learnt that not breastfeeding could put at risk social relationships and the social evaluation of the woman as a mother. The solid position of breastfeeding as the only acceptable way to feed an infant in Kilimanjaro, combined with the recent results of Coovadia and colleagues (2007) which show that exclusive breastfeeding is as safe as replacement feeding in terms of HIV transmission (provided that it is practiced exclusively) pave the way for the promotion of exclusive breastfeeding to all mothers. The major recommendation springing out of the present work then is that infant feeding counselling should recommend exclusive breastfeeding as the first choice of infant feeding method also to HIV-positive mothers and that substantial efforts should be put into strengthening breastfeeding practices.

Limited resources and shortage of staff in health facilities (*as reported in paper II*) challenge the extension of the hospital-based initiatives into the community level. It has been documented that mothers face new pressures and challenges during critical times in the early post partum period and it is suggested that mothers need confidence, knowledge, and skills to overcome these challenges at this period (Doherty et al., 2006). All these evidences warrant collaborative community approaches and other interventions in promoting exclusive breastfeeding beyond health-based facilities. Community support can help to create a stronger sense of self-efficacy among HIV-positive mothers when implementing their infant feeding choices.

The establishment of the collaborative efforts to recruit mother-to-mother support groups and peer-counsellors at the community level in conjunction with the existing community-based support systems i.e. CBOs, for example, KIWAKUKKI in the Kilimanjaro region would be among the promotive extended strategies. This would facilitate home visits, and individualized follow-up infant feeding counselling in the communities regardless of HIV status, hence, increasing and enhancing exclusive breastfeeding in the communities. This might be more effective when combined with other on-going interventions like use of common mass media for example; radio to disseminate universal messages about safer infant

feeding practices and benefits of exclusive breastfeeding. Also design and dissemination of supportive messages directed to other influential family members such as husbands/partners and mothers' in-law might create more awareness of safer feeding practices, encourage disclosure of HIV status and more support to the mothers when feeding their babies, hence, reducing stigma and creating environment for safer feeding practices in the communities.

Strengthening counselling services

Nurse-counsellors are the most numerous group of health workers who advise HIV-positive mothers how to safely feed their babies at pMTCT programmes in Tanzania. Therefore, the success of pMTCT initiatives relies on the quality of services provided by these nurse-counsellors. However, they are faced with many challenges and limitations as reported (*in paper III and IV*) in this thesis, and several other reports elsewhere in sub-Saharan Africa. There is a need for intensive efforts to invest on nurse-counsellors to strengthen pMTCT counselling services.

Counsellors being in a key position to help mothers to decide and choose an infant feeding option suitable to their own situations, they need to have a deep understanding of the cultural and social issues and the home situations of the women they are counselling. They need to provide consistent, updated information, and reassure mothers of their abilities to feed their babies and to show them how to master the techniques. Counsellors should have the ability to share their knowledge in such a way that it becomes useful and accessible to mothers. Strategies to enhanced counsellors training and on-going support to change the reported shortcomings in counselling are required for them to guide the mothers' appropriately. Not only that, a need for continuing education, supportive supervision and refresher courses at the workplace would enhance professional development for nurse-counsellors but will also strengthen their knowledge, skills and attitudes. Enhanced infant feeding counselling postnatally that use motivational and empowerment strategies for both counsellors and mothers would assist in achieving safer infant feeding practices. Enhanced one-to-one counsellor-based support complemented with peer-support groups in the communities might improve infant feeding counselling services.

In addition to proper training and supportive supervision, counsellors will also require various counselling tools and algorithms that could provide some structure of the needed information and ways of assessing individual woman's situation. This will assure standardization of the information given as well as reminding the counsellor of the basics during counselling on infant feeding methods. The job aids we have developed through this study should continue being revised accordingly and scaled up as planned nationally.

Given the limitations for further training after basic education, and since, HIV and infant feeding is a neglected area in the basic training of nurses, a need for improving the basic education for nurses would be of up-most importance. This can be achieved by strategically include HIV and infant feeding guidelines in the pre-service nurse/midwifery curriculum to improve knowledge and skills of future nurse-counsellor.

9.2 Recommendations for future research

Several research questions have emerged from this present study which would benefit significantly from further investigation within the same community or in other communities with similar socio-cultural and economic characteristics. In order to ensure quality counselling, there is a need to investigate further into the factors which may facilitate informed choices of infant feeding method among HIV-positive women. Further exploration of factors influencing infant feeding decision-making, including identification of characteristics of women who have succeeded in maintaining exclusivity of their infant feeding options, and their environments that contribute to success may provide important inputs to improve pMTCT services. Moreover, there is a need to investigate if and how support, mentoring and transferring of practical skills on infant feeding can influence mothers' success in adhering to exclusive breastfeeding and early cessation of exclusive breastfeeding.

Given the findings of this thesis; that significant others are among the key determinants for successfully infant feeding decisions and implementations, exploration of their perceptions and attitudes about pMTCT in general and infant feeding methods in particular would be important. This should also include the identification of strategies to involve the family members in the efforts to reduce MTCT of HIV. Identification of factors that hinder

exclusive breastfeeding practices, including the exploration of factors that may enhance its feasibility in the communities for all mothers who breastfeed their babies, and determination of innovative approaches outside the formal health sector that can strengthen women's ability to choose and practice safer infant feeding methods in the communities would be of great benefit. Furthermore, determination of the effectiveness of the counselling tools and enhanced counselling in promoting safer infant feeding practices would be of significant value, given the current national pMTCT scaling-up and the reported limitations of the small study done under this thesis (*paper IV*).

9.3 Recommendations for policy measures

To ensure quality counselling on HIV and infant feeding, it is important that information updates including infant feeding guidelines reach the pMTCT counsellors, who have to put the HIV and infant feeding related knowledge into practice. However, the lack of awareness of the guidelines among counsellors raises a need for policy makers to pay more attention to how infant feeding policies/guidelines are disseminated and implemented. The findings that the nurse-counsellors in this study were not clear on how to assess individual woman's situation raise a major concern and indicates the need for a further specification on how AFASS can be assessed in particular contexts.

The researcher of this study has been sceptical throughout the study period about the wording of the international guidelines on HIV and infant feeding (WHO, 2001). The major concern was its ambiguity which favoured formula feeding when AFASS. It was obvious from the practical point of view that exclusive breastfeeding should be promoted as ideal for most babies given the cumulative and current evidence-based information that;

- i) There was no difference in HIV transmission whether a baby was formula fed or exclusively breastfed, and mothers can be supported to implement exclusive breastfeeding (Coovadia et al., 2007).
- ii) Babies given a mixed feeding were much more likely to become infected with HIV than those who were exclusively breastfed (Coovadia et al., 2007; Iliff et al., 2005; Coutsooudis et al., 2001)
- iii) Increased mortality and morbidity due to out-break of severe diarrhoea and malnutrition associated with formula feeding of babies versus breastfed babies in Botswana (Creek et al., 2006)
- iv) The experiences of irresistible pressures forcing HIV-positive mothers mixed feeding while replacement feeding their babies;

- v) Exclusive breastfeeding has a two-fold to four fold lower risk of HIV transmission than mixed feeding (Iloff et al., 2005)
- vi) Exclusive breastfeeding can be supported successfully in HIV-positive mothers (Coovadia et al., 2007)

Fortunately, during the process of finalizing this thesis, an update of the International infant Feeding Guidelines was made which to some extent restores breastfeeding as a safe infant feeding option also for HIV-positive women (see wording box 2 page 12) (WHO 2007). Nevertheless also the updated version continues to recommend the avoidance of all breastfeeding by HIV-positive women when replacement feeding is AFASS. This remaining ambiguity allows for different interpretations and leaves considerable loopholes for the promotion of formula feeding as a priority recommendation in cases of uncertain AFASS. Therefore, the researcher of this thesis recommends a further revision of the guidelines for a **clearer** emphasis on exclusive breastfeeding. The researcher also recommends that the policy guidelines should allow the principle of informed choice to be overlooked in situations where replacement feeding could be a deadly choice.

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PAPER I - IV

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Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania



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ABSTRACT

Infant feeding represents a great challenge in the prevention of mother-to-child transmission of HIV (pMTCT). The international guidelines informing infant feeding counselling suggest feeding methods that reduce the risk of HIV transmission, and discourage mixed feeding (combining breastfeeding with other fluids and solids). The feasibility and the social acceptability of the recommended feeding methods are hotly debated currently. Through the documentation of HIV-positive women's experiences, this article aims to provide empirically grounded knowledge on the relevance of the proposed feeding methods. Drawing upon cultural theory and a view of infant feeding practices as socially and culturally embedded, the article discusses the so-called 'informed choice' of infant feeding method among women enrolled in the pMTCT programme at Kilimanjaro Christian Medical Centre in northern Tanzania. The study is based on interviews and follow-up of 20 HIV-positive mothers during the last part of pregnancy, delivery and the first six months after birth. The article details four of these cases describing the challenges linked to exclusive breastfeeding, cow's milk feeding and formula feeding. The study demonstrates the gap between intentions and infant feeding practice in a context where the social expectations to breastfeed are high, and where kin and neighbours are part of the decision-making team surrounding infant feeding. It highlights the tension between the competing concerns of the medical and social risks involved in the choice of infant feeding method, and documents that the feeding options may be difficult to adhere to, whether a mother chooses exclusive breastfeeding or replacement feeding.

Keywords: Infant feeding choices, breastfeeding, social and medical risks, pMTCT.

RÉSUMÉ

Infant feeding represents a great challenge in the prevention of mother-to-child transmission of HIV (pMTCT). The international guidelines informing infant feeding counselling suggest feeding methods that reduce the risk of HIV transmission, and discourage mixed feeding (combining breastfeeding with other fluids and solids). The feasibility and the social acceptability of the recommended feeding methods are hotly debated currently. Through the documentation of HIV-positive women's experiences, this article aims to provide empirically grounded knowledge on the relevance of the proposed feeding methods. Drawing upon cultural theory and a view of infant feeding practices as socially and culturally embedded, the article discusses the so-called 'informed choice' of infant feeding method among women enrolled in the pMTCT programme at Kilimanjaro Christian Medical Centre in northern Tanzania. The study is based on interviews and follow-up of 20 HIV-positive mothers during the last part of pregnancy, delivery and the first six months after birth. The article details four of these cases describing the challenges linked to exclusive breastfeeding, cow's milk feeding and formula feeding. The study demonstrates the gap between intentions and infant feeding practice in a context where the social expectations to breastfeed are high, and where kin and neighbours are part of the decision-making team surrounding infant feeding. It highlights the tension between the competing concerns of the medical and social risks involved in the choice of infant feeding method, and documents that the feeding options may be difficult to adhere to, whether a mother chooses exclusive breastfeeding or replacement feeding.

Keywords: Infant feeding choices, breastfeeding, social and medical risks, pMTCT.

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Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania

INTRODUCTION

The documentation of the risk of HIV transmission through mother's milk has rendered infant feeding choice a most exigent issue, and has created considerable uncertainty and fear among HIV-positive childbearing women. The national and international guidelines on HIV and infant feeding are by definition meant to provide infant feeding recommendations in general terms, and are thus not immediately relevant or appropriate on the local level unless, as explicitly spelt out by WHO, they are adapted to the particular social and cultural context in which women make their choices of infant feeding method. The aim of this article is to demonstrate the importance of empirically grounded knowledge on the relevance and acceptability of diverse approaches to infant feeding, in order to enhance their applicability in ongoing pMTCT projects. The article explores HIV-positive women's situated concerns and experiences related to choice of infant feeding method in the social and cultural context of the Kilimanjaro Region, northern Tanzania.

BACKGROUND

Mother-to-child transmission of HIV

Approximately 700 000 children under 15 years of age were newly infected with HIV in 2005, and more than 60% are living in sub-Saharan Africa (UNAIDS, 2005). Without intervention to prevent mother-to-child transmission, 30–45% of infants born to HIV-positive mothers in developing countries become infected during pregnancy, delivery and breastfeeding (De Kock *et al.*, 2000).

The magnitude of the problem of mother-to-child transmission (MTCT) and the potential for prevention has made pMTCT an essential element of the worldwide HIV/AIDS control strategy (WHO, 2003). Safe and cost-effective interventions to reduce mother-to-child transmission of HIV are rapidly being disseminated throughout sub-Saharan Africa, offering voluntary counselling and testing, single dose anti-retroviral prophylactics for mother and child, and infant feeding counselling based on international guidelines. The availability of short course anti-retroviral drugs through pMTCT programmes enhances the possibility of reducing transmission in pregnancy and during labour and delivery from 20% to 10% (Guay *et al.*, 1999), but it does not solve the problem of infant feeding which is responsible for as much as 5–20% of infections (De Kock *et al.*, 2000).

However, several trials/cohort studies assessing the efficacy of short term regimens of anti-retrovirals have shown promising results, bringing MTCT rates down below 5% (Dabis *et al.*, 2005; McIntyre, 2005). Extended anti-retroviral prophylaxis to infants born to HIV-positive mothers is being tried out, for example in the Nigat study in Ethiopia (Bedri *et al.*, 2005) and in the MITRA study in Tanzania (Kilewo, 2005). HAART (highly active antiretroviral treatment) administered to mothers during the entire breastfeeding period is currently being tested, for instance in the Kesho Bora study (Gaillard *et al.*, 2004) and in the Kisumu breastfeeding study (Thomas *et al.*, 2005). Recently published findings from sub-studies of the Mashai trial in Botswana (Clayden, 2005; Shapiro *et al.*, 2005) and a controlled trial conducted in Nairobi (Chung *et al.*, 2005) suggest that anti-retrovirals, and in particular nevirapine, reduce the viral load in mothers' milk, and are probably more effective in reducing mother-to-child transmission of HIV than anticipated.

MTCT and infant feeding methods

The current international guidelines for HIV and infant feeding state that, "if it is acceptable, feasible, affordable, sustainable and safe (AFASS), exclusive replacement feeding is recommended. If not, exclusive breastfeeding is recommended during the first months of the baby's life" (WHO, 2003 p.9). The AFASS of diverse alternatives to breastfeeding are currently being tried out (e.g. in the ZEBS study in Zambia, the ZVITAMBO study in Zimbabwe, and the DITRAME Plus study in Cote d'Ivoire) including replacement feeding with modified animal milk or infant formula, wet-nursing, and expressed and heat-treated breast-milk (Rollins *et al.*, 2004). However, the superiority of breastfeeding in reducing child morbidity and mortality is unquestionable, as it greatly reduces the risks of enteric infection and of defective nutrition, particularly in resource-poor settings (Bhandari *et al.*, 2003; Cava *et al.*, 2002; UNICEF, 2001; WHO, 2000). Hence, in recommending an infant feeding method to HIV-positive women, the risks implied in breastfeeding must be carefully balanced with the competing risks of not breastfeeding (Kuhn *et al.*, 2004).

MTCT and challenges of exclusive breastfeeding

The documentation that exclusive breastfeeding (*giving only breast milk and no other liquids or solids, not even water, with the exception of drops or syrups consisting of vitamins, mineral supplements or medicines*) involves a lower risk of

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MTCT of HIV than mixed feeding (*feeding both breast milk and other foods or liquids*) (Coutsoudis *et al.*, 1999; Iliff *et al.*, 2005) has raised hopes that MTCT can be reduced where breastfeeding is culturally normative. Mixed feeding in fact involves a four-fold increase in the risk of HIV transmission from an HIV-positive mother to her child during the first six months of life, compared to exclusive breastfeeding (Coutsoudis *et al.*, 2005; Iliff *et al.*, 2005; Leroy *et al.*, 2003). An observational sub-study in Durban, South Africa, indicated that MTCT in HIV-positive mothers who reported that they were breastfeeding their children exclusively up to three months of age was similar to that of mothers who exclusively fed their children with formula milk (Coutsoudis *et al.*, 1999). In view of these findings, it was suggested that the more strictly HIV-positive mothers are able to breastfeed exclusively, the lower the risks of HIV infection and death in their infants (Iliff *et al.*, 2005).

The prime obstacle to this strategy lies in the fact that mixed feeding patterns and not exclusive breastfeeding are practised throughout Africa (Bland *et al.*, 2002; de Paoli *et al.*, 2002; Piwoz & Humphrey, 2005). In fact, exclusive breastfeeding has been noted to be an alien concept in most African cultures (Magoni & Giuliano, 2005), the prevailing form of breastfeeding worldwide being mixed breastfeeding (WHO, 2001). Studies from various countries in sub-Saharan Africa document very high breastfeeding initiation rates among rural women of unknown HIV status (Bland *et al.*, 2000; de Paoli *et al.*, 2001). Exclusive breastfeeding is, however rare, while early mixed feeding is common (Becquet *et al.*, 2005b; Coutoudis, 2005). A study from South Africa found that women of unknown HIV status, who started out exclusively breastfeeding, introduced formula and/or solid foods from one to three months after birth (Chopra *et al.*, 2000). Other studies from South Africa reported that fluids were commonly introduced within the first 48 hours of life, and infant formula from six to eight weeks after birth. Mothers tended to view formula as beneficial to the baby (Bland *et al.*, 2000), and when mothers were absent from home, formula was given (Bland *et al.*, 2002). A study from Abidjan, Cote d'Ivoire also reported that exclusive breastfeeding was not practised, since all women who participated in this study had given water to their children starting one day after birth (Becquet *et al.*, 2005a). An early study from Zambia showed that women of unknown HIV status who started out

exclusively breastfeeding also switched to mixed feeding within a few days after delivery (Ndola District Health Management Team *et al.*, 1999). Another study in Uganda indicated that while all HIV-positive mothers started out exclusively breastfeeding, they had switched to mixed feeding by the time their baby was three months old (Bakaki, 2002).

MTCT and challenges of exclusive replacement feeding

In countries where breastfeeding is the norm, formula feeding has been noted to alert a woman's family or community that she is HIV-positive, and may result in stigma or other negative repercussions (de Paoli *et al.*, 2002; Nduati *et al.*, 2000; Rollins *et al.*, 2002). In Botswana, where formula feeding in HIV-positive women is strongly encouraged and offered free of charge in PMTCT programmes, Shapiro and colleagues concluded that adherence to exclusive formula feeding was sub-optimal and potentially over-reported (Shapiro *et al.*, 2003). However, the Mashi sub-study in Botswana reported very high levels (91%) of adherence to formula feeding compared to only 18% adherence to exclusive breastfeeding (Thior *et al.*, 2005). A study in Zambia similarly reported that HIV-positive women changed to mixed feeding very early, whether they started out with replacement feeding or exclusive breastfeeding (Omari *et al.*, 2000). A Cote d'Ivoire study, by contrast, found that 69% of HIV-positive mothers who selected replacement feeding reported still doing so successfully at three months (Leroy *et al.*, 2002). However, we have to keep in mind the difficulty of securing reliable data on this sensitive area, as mothers will obviously under-report failure to adhere in a situation where non-adherence may be risky for child survival. Hence, most studies of choice of infant feeding method show that while HIV-positive women commonly make a distinct choice to exclusively breastfeed or exclusively replacement feed during pregnancy, they often end up practising mixed feeding early in the baby's life (Koniz-Booher, 2004; Thairu *et al.*, 2005).

Challenges to early and abrupt cessation of breastfeeding

International guidelines have indicated that exclusive breastfeeding should be accompanied by early and abrupt cessation of breastfeeding. Studies in Zimbabwe (Iliff *et al.*, 2005), West Africa (Leroy *et al.*, 2003), South Africa (Coutsoudis *et al.*, 2001), and Tanzania (Fawzi *et al.*, 2002), which show that more than two-thirds of all postnatal transmission occurs after the first six months

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of the baby's life, provides a strong justification for supporting early breastfeeding cessation among HIV-positive women. Some studies however, have reported that many women have difficulty breastfeeding exclusively or weaning their children early (Becquet *et al.*, 2005b; Coutoudis, 2005). Although there are studies documenting successful cessation of breastfeeding, for example in the Cote d'Ivoire study (Becquet *et al.*, 2005b), the cultural inclination toward prolonged breastfeeding patterns in sub-Saharan Africa in general makes early cessation difficult (de Paoli *et al.*, 2001; Isiramen, 2002; Shapiro *et al.*, 2003; Williams, 2001).

Hence, several studies in diverse contexts have documented poor adherence to the recommended feeding methods (de Paoli *et al.*, 2002; Kiarie *et al.*, 2004; Omari *et al.*, 2003), but there is limited empirical evidence regarding why this is so. Research efforts linked to pMTCT programmes have been focused on a medical or nutritional point of view, while women's experiences with infant feeding have largely been neglected. Kuhn and colleagues pointed out that "A uniform infant feeding policy for all communities is inappropriate" (Kuhn *et al.*, 2004 p. 11). This study aims to add empirical evidence to this assertion and in the same vein appeal for local adaptations both in the content and in the organisation of infant feeding counselling.

The study setting

The study on which this article is based took place in Moshi town in the Kilimanjaro Region and its rural and semi-urban vicinity. The population of the study area is multi-ethnic; the major group being the coffee- and banana-cultivating Christian Chagga farmers who are known for their relatively high educational level and their development-oriented attitude (Klepp *et al.*, 1995). The patrilineal kinship system and customary inheritance and ownership rules work against women, who have only usufruct rights to land through husbands and sons (Setel, 1999). The virilocal residence pattern, implying that women move to their husband's homes at marriage, is still practised in rural areas. This practice places a married woman in a position of dependence on her affinal kin, especially her mother-in-law, who customarily cares for her son's wife and the new-born after delivery, making sure that the confined woman gets enough nutritious food to produce sufficient milk for her infant (Moland, 2002).

Breastfeeding is universal in the area and prolonged breastfeeding is widely practised. The median duration of breastfeeding in the Kilimanjaro Region was reported to be 22.6 months in the 1999 Demographic and Health Survey (TDHS, 1999), while the median duration of exclusive breastfeeding was only about one month, as many young infants are given water in addition to breast milk. A mixed feeding pattern, where the baby is partly breastfed and partly fed with water, cow's milk and porridge is common (de Paoli *et al.*, 2001).

The HIV prevalence in pregnant women attending antenatal clinics is 5.7% (Ministry of Health, 2005). Since 2000, the pMTCT pilot site at KCMC (Kilimanjaro Christian Medical Centre) has offered VCT (voluntary counselling and testing) to all women enrolled in the antenatal clinic as well as anti-retroviral prophylactics and infant feeding counselling to all HIV-positive women (Ministry of Health, 2004a). The infant feeding counselling follows the national guidelines (adapted from the global recommendations) and promotes the three methods found to be relevant in the Tanzanian context, namely commercial formula, home-modified cow's or goat's milk and exclusive breastfeeding. The principle of informed choice is strongly emphasised and mixed feeding is discouraged (Ministry of Health, 2004b; NACP, 2001).

Study design and methods

This exploratory descriptive qualitative study was conducted between August 2003 and June 2004. The study consisted of a hospital-based and a community-based phase and was designed to follow the study participants for 8-9 months. The data collection was carried out by the first author and follow-up visits made by the first and the last author. All participants were recruited during the first two months of the study. With the assistance of a contact nurse-counsellor, 22 HIV-positive pregnant (around 36 weeks) women who were attending the KCMC antenatal clinic were recruited and consented to take part in the study. None of the women approached refused to participate (the refusal rate for VCT at KCMC in general is about 10%), but two were later excluded as they travelled to stay with relatives after delivery. Recruitment was done after pMTCT post-test counselling on a twice weekly basis following the duty roster of the nurse counsellor. There is no reason to believe that this group of women differed in significant ways from women attending the

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antenatal clinic on other days of the week. All the women were counselled by the same nurse counsellor, who was thoroughly informed about the purpose of the study. The 20 women were followed in connection with antenatal visits through the last part of pregnancy, during delivery, the post-natal phase in hospital, and through the critical first six months of the infant feeding period in the home areas/villages. The issue of confidentiality was carefully considered, and informed consent was obtained before each interview session. The participants were concerned about the risks of disclosure, and a few of the women did not wish to be visited at home. In such cases, a location considered neutral was used for follow-up interviews. All names appearing in this article are fictive.

The data collection methods included participant observation in the hospital for antenatal visits and delivery, exit interviews after post-test counselling in the pMTCT clinic, and participant observation and in-depth follow-up interviews at home (or other appropriate place) during the period of infant feeding. During the first two weeks, when infant feeding was being established, each of the 20 women was visited at least three times, and thereafter monthly until the baby reached six months.

In order to acquire a broader understanding of the context of infant feeding choice, local concepts of breastfeeding and HIV were explored through four focus group discussions with men and women, where division by age and gender were the criteria employed in attempts to create well-functioning and articulate groups.

The large majority of the informants spoke openly during all the interviews, and they commonly indicated their appreciation of being given the chance to speak about an issue that troubled them so much. All interviews – both the individual and the group interviews – were conducted employing semi-structured interview guides, and were tape-recorded, transcribed and translated into English. The ethnographic material was recorded in the form of detailed field notes. The complex material collected was analysed using qualitative analytical frameworks, which consisted of reading and re-reading the field notes and transcribed texts, manual coding in the margins, synthesising and grouping of data in relatively exhaustive categories (Burnard, 1991; Kvale, 1996).

The four cases that are presented in detail below were selected because they brought up the most common and most critical issues that emerged in the interviews conducted. However, they are not held to be representative of the overall material in the strict sense of the term. The cases nonetheless present the complexity of HIV-positive women's experiences with respect to infant feeding methods.

Approval to conduct the research was obtained from national, regional and local authorities, including the Tanzania National AIDS Control Programme (NACP), the medical authorities in the Kilimanjaro Region, and the ethics committees of the KCMC and Muhimbili University College of Health Sciences (MUCHS) and the University of Bergen.

STUDY FINDINGS

Challenges of infant feeding in a context of HIV infection

The social and demographic characteristics of the study participants

The 20 HIV-positive women who participated in the study were between 20 and 32 years of age. Twelve of them were from rural areas in the vicinity of Moshi town, while eight were from Moshi town itself. All but one had finished primary education; 16 were married, while four were single mothers. Nine of the women were living in an extended family, six were living in a nuclear family, and four were living alone. Five had a permanent income from employment, and 15 were not employed. Five had disclosed their HIV-positive status to either a partner or close relative, while the remaining 15 had not disclosed their HIV-positive status to anyone.

Choice and the rationality of choice of infant feeding method

In the following section we discuss who, in terms of the social and demographic characteristics, opted for what infant feeding method and why she did so.

After delivery and infant feeding counselling, 13 of the 20 study participants opted to exclusively breastfeed and seven opted to replacement feed. Among the latter, three decided to feed the baby infant formula while the remaining four decided to use cow's milk.

The social conditions and the rationality of choice of infant feeding method as conveyed by the individual study participants indicated a close relationship

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between a woman's economic status and her dependence on close kin on the one hand, and her choice of infant feeding method and status of disclosure on the other. The 13 women who chose exclusive breastfeeding had not disclosed their HIV-positive status to their partner or to anyone else. Nine of them were living in an extended family, mostly with affinal kin including mother-in-law, and none were formally employed. Fear of disclosure of HIV-positive status, purchasing power and social pressure were major concerns conditioning choice, as was the strong cultural position of breastfeeding as the only acceptable infant feeding method and the only way to fulfil ideals of being a good mother. These diverse and complex concerns surfaced in expressions such as: "*Babies grow well on breast milk.*"; "*It is the only acceptable way of feeding babies less than two months of age.*"; "*All good mothers breastfeed their babies, what reason will I give for not breastfeeding?*"; "*It is the only way of avoiding people suspecting my HIV status.*"; "*My husband and in-laws will not understand me if I don't breastfeed my baby.*"; "*Buying formula is too expensive, I cannot afford it.*"

Among the seven women who chose replacement feeding (formula or cow's milk), five had disclosed their HIV status to their partner. The same five were employed and had a regular income. Six were living alone or in a nuclear family and were not under the daily control of their mothers-in-law. For these women the risk of HIV transmission to the baby through breastfeeding, maintenance of the mother's health and access to replacement milk provided important conditions of choice. The rationality behind their choice emerged in statements such as: "*It is the only way to prevent transmitting the HIV infection to the baby.*"; "*I'm worried about my health, – if I breastfeed I would become very weak and it would shorten my life.*"; "*I chose cow's milk because my neighbour sells cow's milk at a cheaper price and I want my baby to be healthy.*"; "*I cannot believe that the virus is in my blood and not in my breast milk because breast milk comes from blood.*"

Among those who chose to replacement feed, two had not disclosed their HIV status to anyone and were not employed. They had, however, had caesarean sections and when people enquired why they did not breastfeed, they explained: "*My breast milk dried up because of the operation*" or "*I was advised by a doctor to only breastfeed my baby at night because I don't have enough breast milk after the operation*". The effects of a caesarean

section on a woman's body in general and on the production of mother's milk in particular are regarded as uncertain, and generally such a surgical procedure causes worry. A caesarean section was thus perceived to be a socially acceptable reason for not breastfeeding.

Four cases

Let us at this point review condensed versions of four of these cases, which emerged as 'representative' in the sense that they bring up the major challenges that were revealed in the interviews regarding decision making processes of choice of feeding method and the handling of the chosen feeding method.

Case 1. Opting for exclusive breastfeeding for six months

Maua is 29 years old, married and is living with her husband, her parents-in-law, and their four children in a rural area a few kilometres out of Moshi town. She is a housewife and does some petty trading. Her husband is a business man and secures the family a fair income. Maua has completed standard six and can read and write.

During her last pregnancy, Maua agreed to be counselled and tested for HIV. When she tested positive, she was shocked. She did not feel sick. After receiving counselling, she worried about how to feed her infant because she had heard from different sources that HIV-positive women should not breastfeed. The counsellor had also emphasised the risk of HIV transmission involved, but since Maua was not willing to formula feed her baby, she encouraged Maua to breastfeed without any supplementation for six months. She did consider replacement feeding, but would then have had to reveal her status to her husband, and could not bear that thought. She said: "*What reasons will I give to the people around me for not breastfeeding the baby? How will other people react when they see me holding my baby, in particular when he cries and I do not give him my breast?*" Maua was therefore determined to keep her status a secret, and opted for exclusive breastfeeding of her baby for six months. When asked about other reasons for choosing breastfeeding she said, "*If I don't breastfeed my baby some people may think that I have a lover outside marriage and they will never respect me again. I also think I would feel very guilty if I did not breastfeed my baby and besides, you need to be very rich to afford to buy formula*".

In the confinement period after delivery Maua stayed in the house of her mother-in-law as custom prescribes. Her mother-in-law took good care of her, cooked confinement food, washed her own and the

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baby's clothes and assisted in the care of the baby. Her mother-in-law insisted that the baby be given water at least once a day because, as she said: "*The grasses need to be watered to grow well, so the baby should be given water, because milk alone does not quench the baby's thirst and the baby will cease to grow*". Maua carefully avoided giving the baby water, but she worried about how her mother-in-law would react if she discovered her disobedience, and she could not prevent her mother-in-law from giving the baby water in her absence. Maua became obsessed with the danger of HIV transmission implied in the combination of breastfeeding and water fed to the child, but after two months the anxiety came to an end as her mother-in-law had to resume her petty business at the local market and Maua could go back to her own house.

At this point Maua started to lose weight, and friends and her husband soon started commenting upon it. She got increasingly anxious that people might suspect her being HIV-positive. Simultaneously the baby started to cry more and was unsettled at night, and her husband suggested that the baby be given porridge mixed with cow's milk. Maua hesitated, but after a few sleepless nights, her husband demanded that the baby be given porridge. Maua gave in, but the risk of HIV transmission and the need to keep this a secret created an immense stress that became increasingly hard to handle. After three months, Maua decided to discontinue breastfeeding. She left for her mother's home, disclosed her status to her mother and stayed with her for the next three months. When she came back, the child was six months old and no one bothered any longer about how she fed her child.

Case 2: Opting for abrupt cessation of breastfeeding after three months

Halima is a 32-year-old housewife living in a neighbourhood in Moshi town. She is a primary school leaver, is the first wife of two and has four children. She has no regular income. During her last pregnancy, Halima tested positive for HIV and was counselled on infant feeding. She became very confused by the information she received, but finally decided to breastfeed because, as she put it, "*breastfeeding is the only way to feed an infant*". She did not tell anybody about her HIV status and lived in constant worry that people might find out. After the delivery, her mother came to stay with her to help her with household chores.

Halima had planned to abruptly stop breastfeeding after three months as advised by the counsellor in order to avoid 'mixed feeding', and immediately introduce infant formula. She was very concerned about doing this the right way without drawing too much attention and had prepared herself well for the

morning the child reached three months. She had bought a tin of infant formula, but had hidden it carefully so that no one would find it and start asking questions. In particular, she worried about her mother who was constantly around in the house, and who she knew would become upset to find her daughter not breastfeeding her three-month-old grandchild.

On the critical day of transition she got up early in the morning to prepare the bottle and to smear her nipples with garlic to discourage her child from suckling. When the baby woke up, he was hungry and sought for the breast as usual. Halima took the baby in her arms and put the bottle carefully into his mouth while she prayed to God. But the baby refused to suck from the bottle and started screaming furiously. Alarmed by the continued screaming of the baby, Halima's mother, and later her neighbours, came to ask what was wrong. They enquired why Halima did not put the child to her breast to comfort it. The child continued to scream, and angered by the situation, Halima's mother suddenly rushed over to her daughter, pulled her clothes aside and put her mouth around the nipple. She was furious when she tasted the garlic, and shouted at her daughter for refusing to feed her grandchild properly. Halima was called a bad mother. In the midst of this scene, Halima's husband turned up and became no less upset. Halima was accused of being more concerned about her own physical shape than about the health of her baby, and she was accused of having a lover. This was more than Halima could take, and so she reassumed breastfeeding, to the great comfort of her child and her family. But as she said: "*I feel very shameful. People have started gossiping about me – they suspect that I stopped breastfeeding because of extramarital relations. Therefore I cannot mention the use of condoms to my husband anymore. I am very worried about the health of my baby now. I would have been better off not knowing*".

Case 3: Opting for cow's milk feeding

Asha is 26 years old and single. She has three children with three different men and has no permanent means of income. Her parents greatly disapprove of her childbearing out of wedlock, but have given her a room to stay in at the back of the house on their farm outside Moshi town. Both parents are employed and spend all day out of the house. The family has three cows that Asha and her younger sister look after and milk every morning and evening. When Asha tested positive for HIV during her last pregnancy, she was counselled on infant feeding and advised to avoid breastfeeding if possible. Since she has continuous access to cow's milk she decided to feed her baby modified cow's milk. She shared her HIV status with her younger sister, and planned to feed her baby cow's milk in secrecy without her parents' or other's knowledge.

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After milking the cows, Asha put some milk aside for the baby, and she hid in her room while feeding the baby. With her parents away all day, this was not particularly difficult. In fact, her parents rarely entered her room even when they were at home, although her mother constantly told Asha to breastfeed when she heard or saw the baby crying. The baby was frequently constipated however, and already when the child was three weeks old, Asha felt it was necessary to give the baby some water to ease the problem. Although Asha had completed standard seven and could read and write, she was uncertain about the preparation and storage of the cow's milk. She could not quite remember what the counsellor had told her and had no written information about the procedure to follow. She mixed the milk with water in equal amounts, and kept the milk in a thermos throughout the day. Unfortunately, the baby did not gain weight well, and Asha worried constantly about the health of her baby. She felt guilty for not breastfeeding him, and thought that the lack of breast milk could be the reason for his poor weight gain.

Case 4: Opting for formula feeding

Mona is 29 years old. She has completed primary school, is married and lives in a semi-urban area with her husband and her baby. Her older son is in boarding school. Mona is employed and had three months' paid leave in connection with her delivery. Her husband is unemployed. They are both strong Christian believers. During her last pregnancy, Mona tested positive for HIV. She immediately told her husband the result, and brought him for testing. He also tested positive. The results did not come as a great shock to them as they had both experienced signs of the infection. In fact, people had been gossiping about them for some time, especially when they lost an infant a couple of years earlier. Mona had breastfed the baby who died, and she suspected that the baby might have become HIV-infected through her milk. After infant feeding counselling, Mona therefore decided to feed her baby infant formula.

Infant formula feeding however turned out to be very costly, and sometimes Mona and her husband had to make compromises with regard to their own food in order to be able to afford the expensive tins. Even so they were determined to feed the infant only formula for the first three months of the child's life, and then switch to cow's milk and porridge. Mona said: "*Buying formula is too expensive for us, but we will do whatever possible to prevent our baby from becoming HIV-infected*".

Mona and her husband were also very worried about disclosure in the community, but did disclose their HIV-positive status to several church elders. Mona's husband assisted her during the confinement period

because as they said: "*We want to make sure nobody else gets to know of our HIV status*". The neighbours became increasingly suspicious, but since nothing was said, nothing was known for certain, and Mona said: "*We don't want to show that their suspicions are right. HIV-infected people are seen as sinners in this community – people isolate them. They are seen as useless – after all, they will die*". An unforeseen difficulty in the project to hide their status was getting rid of the empty formula tins without drawing the attention of their neighbours. They ended up hiding the large number of empty tins in their bedroom.

The couple remained firm about their decision not to breastfeed, but found it increasingly difficult to calculate the right amount of infant formula as the child grew. Mona actually thought the baby could have been better off if she had been able to breastfeed him, and said that "*a real mother should breastfeed her child*".

The problem of adherence to one feeding method

All of the 20 informants experienced severe hardship implementing their infant feeding choice, and only one of them managed to stick firmly to the feeding method she had opted for, which in this case was cow's milk feeding. She had delivered by caesarean section, had an independent income as a primary school teacher and had disclosed her HIV-positive status to her husband. Three of the other six who opted for exclusive replacement feeding said that they had felt pressured to breastfeed on certain occasions – particularly when their mother-in-law was around or when neighbours and friends commented that they should breastfeed if the baby was crying. One said: "*Friends came to my house and told me that they had heard from others that I was not breastfeeding my baby. They asked me if this was true. So to prove them wrong I picked up my child and put him to the breast to suck*". The remaining three mothers who chose replacement feeding said that they did not breastfeed their child on any occasion, but they all reported that they had given extras in the form of juice, porridge and water because they were worried about poor weight gain or, in the case of cows' milk feeding, because the baby was constipated.

All thirteen mothers who opted for exclusive breastfeeding encountered problems practising breastfeeding exclusively without any form of supplementation. Eleven of the infants were given water in early infancy. Six of these plus another two of

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the breastfed infants were given supplements in the form of porridge and cow's milk from the third or the fourth month of life while they were still being breastfed. All 13 mothers, contrary to their intentions, ended up practising mixed feeding, giving water in early infancy, supplementing milk and porridge later or both. The major reason given was pressure from kin and neighbours, work outside the home and the need to leave the child with others. Some mothers also complained of energy loss and were worried that they would lose weight, which again could alert other people around them to the fact that they were HIV-positive. They explained further that after two and a half months, the baby also started to lose weight and that they were advised by either friends and/or relatives to give supplements.

Hence, among the 20 mothers only four managed not to mix breastfeed with other foods or fluids, while sixteen ended up mixed feeding.

The context of choice

The findings presented above suggest that the recommended feeding options may be difficult to adhere to, whether a mother chooses exclusive breastfeeding or exclusive replacement feeding. This is substantiated in the four cases presented. These findings are not unique to this particular study, but are consistent with findings in other studies (Becquet *et al.*, 2005a; de Paoli *et al.*, 2001; Thairu *et al.*, 2005). All the women interviewed in the present study were informed about the potential risks linked to HIV transmission through breastfeeding. Nevertheless, the majority decided to breastfeed their babies. As we saw, this decision is not merely linked to alternative feeding options being costly and technically complicated, as illustrated in the examples of replacement feeding. It is also because infant feeding is imbued with meaning beyond the purely nutritional aspects and the physical feeding of a baby. The meaning attached to the feeding methods is embedded in concepts and norms of breastfeeding, procreation and motherhood. The study findings strongly demonstrate the power of breastfeeding as a culturally-anchored practice and as a moral commitment on the part of the mother. These norms and moral commitments can carry additional or new meaning in the context of HIV/AIDS. The HIV epidemic has in fact brought renewed attention to the cultural and social significance of breastfeeding (Moland, 2004). Infant feeding in general and

breastfeeding in particular are intimately related to ideas of reproduction, fertility and survival (Maher, 1992). As such, they are socially and culturally embedded practices that need to be understood in particular local contexts.

Breastfeeding was seen as vital to child survival, and was experienced as essential to the survival of the social relations surrounding mother and child. To abstain from breastfeeding and feed the child only cow's milk or infant formula in early infancy thus implied going against the rules of good motherhood and entailed immense personal emotional stress as well as social pressure and censure. The cases of Asha and Mona, who chose replacement feeding (cow's milk and formula), illustrate the tension experienced between the medical knowledge of HIV transmission through breastfeeding as conveyed through counselling, and the mother's desire to breastfeed. Although both mothers expressed confidence in their choice of feeding method in terms of the medical risk of HIV transmission, they simultaneously resented not being able to breastfeed their infants. Asha's remark: "*It is so frustrating not breastfeeding my baby. It is as if I'm not his real mother*", underscores the emotional strain experienced.

In the Kilimanjaro Region and beyond, but among the Chagga in particular, the confinement period after birth is a highly appreciated period of rest when the woman is celebrated as a mother; she is fed nutritious foods and is left in peace to regain her own health and to breastfeed her infant. But the privileges enjoyed by the postnatal mother are closely attached to her breastfeeding the child. If she is not breastfeeding, the services may be withdrawn. In the present study, non-breastfeeding mothers were described as irresponsible, and were not considered deserving of the customary privileges of a new mother, as expressed by focus group participants:

- *If a woman does not breastfeed her baby she does not deserve the rest, the attention and the special foods given during postpartum confinement – she is useless, disrespectful and an irresponsible mother.* (Male focus group participant)
- *Why should I cook for a daughter-in-law who is disobedient to me and who will kill my grandchild? Not breastfeeding a baby is like killing it.* (Female focus group participant)

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In their study of child malnutrition in Kilimanjaro, Howard and Millard (1997) describe the failure of a mother to breastfeed as 'a significant failure', pointing to the substantial failure to live up to practices deeply embedded in a culturally constituted moral universe.

The experience of social pressure to mix-feed

Breastfeeding in the Kilimanjaro Region is intimately associated with ideas about fertility and procreation, and as such concerns not only the mother and her infant, but also her kin, in particular her affinal kin (Moland, 2004). In addition to putting the life of the child at risk and violating the rules of good motherhood, not breastfeeding an infant is thus interpreted as an act of disrespect to the lineage and to the mother-in-law. The social relations surrounding infant feeding are therefore of utmost importance for the mother's initial choice and her potential to adhere to that choice. Although a woman makes a decision on how to feed her infant during or after counselling, she may, as we have seen, simply not be able to execute that decision in practice because her mother or mother-in-law wish it otherwise. The role of mothers-in-law as a complication to achieving safer infant feeding through exclusive breastfeeding and early cessation has also been reported in a study in Abidjan, Cote d'Ivoire, where HIV-positive women who failed to cease breastfeeding early or before introducing supplements reported to be under social pressure from their mothers-in-law (Becquet *et al.*, 2005b).

Moreover, even if breastfeeding is culturally mandatory, the practices of *exclusive breastfeeding and early and rapid cessation of breastfeeding* as promoted in an HIV/AIDS context are not necessarily easy to put into practice, as demonstrated by Maua and Halima's cases. The advice given by counsellors to breastfeed exclusively for three, four, or up to six months entails substantial apprehension for many mothers, as it simply goes against the local norm of early supplementation of water, juices, cow's milk and porridge, and of prolonged partial breastfeeding for up to two years. Breast milk is perceived to feed the babies insufficiently both in quality and quantity. This finding is consistent with studies conducted previously in Tanzania and other African countries where it was observed that the practice of prolonged partial breastfeeding is prevalent (Becquet *et al.*, 2005b; Coutoudis, 2005; de Paoli *et al.*, 2001; Shirima *et al.*, 2001; TDHS, 1999). Hence, early and abrupt cessation of breastfeeding within this

cultural context proved to be challenging. The consequence was succumbing to the social demands at the cost of adherence to the feeding choice. Indeed, Magoni and Giuliano (2005) hold that it is near impossible to adhere to exclusive breastfeeding and early cessation because both are alien concepts in African societies.

Disclosure and replacement feeding

As indicated in the findings above, replacement feeding may be interpreted as a sign of HIV, especially if no good and legitimate explanation for replacement feeding, such as caesarean section, can be produced. As knowledge of HIV transmission through breastfeeding is disseminated into local communities, a woman who opts for replacement feeding will be carefully watched. The costs involved, combined with the scorn and suspicion that it is perceived to foster, thus make replacement feeding an option only for women who have disclosed their HIV status to their partner, or who are not married, or who are not living in close proximity to another family member. Disclosure of HIV status to the partner is usually a major condition for successful replacement feeding. However, disclosure of HIV-positive status to a partner was, in the present study as in many other studies, greatly feared by the study participants, and this had a bearing on and was an obstacle to the practice of replacement feeding. Kuhn and colleagues (2004) similarly assert that fear of disclosure may be an impediment to choosing formula feeding, and a study in Uganda found that women who succeeded in adhering to replacement feeding had family support (Matovu *et al.*, 2002). The importance of partner disclosure for successful replacement feeding is clearly illustrated in the case of Mona and her husband. The couple disclosed their status to church elders and secured a certain social life through the church. But, as in Asha's case, they did not disclose their status to their parents or to neighbours and the cost they paid was social exclusion and isolation from family and community life.

In a context of continued HIV-related stigma, disclosure of HIV-positive status demands immense confidence and self-determination. In this study only the women who were employed and had a regular income making them economically independent, disclosed their status to their partner. However, the large majority of women in Kilimanjaro are dependent on their husbands as providers, and fear for both their

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social and economic future should their HIV-positive status be revealed to their spouses.

Concluding remarks

The basic principle of 'informed choice', promoted through the international guidelines on HIV and infant feeding, requires that an HIV-positive woman be provided with adequate information about the recommended feeding options to make her choice (WHO, 2003). Since the choice of infant feeding method is not made in a social vacuum unlinked to the circumstances in which the decision is made, informed choice may indeed be a rather fictive concept. As we have seen, decision-making on infant feeding is not only based on knowledge about medical risks, but also on the social risks regarding disclosure, rejection and stigma. The present study has demonstrated the gap between the individual woman's intentions and her possibilities to put her intentions into practice, in a context where kin and neighbours make up part of the decision-making team surrounding infant feeding. The concept of 'informed choice' in this context therefore emerges as awkward and misleading, as it does not address the true challenges associated with decision-making and adherence to infant feeding as experienced by HIV-positive mothers. As Kuhn *et al.* (2004, p. 14) assert, "It is not in dispute that the HIV-positive woman, once adequately informed, should herself decide how to feed her newborn child". They argue, however, that since the risks of any infant feeding option are complex, and since no method can guarantee effective prevention of HIV transmission to the infant, the task of the counsellor who aims to implement informed choice is extremely difficult. They conclude that in these difficult circumstances "truly informed choice is seldom a reality". Our study adds empirical evidence to this assertion.

PMTCT programmes are developed as a strategy to be applied globally, regardless of socio-cultural differences. The present study has illustrated the importance of taking the complexity of lived lives and local contexts of choice into account when implementing infant feeding counselling with HIV-positive mothers. How breastfeeding is practised, where and for how long it is appropriate to breastfeed, who is allowed to breastfeed, and the meaning attached to breastfeeding varies both within and between communities and generations. We have to recognise that women in Kilimanjaro as

elsewhere have not only one, but numerous simultaneous concerns related to infant feeding, and this is especially the case when we are dealing with HIV-positive mothers. The tension between medical and social concerns, and between risk and reputation, put HIV-positive women in a particularly demanding situation with respect to infant feeding choice. Counselling services must therefore to a greater extent recognise the cultural position of breastfeeding, and consider each woman's life situation, as well as the feasibility of the different feeding methods, lest infant feeding counselling add to the HIV-positive woman's stress, worries and feelings of guilt, rather than providing support and easing the immense burdens she already experiences.

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Research

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HIV and infant feeding counselling: challenges faced by nurse-counsellors in northern Tanzania

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Abstract

Background: Infant feeding is a subject of worry in prevention of mother to child transmission (pMTCT) programmes in settings where breastfeeding is normative. Nurse-counsellors, expected to counsel HIV-positive women on safer infant feeding methods as defined in national/international guidelines, are faced with a number of challenges. This study aims to explore the experiences and situated concerns of nurses working as infant feeding counsellors to HIV-positive mothers enrolled in pMTCT programmes in the Kilimanjaro region, northern Tanzania.

Methods: A qualitative study was conducted using in-depth interviews and focus group discussions (FGDs) with 25 nurse-counsellors at four pMTCT sites. Interviews were handwritten and FGDs were tape-recorded and transcribed, and the programme Open Code assisted in sorting and structuring the data. Analysis was performed using 'content analysis.'

Results: The findings revealed a high level of stress and frustration among the nurse-counsellors. They found themselves unable to give qualified and relevant advice to HIV-positive women on how best to feed their infants. They were confused regarding the appropriateness of the feeding options they were expected to advise HIV-positive women to employ, and perceived both exclusive breastfeeding and exclusive replacement feeding as culturally and socially unsuitable. However, most counsellors believed that formula feeding was the right way for an HIV-positive woman to feed her infant. They expressed a lack of confidence in their own knowledge of HIV and infant feeding, as well as in their own skills in assessing a woman's possibilities of adhering to a particular method of feeding. Moreover, the nurses were in general not comfortable in their newly gained role as counsellors and felt that it undermined the authority and trust traditionally vested in nursing as a knowledgeable and caring profession.

Conclusion: The findings illuminate the immense burden placed on nurses in their role as infant feeding counsellors in pMTCT programmes and the urgent need to provide the training and support structure necessary to promote professional confidence and skills. The organisation of counselling services must to a larger extent take into account the local realities in which nurses construct their role as counsellors to HIV-positive childbearing women.

Background

Infant feeding counselling based on international guidelines is considered a cornerstone in the prevention of mother-to-child transmission of HIV. Whereas perinatal anti-retroviral prophylaxis currently administered through standard pMTCT programmes in sub-Saharan Africa greatly reduces the transmission of HIV to the baby during labour and delivery, it does not reduce transmission during breastfeeding. Despite routine counselling on infant feeding, HIV-positive women enrolled in pMTCT programmes are commonly left desperately uncertain about how best to feed their infants. Exposed to pressures from family and friends, many end up feeding their infants in ways that may increase the risk of HIV transmission. In this context, the quality of the infant feeding counselling and the knowledge and practices of nurses providing the services have been called into question.

An increasing body of research documents the shortcomings of infant feeding counselling particularly in terms of counsellors' knowledge about pMTCT and counselling skills [1-4]. However, the experiences of counsellors have not been the focus of previous enquiry, and little is known about how the counsellors themselves perceive and experience their work in pMTCT programmes. With the aim of increasing our knowledge of the problems associated with the provision of infant feeding counselling, this study sets out to explore the experiences and situated concerns of nurses working as infant feeding counsellors to HIV-positive mothers enrolled in pMTCT programmes in the Kilimanjaro region, northern Tanzania.

Mother-to-child transmission of HIV (MTCT) represents a major threat to the gains in child health achieved during the last decades and represents a huge public health problem in HIV-affected populations, especially as it threatens breastfeeding [5]. It is estimated that in the absence of any intervention, 30–45% of infants born to HIV-positive mothers who breastfeed for 18–24 months will be infected with HIV either during pregnancy and birth or during the period of breastfeeding. Perhaps as much as 40% of these infections may occur during breastfeeding when this is extended for two or more years [6]. Partial and mixed feeding, in which breastfeeding is combined with other fluids or solids and fluids respectively, carries a higher risk of HIV infection than exclusive breastfeeding (breastfeeding only with no supplementation of any kind) [7-10]. In a study from Zimbabwe in 2005, Iliff and colleagues found that early mixed feeding was associated with a four-fold increased risk of postnatal HIV-1 transmission at six months compared to exclusive breastfeeding [9]. Exclusive breastfeeding, moreover, has protective properties and prevents common infections in babies [11].

In response to the risk of HIV transmission through breastfeeding, the current international guidelines for HIV and infant feeding state that "*when replacement feeding is acceptable, feasible, affordable, sustainable, and safe (AFASS), avoidance of all breastfeeding by HIV-positive mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life*" [12]. The guidelines also state that HIV-positive mothers should receive individual counselling on the risks and benefits of the different infant feeding options including exclusive breastfeeding or exclusive replacement feeding with either animal modified milk or industrial infant formula. Furthermore, based on the principle of informed choice, women should be given the necessary guidance and support to enable them to choose the most appropriate option for their particular life situation while taking the AFASS criteria into account [12].

These guidelines give details of infant feeding counselling in projects to prevent MTCT which routinely offer a standard package of voluntary counselling and testing (VCT), anti-retroviral prophylaxis and modified delivery services in addition to infant feeding counselling [13,14]. Nurses/midwives constitute the backbone of pMTCT programmes and represent the largest group of health workers available to counsel women on the recommended safer infant feeding practices in most African countries [15]. Holding a key role in service provision, close to the patient, and provided with accurate information on the risks and benefits of different feeding options, nurses are considered a group that is able to influence mothers' decisions on infant feeding and that can thus contribute to the reduction of postnatal transmission of HIV [16,17]. Advocates of exclusive breastfeeding have concluded that with formal training and supportive supervision, health workers can effectively increase rates of exclusive breastfeeding [18-20]

The experience from United Nations Children's Fund (UNICEF) pMTCT programmes' evaluation clearly shows that the infant feeding component is still weak [21]. A number of studies have documented that the quality of counselling on infant feeding remains unsatisfactory [1,2]. It has been documented that both counsellors and mothers are not sufficiently well informed about how to protect the infants from HIV transmission [2], and that counsellors are not always aware of the existence of current international guidelines on HIV and infant feeding [2,22]. In fact, not all pMTCT counsellors are trained in infant feeding counselling [21]. In addition to the documented breach in updated knowledge on HIV and infant feeding, the counsellors' practices as care providers have been heavily criticised [23,24]. Counsellors are frequently pressured for time and have too little insight into the mother's personal circumstances to offer appropriate

comment and recommendations on the basis of the AFASS criteria [25]. After a mother makes her infant feeding choice the support available to assist her to practise her choice successfully is even more limited [1].

A study in South Africa which observed and interviewed counsellors about how they informed mothers about infant feeding found that the HIV-negative women had been informed about the advantages of exclusive breastfeeding, but only a minority of the HIV-positive women had been told about the risk of breast milk transmission when complementary food was added [1]. None of the mothers had been properly informed about the advantages and disadvantages of replacement feeding [1]. In a study of the differences between the international recommendations on breastfeeding and counselling messages of health workers in Malawi, Piwoz and colleagues found that misconceptions were common and that counsellors were strongly influenced by cultural beliefs about infant feeding [26].

To date only few studies have focused specifically on counsellors' perspectives in providing infant feeding counselling. A sub-study in a VCT efficacy study from sites in Kenya and Tanzania documented a high level of stress among the counsellors related to the emotional burden of dealing with issues closely associated with life and death as well as with heavy patient flow and a limited staff support system [27].

PMTCT efforts in Tanzania started in 2000 through PMTCT pilot sites and are currently being rolled out nationally. With an estimated HIV prevalence rate of 12% for antenatal women and a total vertical transmission rate of approximately 40%, an estimated 72,000 babies in Tanzania will become infected with HIV from their mothers per year [13]. Approximately 25,000 of these will be infected through breastfeeding [13]. The national infant feeding guidelines follow the international guidelines, and women are counselled to choose either (a) exclusive breastfeeding with early weaning at four to six months or at any time convenient in the individual woman's situation, or (b) replacement feeding with commercial infant formula, and/or (c) replacement/home-modified formula (cow's or goat's milk) when AFASS criteria can be met [13]. No free infant formula is provided as part of the programme.

The guidelines further explain that HIV-positive mothers who choose not to breastfeed should receive education and support on how to prepare and give their infant the replacement food. Mixed and partial breastfeeding is strongly discouraged. It is emphasised that the mother herself should make the final choice of feeding method and that whatever her choice, a counsellor should provide

support to ensure optimal nutrition of mother and child [13]. It is also clearly stated that the counsellors in PMTCT programmes should be nurses/midwives who have undergone at least six weeks' training in counselling including VCT [13]. In spite of policy guidelines at the international and national level, infant feeding counselling remains a major challenge and a controversial issue in PMTCT in Tanzania [2].

A qualitative study in Moshi, Kilimanjaro region in 2000, investigating counsellors' infant feeding advice to HIV-positive women, concluded that infant feeding options were not accurately explained and that informed choice of infant feeding method, as recommended in the guidelines, was seriously compromised by inadequate information, directive counselling, lack of time, and lack of follow-up support [2]. Using this study as a point of departure, we have gone one step beyond investigating nurse-counsellors knowledge and practices to ask: *Why is the quality of counselling not good enough?* Situated at the centre of the PMTCT programme as service providers and at the same time being women exposed to the same risks as their clients, nurse-counsellors are invaluable sources of information. The aim of this study is to represent the perspectives of nurse-counsellors. The article seeks to explore nurse-counsellors' perceptions of the relevance of the infant feeding guidelines in the particular cultural and social setting of the Kilimanjaro region, northern Tanzania; the dilemmas facing nurse-counsellors in their everyday work; and their job satisfaction as counsellors in the PMTCT programme.

Methods

Study setting

This study was conducted at four PMTCT sites in Moshi Town, the administrative capital of the Kilimanjaro region in northern Tanzania. These four sites comprised the two largest health centres in Moshi town, the regional hospital and the referral hospital. The four sites are all characterised by heavy patient load and target both urban and rural populations. The catchment area includes the Moshi district, which has an estimated population of 144 336 people living in Moshi town and 402 431 people living in the surrounding rural areas [28]. The HIV prevalence rate in the antenatal population in Kilimanjaro region is estimated at 5.7% [29]. According to the latest National Demographic and Health Survey, 98% of all pregnant women in Kilimanjaro region attend antenatal clinic at least once during pregnancy, and female literacy rate is estimated at 91.6% [30]. The same survey report documents that 35% of the population of Tanzania have access to piped water, 13% to a protected well and 6% to a protected spring [30]. About 88% of Tanzanians use firewood as fuel for cooking and only 1% of the rural population have access to electricity [31].

The most dominant ethnic group in the study area is the Chagga who inhabits the slopes of Mt. Kilimanjaro. In the Kilimanjaro region prolonged breastfeeding and early supplementation with water, cow's milk and porridge is common [32]. All four study facilities provide services to both urban and rural populations. Three of the facilities offer mainstream HIV services, such as VCT, infant feeding counselling, and the treatment of opportunistic infections, but do not offer antiretroviral prophylactics. The fourth pMTCT site was at Kilimanjaro Christian Medical Centre (KCMC) which is one of the five national pilot pMTCT sites. KCMC serves primarily as a referral pMTCT centre for these other facilities and provides anti-retroviral prophylactics to HIV-positive pregnant women and their newborns. All pregnant women attending the antenatal clinics were offered VCT. The HIV test result was disclosed on the same day in a one-to-one post-counselling session followed by 'healthy living' information, including infant feeding counselling. HIV-positive women were encouraged to bring their husbands/sexual partners for VCT free of charge.

Study participants

The study participants were 25 female nurse-counsellors, working at the four pMTCT sites in Moshi town. All nurse-counsellors working at the pMTCT areas in these facilities were eligible to participate and they were informed about the purpose and relevance of the study. Six counsellors were recruited from each of the four sites and from different sections of maternity care within each site including antenatal clinics, labour wards, postnatal and neonatal wards. In addition, the overall supervisor of the pMTCT programmes in Moshi district was included in the study. The recruitment of study participants was based on their availability and willingness to participate. At all facilities, the counselling work was organised on a part-time basis. No full-time counsellors were employed at the time.

The counsellors were given a small sum of money called 'transport allowance' as motivation. The counsellors were all nursing officers holding diplomas in nursing and midwifery; six of them had an additional diploma in public health. Their ages ranged from 26 to 52 years. Only two of the counsellors, including the supervisor, had been trained specifically in HIV and infant feeding counselling, while sixteen had received four weeks of orientation training for general HIV counselling. Eleven had also been trained in breastfeeding counselling in the 1990s during the Baby Friendly Hospital Initiative (BFHI) campaigns. All had counselled mothers on breastfeeding in general and/or HIV-positive mothers on safer infant feeding options. Their experiences in HIV counselling ranged from 1 to 3 years. During the study period each of the four pMTCT sites counselled 7 to 12 women per day.

Study design and data collection

The study was designed as part of a formative research study aimed at developing locally adapted counselling tools, and was based on fieldwork in the Kilimanjaro region from August 2003 to June 2004. In order to strengthen the credibility of the study findings, a triangulation of methods was used. Twenty-five in-depth interviews and three FGDs with the same study participants (8 participants in each group) were held using semi-structured interview/topic guides. The counsellors' supervisor was purposely excluded during FGDs to allow a free-flowing discussion. The first author of this article (who is a nurse/midwife and a counsellor with a background in sociology and public health, and a native of this area) conducted the interviews. She was assisted by a research assistant during FGDs and she served as a moderator. The interview/topic guides were developed by the research team and were partly adopted from the WHO-recommended sample questions for formative research on HIV and infant feeding [33].

In-depth interviews aimed at eliciting individual perceptions and experiences with infant feeding counselling, while FGDs were to explore collective norms, ideas, experiences and possible divergent views related to their role as infant feeding counsellors. Each interview/discussion built on the previous one with slight modification, elaboration or a better-focused set of themes for discussion. No stratification of the focus groups took place because each participant registered according to the time most convenient personally. While the FGDs were tape-recorded, the individual interviews were recorded in writing. Hence, all interviews were conducted in Swahili, the national language. In addition, the pre-service training curriculum for nurse/midwives was reviewed to investigate how nurse-counsellors were prepared for the role as counsellors in general and as infant feeding counsellors in particular.

Ethical clearance

Ethical clearance for the study was obtained from Muhimbili University College of Health Sciences (MUCHS), the KCMC Ethical Committee and the Norwegian Committee of Medical Research Ethics. All participants gave their written consents to participate in the study. Nobody refused to participate or withdrew during the study period. In order to ensure confidentiality and anonymity, each participant's name was changed into a number during the interview.

Data analysis

The FGDs were transcribed and the transcripts along with in-depth interviews were translated from Swahili to English. The transcripts and the interview notes were read several times and any ambiguous or unclear sections of the translation were checked against the original interview

written in Swahili. A qualitative software programme 'Open code' assisted in sorting, classifying and coding the data [34]. The data was analysed using content analysis according to the qualitative analytical framework [35], which consisted of the researcher reading and re-reading the texts, manual coding in the margins, synthesising and grouping of data in the relatively exhaustive categories.

Results

In the following results section, we will discuss issues related to counsellors' perspectives about the recommended infant feeding options for HIV-positive women and their roles as infant feeding counsellors. Thereafter, we will discuss their perceptions about their working conditions and experiences of stress and frustration connected to the counselling work.

Counsellors' perspectives concerning the recommended infant feeding options for HIV-positive women

Breastfeeding

Data from the interviews and FGDs clearly showed that with few exceptions nurse-counsellors did not see breastfeeding as a safe infant feeding option for HIV-positive women. Almost all counsellors stated that from their point of view infant formula was the preferred infant feeding method for HIV-positive women. When they were asked "What are your opinions about HIV-positive women who breastfeed?" only the two counsellors who had participated in the national HIV and infant feeding training said that the women were doing the right thing to breastfeed, while 19 said that the women were doing the wrong thing to breastfeed. Four were neutral, saying that it was the woman's choice. Similarly, in response to the question "What are your opinions about HIV-positive women who do not breastfeed?" 21 said that HIV-positive women did "the right thing" not to breastfeed, while one thought it was an unfortunate decision and three were neutral. Finally, in response to the question "Do you think there is one best infant feeding method for HIV-positive women?" 20 out of 25 counsellors replied "yes, infant formula". Two replied exclusive breastfeeding for four to six months, and the remaining three said there was no single best method.

Exclusive breastfeeding

One counsellor questioned the feasibility of exclusive breastfeeding on the basis of the customary way that childcare is organised in Chagga communities. The fact that Chagga women customarily do not carry their babies on the back appeared to have negative implications for the feasibility of exclusive breastfeeding. As one counsellor explained:

"Chagga mothers do not carry their babies on the back when they leave the house like women in the coastal areas do. Babies are usually left with their elder siblings or elderly

people like a grandmother, and they are given cow's milk or porridge mixed with cow's milk at a very early age, mostly from two months when the mother is away." (Interview no. 12; with 2 years PMTCT counselling experience)

Most counsellors during FGDs were concerned that the poor nutritional status of the mother is a major obstacle to exclusive breastfeeding. The following quote illustrates:

"Most women do not have enough food to have sufficient breast milk for the babies after two to three months. It is a waste of time preaching exclusive breastfeeding of a baby at that age – they will mix feed anyway."

While traditionally the confinement period was six months among the Chagga, very few families can afford such a long period of rest after delivery these days. The conditions for exclusive breastfeeding have thus become weaker in the course of modernisation and increasing poverty. This was quoted during FGDs:

"Nowadays most mothers do not stay indoors for more than two months after delivery. They are expected to go out to work so that they can supplement the family income. Life is becoming more and more expensive."

Replacement feeding

The counsellors were sceptical about the affordability, feasibility, acceptability and safety of infant formula. They all agreed that it is simply too costly for ordinary people to buy the number of tins necessary to feed their infants in a safe way with infant formula:

"Most families cannot afford to buy their own meals. Where will they get the money for buying formula or cow's milk until the baby is six months of age? A month's supply of formula costs approximately 30,000 Tsh. – almost a minimum wage."

The counsellors explained that the issue is not only one of cost. The practical problems involved in preparing and storing the infant formula makes it an option that is extremely difficult to adhere to exclusively:

"Preparing formula is time-consuming, especially without refrigeration, running water, or an adequate supply of fuel for boiling water. These problems cause many HIV-positive mothers to breastfeed or practise mixed feeding, even if they have access to formula."

The counsellors warned about the problems associated with the storage of formula and cow's milk in a situation where only few people have a refrigerator at home:

"Replacement milk is often kept in a thermos during the day and also at night. This may cause more harm than benefit to the health of babies."

According to the counsellors, not only the storage of the milk, but also the quality of purchased fresh cows' milk may compromise the safety of this feeding method:

"The safety (dilution) of fresh cow's milk is generally questionable unless the family owns a cow because most sellers are not trustworthy any more – they add some water before selling the milk."

Another major threat to both feasibility and acceptability of replacement feeding is connected to disclosure to partner. Mixed feeding in situations of non-disclosure to partner is, according to the counsellors, a likely outcome.

"Formula feeding is easier if the baby's father knows the mother's HIV status and supports her decision. But stigma and secrecy surrounding HIV/AIDS lead most women not to disclose their HIV status."

Heat-treated breast milk

When it comes to expression and the heat treatment of breast milk the counsellors doubted that the women would be able to express sufficient amounts of milk. More important, however, was their concern that this method would not be acceptable in the community. They explained that the expression of breast milk is highly associated with the death of a child and that it is considered abnormal for a woman with a healthy baby to express her breast milk. One of the counsellors added: *"She becomes a witch – she does not crave for the survival of her child"* (Interview no. 5; with 1 year pMTCT counselling experience)

Wet-nursing

Counsellors were reluctant to promote wet-nursing, citing an incident where a grandmother purportedly contracted HIV from the grandchild that she was nursing following the death of the child's mother. (There was no evidence, however, that the grandmother was tested prior to initiating wet-nursing). They also commented that very few women in the community know their HIV status and that because of the high HIV prevalence in that area, women fear being tested. Wet-nursing was therefore considered very risky in terms of HIV transmission. Besides being considered unacceptable and unsafe respectively, both expressed, heat treated breast milk and wet-nursing raised serious concerns among the counsellors about the risk of disclosure of the mother's HIV status. One of the counsellors elaborated:

"I find it difficult to talk about wet-nursing or expression and heat treatment of breast milk. With the rapid spread of

HIV knowledge in the community nowadays it will automatically disclose a woman's HIV status." (Interview no. 22; with 2 years pMTCT counselling experience)

Study participants' roles as infant feeding counsellors

Mothers' expectations

Some counsellors during discussions said they had problems waiting for the patients to decide for themselves what they would do in terms of infant feeding. It was very tempting for many to tell the women what "would be best for them", to give them "the correct answer". The following quote illustrates:

"We are used to instinctively giving advice on health issues and health behaviours. Now counselling is more than this. We are told to let people decide for themselves regardless of whether they are right or wrong. Yet our clients do not understand why we are no longer advising them on what is best for their health. They think we are becoming rude and irresponsible. Their expectations are to get correct answers from us. I'm really in a dilemma and confused. I don't know if I'm doing right to leave my client unsatisfied."

There was a common perception among the counsellors that they, as professional nurses, were supposed to know what would be best for their clients as regards choice of infant feeding method. They said that their clients (women) visiting the pMTCT clinic, expected to get advice and correct answers from the nurses. Now they were worried that their position as knowledgeable professionals was being undermined through their role as pMTCT counsellors. This apprehension of the expectations from the community is reflected in the following comment during discussions:

"When we don't give them a straight answer, they doubt our knowledge, saying nurses do not know much nowadays. We look like fools."

Another issue undermining trust in the nursing profession was, according to the counsellors, that what they were trained to tell the mothers in the pMTCT programme about breastfeeding was very much at odds with the unambiguous messages that they had been trained to teach during the Baby Friendly Hospital Initiative Campaigns.

"It is not very long ago that we were at the frontline advocating for every woman to breastfeed her newborn baby. Now comes another kind of advice – if HIV-positive woman chooses not to breastfeed, we should support that choice. It shows double standards in the care we are giving."

Lack of confidence and skills in HIV and infant feeding counselling

The nurses complained about lack of confidence in their knowledge of pMTCT. The responses during interviews and FGDs reflected their uncertainty about the medical risks of MTCT and the safety of the different feeding methods. They also attributed this to poor training, out-dated training or no training at all. As one counsellor said:

"I have been working for more than twenty years as a public health nurse, routinely educating mothers on prevailing health problems. I have only attended one workshop for one week on promoting exclusive breastfeeding. I'm still using the same knowledge to educate mothers on how to feed their babies. I feel like I'm not knowledgeable enough to give my clients updates, especially in this time of AIDS." (Interview no.23; with almost 3 years pMTCT counselling experience)

The counsellors were concerned that the timing of infant feeding counselling was inappropriate (immediately after a pregnant woman has received her HIV test results). They questioned both the timing and whether a mother would be able to understand or digest any further information. However, the counsellors during discussions perceived this routine as difficult to change since it was part of the pMTCT package decided upon by the hospital management:

"It has been done like this from the beginning of the programme and there is no way we can change it. It was planned by the hospital management and we were not involved."

Conflicting loyalties

Many of the counsellors were uncomfortable with the strict confidentiality rules of counselling. In general, they were concerned about the fact that confidentiality aiming to protect the individual woman could work to expose others in her environment to HIV infection as expressed in the following quote:

"If the husband is your own brother, you are not allowed professionally to warn him to take precautions, even when the wife doesn't want to disclose her HIV status to him. I feel bad because this is killing your own brother, and I'm not sure if this is allowed according to the ethics of prevent- ing diseases."

Working conditions

Workload

A recurring theme in interviews and FGDs was that the counsellors felt overwhelmed by a constantly increasing workload. The pressure to compromise the quality of

work for the sake of increased workload is expressed in the following quotes:

"The introduction of the pMTCT project in the health facilities has placed an extra load on us because there are many clients waiting to be attended in a very limited time."

"We are working like machines now, it is not possible to stay with one client for long because you have to finish the clients outside, and at the end of the day you need to register how many clients you have attended."

But even though the allowance obtained through counselling is referred to as minimal, it was seen as an important contribution to the family income during FGDs:

"We come here during our days off. We are tired, but because we need this small token called transport allowance to complement the low salary, we have to push ourselves to come, but psychologically and physically we are worn-out from working throughout the week without any rest."

Access to information and reference material

The nurse-counsellors reported having very limited opportunities to keep themselves updated. Considering their many competing concerns related to family life, seeking work-related knowledge during time off was not considered a priority. As one counsellor responded during group discussion:

"We have great demands from our own families for survival. I don't think anyone here can get time to go to the library to read after work. We have to look for some extra money to top up our low salaries."

The counsellors also complained about the lack of reference material to help them remember the things they ought to inform the mothers during infant feeding counselling:

"We are overworked, and yet even when you are very tired you are expected to remember all the steps required as written in books. Are we computers that remember everything? We need to have something written down to refer to when counselling mothers."

Lack of tools for demonstrations on how to prepare cow's milk and infant formula was also said to compromise the quality of work as mothers need to see how the preparation should be done to fully understand and remember the procedure.

Inability to make home visits

Another issue that was experienced as unsatisfactory by the counsellors was the lack of support to follow up women after they had given birth:

"There is no transport for us to do follow-up of our clients at home. We cannot say anything about the outcome of our work."

"Our counselling work is not complete because we don't know what happens to our clients when they go home after being counselled at the clinic."

Stress and frustration

Hopelessness and death

Many of the counsellors found that they were trapped in a feeling of hopelessness and that their work had little in common with the ambition to heal, which they saw as the very heart of the nursing profession. The following quotes illustrate:

"HIV/AIDS has increased our feeling of hopelessness. We had chosen this profession to heal, but now we have to watch people dying slowly. We have very little to prevent them from dying."

At the same time, the nurse-counsellors were reminded about their own vulnerability in the HIV epidemic. A high level of identification with the patient added to the feeling of hopelessness:

Thinking about the situation at our work, we feel more hopeless and helpless as it always reminds us that, at the end of the day it may be you in that situation of that client, and there is no cure for HIV infection."

Some counsellors expressed signs of depression and burn-out during interviews, and they were aware that this affected the quality of the services they offered:

"I feel down morally and spiritually when most clients tested on that day are HIV- positive. I get much stressed and I feel very sad deep down in my heart. This feeling distorts all my happiness for that day." (Interview no. 13; with 1 year pMTCT counselling experience)

"You get home exhausted, and when you think back at the end of the day you end up frustrated because you did not give adequate care to your clients, is only counting how many clients you have attended in that day. Sometimes we are rude to clients and to our own children because of stress and tiredness." (Interview no. 2; with 3 years pMTCT counselling experience)

At the same time, some counsellors in the FGDs felt that they were being judged unfairly:

"Like any other human being you become aggressive when you are tired and emotionally distressed. We are like any other human beings, we are always faced with distressed people to whom we have very little to offer, it's frustrating, and it is not fair when people say we are rude."

Discussion

The present study addressed the well-documented widespread problem of sub-optimal infant feeding counselling in pMTCT programmes in low income settings, and set out to explore this issue from the viewpoint of the counsellors themselves. The following discussion will focus on significant issues related to the counselling work that appeared to be of major importance for the quality of the counselling offered in the pMTCT programmes in Kili-manjaro region.

Trust

The HIV pandemic has brought about major transitions in terms of nurses' assignments, not least manifested in the major shift in the nursing role from health educators to counsellors. Counselling is a highly complex relational process which requires both knowledge and professional confidence and skills on the part of the counsellor, as well as trust on the part of the client. It requires a very different approach to patient interaction from traditional nursing – an approach that in the present study was found highly challenging to nurses and clients/patients alike [36]. Skills in infant feeding counselling are not yet covered in the nursing curriculum, and the nurses do not feel that they have sufficient competence in their new roles as counsellors.

Moreover, nurses experience that their roles as educated individuals with particular trusted skills and knowledge have become threatened by their newly gained roles as counsellors operating within an atmosphere of patient self-determination and health-related decisions resting with the patient. According to the nurses in the study, on their part the pMTCT clients do not feel comfortable with the newly gained roles of the nurses either. Patients expect to be told what is right and wrong and what they should do to prevent illness or to heal disease, and they feel betrayed by nurses who appear to lack the necessary authoritative knowledge that can help them. Both nurses and clients feel that the counselling role leaves nurses with a diffuse guiding role, a role that is vague to the extent that it generates a substantial problem of trust. Indeed, in the case of pMTCT, the challenge of trust is perceived as threatening the very confidence and faith that clients or patients have customarily had in nurses.

The problem of trust should also be viewed in the light of the knowledge on which pMTCT rests. In the case of infant feeding counselling in pMTCT programmes, knowledge of how to reduce HIV transmission through breastfeeding is vested in the counsellors. A major counselling dilemma as documented in this study is that most counsellors believed that formula feeding was the 'right way' for an HIV-positive woman to feed her infant. The implications of this perception may however be fatal to the lives of babies in a context where most HIV-positive women are too poor to practice safe replacement feeding. This finding is contrary to the previous findings of a study conducted in the same area by de Paoli and colleagues [32], which documented that the counsellors distrusted replacement feeding and were inclined to advise HIV-positive women to breastfeed. This difference might be explained by the increased public attention given to pMTCT and HIV transmission through breastfeeding during recent years.

A basic condition for successful pMTCT counselling is that the counsellor not only has confidence in her own professional knowledge, but also in the relevance and applicability of this knowledge for the individual woman in her particular situation. The findings in this study show that the nurse-counsellors do not have this kind of confidence in the work they are set to do. Nurse-counsellors would continuously state that they were not well enough informed or skilled about MTCT to be able to present the message well enough for the mothers to make 'informed choices'. What appears as more serious however, is that the nurses in the study simply did not believe that any of the alternative infant feeding methods they were proposing to the mothers – including exclusive breastfeeding, cow's milk feeding or formula feeding – were either socio-culturally acceptable or practically feasible in the social and cultural context of the Kilimanjaro region. Wet-nursing and the expression and heat treatment of breast milk emerged as so farfetched in the present context that they were not introduced as options for the mothers to consider. At none of the research sites did the nurse-counsellors believe that most of the mothers would be able to adhere to either exclusive breast feeding, formula feeding or other replacement feeding, as these methods violated cultural norms or were too impractical. Consequently the nurses simply did not believe in the very health-promoting concept they were set to work with.

Motivation

The experience of job motivation and job satisfaction is closely linked to the experience of doing an important and meaningful job. Lack of trust in both the role as nurse-counsellor and in the measures proposed to prevent mother-to-child transmission was experienced as highly damaging for the motivation of the work as a nurse. The

lack of motivation for and confidence in the work as pMTCT counsellor was encountered in contexts characterised by severe shortage of staff and immense time constraints that left the nurse with merely a few minutes to present and discuss the complex pros and cons of the various infant feeding options with each client. The clients were women who had just received an HIV-positive diagnosis and who had an enormous demand for nursing care and for someone to talk to. The time constraint thus emerged in this context as inhuman and was challenging the very core of nursing care. The combined challenges experienced by the pMTCT counsellors generated immense frustration and an experience of job-related meaninglessness. This is also in line with findings from a study in South Africa by Buskens and colleagues [23,24].

Global policies in local context

The dynamics in the encounter between highly complex and biomedically founded pMTCT regimes and the realities of local African women's lives proved to be challenging to the extent that it caused confusion for nurses and clients alike. Several studies have documented the key role of nurses and midwives in influencing mothers' positive decisions on infant feeding [16,17]. Other studies have documented that, with formal and supportive supervision, nurses can significantly increase the rates of exclusive breastfeeding [18-20]. This study indicates that in the context of the present pMTCT initiatives in the Kilimanjaro region there appears to be a long way to go before similar positive results can be recorded. Based on the challenges encountered by nurse-counsellors in the present pMTCT programme combined with the problems that mothers face trying to adhere to the recommended feeding methods [37], the impact of the infant feeding component of the pMTCT programme on infant feeding outcomes is uncertain.

Limitations

In interpreting the findings of the present study, several limitations must be acknowledged. The relatively small number of pMTCT nurse-counsellors participating in this study may not be representative of the nurse-counsellors working in the Kilimanjaro region and even less in Tanzania as a whole. We do believe however, that the results which are based not on one, but on four pMTCT programmes in Moshi, and which are collected through a triangulation of research methods, have considerable relevance for pMTCT programmes well beyond the four study sites. Furthermore, the scope of the study is limited. A more comprehensive exploration of problems that compromise the quality of counselling would involve other groups of study participants – primarily HIV-positive women (for their views on counselling services) and hospital administrators (for structural issues). These groups

of study participants are however included in a forthcoming publication.

Conclusion

In this paper, we have explored the experiences of nurse-counsellors responsible for counselling HIV-positive women on infant feeding in pMTCT programmes. We conclude that the experiences of the study participants were characterised by combined challenges related to the shift from a health-educator to a nurse-counsellor role and the enormous work burden, as well as a fundamental lack of confidence in the feasibility of the infant feeding component of the pMTCT programme in this local African context. One important question that emerged is: *how can nurse-counsellors implement the proper promotion of a component package they do not believe in?* The paper supports the critical notion that successful counselling is hardly a matter of biomedical or nursing knowledge and practice alone. Counselling, even more than traditional nursing, requires time and a fundamental knowledge of the socio-cultural environments within which particular health-related issues are addressed.

In light of the above findings, the conditions under which nurse-counsellors are expected to provide good quality counselling services are critically questioned. To improve these conditions and the confidence of counsellors, infant feeding counselling training and skills development as reflected in the policy guidelines is fundamental and should be integrated into pre-service and in-service training courses. Furthermore, culturally-appropriate counselling tools can be developed as a way to improve the standardisation and routine of infant feeding counselling. However, though important, elevating the level of knowledge, skills and confidence of the nurse-counsellors does not address the fundamental issue of the acceptability and feasibility of the infant feeding methods in the local community. Community-based approaches to increasing the acceptability of the safer infant feeding options – and in particular exclusive breastfeeding – should be strengthened. At the same time continuing research aiming to improve the safety, feasibility and acceptability of the recommended infant feeding methods for HIV-positive mothers is urgently needed.

Competing interests

The author(s) declare that they have no competing interests.

Authors' contributions

SCL contributed to the conception and design of the study, conducted the data collection, and was responsible for the analysis of the data. She drafted the manuscript and revised it. AB and KMM contributed to the conception and design of the study. AB, MDP and KMM critically

reviewed draft versions of the manuscript. All authors read and approved the final version of this manuscript.

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Translating global recommendations on HIV and infant feeding to the local context: the development of culturally sensitive counselling tools in the Kilimanjaro Region, Tanzania

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Abstract

Background: This paper describes the process used to develop an integrated set of culturally sensitive, evidence-based counselling tools (job aids) by using qualitative participatory research. The aim of the intervention was to contribute to improving infant feeding counselling services for HIV positive women in the Kilimanjaro Region of Tanzania.

Methods: Formative research using a combination of qualitative methods preceded the development of the intervention and mapped existing practices, perceptions and attitudes towards HIV and infant feeding (HIV/IF) among mothers, counsellors and community members. Intervention Mapping (IM) protocol guided the development of the overall intervention strategy. Theories of behaviour change, a review of the international HIV/IF guidelines and formative research findings contributed to the definition of performance and learning objectives. Key communication messages and colourful graphic illustrations related to infant feeding in the context of HIV were then developed and/or adapted from existing generic materials. Draft materials were field tested with intended audiences and subjected to stakeholder technical review.

Results: An integrated set of infant feeding counselling tools, referred to as 'job aids', was developed and included brochures on feeding methods that were found to be socially and culturally acceptable, a Question and Answer Guide for counsellors, a counselling card on the risk of transmission of HIV, and an infant feeding toolbox for demonstration. Each brochure describes the steps to ensure safer infant feeding using simple language and images based on local ideas and resources. The brochures are meant to serve as both a reference material during infant feeding counselling in the ongoing prevention of mother to child transmission (pMTCT) of HIV programme and as take home material for the mother.

Conclusion: The study underscores the importance of formative research and a systematic theory based approach to developing an intervention aimed at improving counselling and changing customary feeding practices. The identification of perceived barriers and facilitators for change contributed to developing the key counselling messages and graphics, reflecting the socio-economic reality, cultural beliefs and norms of mothers and their significant others.

Background

The documentation of breastfeeding as a source of human immunodeficiency virus (HIV) infection in babies born to HIV positive mothers represents a public health dilemma, especially in countries with a high HIV prevalence rate and where breastfeeding is the norm and essential to child survival [1-4]. According to the UNAIDS update for 2005, 700,000 infants are HIV infected every year, with an estimated 5 to 15 percent of children born to HIV positive women being infected through their mother's milk [5]. As knowledge about the risk of HIV transmission through breastfeeding has reached health care workers, the general population, and individual mothers, uncertainty has developed on how best to feed infants in the context of HIV. Women who know or suspect they are HIV positive are faced with difficult and complex choices [6].

Current international guidelines [2] on infant feeding for HIV positive mothers promote *replacement feeding* (infant formula or animal milk) or *exclusive breastfeeding* (with no supplements of any kind). A mixed feeding pattern, where breastfeeding is combined with other milks, liquid foods or solids, has been shown to increase the risk of transmission [7-9] and is strongly discouraged. Current guidelines state: 'When replacement feeding is *not* acceptable, feasible, affordable, sustainable and safe (AFASS), exclusive breastfeeding is recommended during the first months of life' [2]. Based on the principle of *informed choice*, health workers are encouraged to give HIV infected women the best available information on the risks and benefits of each feeding method, with '*specific guidance in selecting the option most likely to be suitable for their situation*' [2].

Prevention of Mother To Child Transmission (pMTCT) programmes are rapidly expanding throughout sub-Saharan Africa, with several key intervention pillars: voluntary counselling and testing (VCT), anti-retroviral prophylaxis and infant feeding counselling [10]. However, inadequate training of health workers, particularly pMTCT counsellors, related to the relative risks associated with infant feeding in the context of HIV, the feasibility and safety of replacement feeding, lack of culturally sensitive counselling tools and the stigma associated with both replacement feeding and exclusive breastfeeding make appropriate and effective infant feeding counselling difficult [7]. According to previous research, mothers' adoption of and adherence to the recommended feeding methods is also a problem [11-13]. A study in Nairobi, Kenya, that aimed to determine feeding practices and the nutritional status of infants born to HIV-1 infected women, for example, reported that 31% of the HIV positive, counselled mothers participating in the study practised mixed feeding six weeks after delivery [14]. One of the major challenges facing women in adopting and adhering to current recommendations is access to good

quality information [15]. Research shows that many counsellors are not adequately informed about how to protect infants from HIV transmission and may not even be aware of the existence of updated guidelines [6,11]. Few have received sufficient training on counselling in the context of HIV [16], and pMTCT programmes in general lack counselling tools and other resources [17]. Staff shortages and the associated lack of time to counsel properly, even for those adequately trained in infant feeding counselling are further barriers to the provision of informed infant feeding choices [18].

This article describes the development of an integrated set of counselling tools, referred to as 'job aids', based on the updated international guidelines and related World Health Organization (WHO) and UNICEF generic counselling materials. The development process followed an intervention mapping (IM) framework [19], with the ultimate aim of producing a cost-effective, culturally sensitive and technologically appropriate set of tools to improve the quality and relevance of infant feeding counselling. A further objective was to strengthen HIV positive mothers' ability to both make an informed choice and safely execute a feeding method appropriate to their personal situation.

Job aids have gained status in health promotion as a cost-effective way to improve the *performance* of service providers, such as nurses, and are often defined as tools that reduce guesswork, minimize reliance on memory and promote compliance with standards [20,21]. Decision aids, or client oriented job aids, are often used to guide patients through a series of steps, giving them personalized information and/or helping them clarify their values and risk exposure in the context of health related options [20,22]. Job aids often feature visual images or graphics to enhance users' understanding of written information. To strengthen the relevance and potential for identification, both the images and the written messages should resonate with people's beliefs. In the development of the job aids reported here, both written messages and visual images were developed to reflect the local social and cultural context in the communities.

The study was located at the pMTCT clinic at KCMC (Kilimanjaro Christian Medical Centre) outside Moshi town in Kilimanjaro Region in northern Tanzania, where the HIV prevalence rate in the antenatal population is estimated at 5.7% [23]. Breastfeeding is normative in the area, but early supplementation with water, cow's milk and porridge ('partial' or 'mixed' breastfeeding) is standard practice [11]. The pMTCT clinic at KCMC recruits patients from the antenatal clinic, which primarily serves women from Moshi town and its rural outskirts. It offers the standard package of VCT, ARV prophylactics and infant

feeding counselling to pregnant women and their partners.

Methods

Use of intervention mapping (IM) in the planning process

The importance of careful theory based intervention planning has been recognized since the publication of the Precede-Proceed model [24], where a needs assessment is conducted to identify the health problems to be addressed, the health behaviours that should change, and the psychosocial and environmental determinants to be translated into interventions. Building on the needs assessments, IM uses a stepwise approach in developing programme objectives (i.e., performance and learning objectives) and guiding the selection of intervention strategies and intervention tools [19,25]. IM promotes close collaboration between programme developers, the target population and programme users, increasing the probability of developing a user relevant intervention. IM suggests five steps based on established theories, empirical evidence and additional qualitative and quantitative research [19]. This study addresses IM steps 1 to 3.

IM Step 1 is to define the performance objectives or the behaviours that need to be taught to achieve the overall aim of the intervention programme. In turn, learning objectives are specified (e.g. mothers recognizing the importance of exclusive breastfeeding) based on the individual and environmental determinants (e.g. awareness, attitudes, social support and self-efficacy) of those performance objectives (exclusive breastfeeding). For mothers to accomplish behaviour change related to breastfeeding, recognizing the importance of that behaviour (attitudes) and utilizing external sources (social support) and personal skills to cope with barriers (self-efficacy) might be important learning objectives. Potential individual and environmental determinants of recommended practices were identified from literature reviews, focus group discussions (FGDs) as well as reviews of theoretical models [19]. The learning objectives specified were thus intended to answer the question: "What does the target group need to learn about a specific behavioural determinant in order to accomplish the performance objectives?"

Step 2 of IM uses theory as a foundation for selecting educational methods and strategies that match the learning objectives. Bandura's Social Cognitive Theory (SCT) provides a framework for articulating learning objectives, combining individual and social factors that influence practices. In accordance with SCT, it was postulated that 1) mothers who have inadequate *knowledge* about mother to child transmission of HIV would not decide to change their infant feeding practice, 2) mothers who consider their baby to be constantly *at risk of HIV infection* will be

hampered in their decision to change their feeding method, 3) mothers who perceive serious *disadvantages* associated with recommended feeding methods would not change existing feeding habits, 4) mothers whose *significant others* (e.g. husbands and/or mothers in law) insist on a mixed feeding pattern will not easily choose or adhere to exclusive breastfeeding and 5) mothers who lack *confidence* in their ability to carry out a recommended feeding method may end up feeding their infants in a customary manner. Following the SCT [26], specific techniques that include information transfer, role modelling, skill building, social support and reinforcement have been developed to modify self-efficacy and other beliefs. These techniques have been widely applied and found to generate behaviour change [19,27]. These selected educational methods were further translated into practical strategies and key messages. Step 3 of IM is to develop the programme and to pre-test materials which are the major focus of this paper. Step 4 and 5 consist of programme adoption, implementation and evaluation, which will be discussed in a subsequent paper.

Using a participatory approach

Strategic participation and consensus building between all major stakeholders was seen as critical to the process of developing the intervention, in order to ensure its social and cultural relevance and scale-up. Policy makers, technical experts, service providers and clients were involved in various phases of the process. HIV positive mothers, local community members and nurse counsellors responsible for the day to day running of the pMTCT programme participated in the formative research and in the field testing of draft materials. Members of the national consultative group responsible for developing guidelines on human immunodeficiency virus and infant feeding (HIV/IF) and other national and international technical experts provided technical guidance during the planning process as well as during the materials' design/adaptation of technical content and images from existing generic materials. A broad participation in the technical review of draft materials was achieved through electronic correspondence and the simultaneous transfer of digital graphic files to reviewers via the internet.

Formative research

The study team conducted formative research between August 2003 and February 2004 with a double purpose: 1) to identify existing, strongly held beliefs and behaviours to be addressed by the intervention, and 2) to determine how to effectively communicate these messages in a culturally appropriate and relevant manner through key messages and illustrations. All discussions and interviews were conducted in Swahili (Tanzania's national language) using interview/discussion guides and were tape recorded, transcribed and translated into English.

With the assistance of community leaders, the team conducted 15 interviews with key informants: traditional birth attendants, community elders, members of community health committees and nurse counsellors. Eight focus group discussions (FGDs), each with 8–12 participants, were conducted among 'ordinary' community members in two wards in Moshi District. The aim was to assess knowledge, beliefs and attitudes about pMTCT, breast-feeding, replacement feeding, mixed feeding and safe sex. In order to promote homogeneity and active participation, participants were recruited by age and gender (young women, older women, young men and older men). Ten HIV positive mothers who were recruited through the pMTCT programme at KCMC, and who gave their consent to participating in the study, were visited at home and interviewed about their views of and experience with infant feeding. In order not to raise suspicion and cause involuntary disclosure of HIV positive status, other post-natal mothers were also visited in their homes and interviewed on infant feeding.

Field testing of illustrations and draft materials

As part of the intervention, the study team aimed to develop culturally appropriate images for the job aids that reflected the local environment, dress code and ideals related to family life and infant feeding. Digital photographs were taken in homes and communities for use as references for the development of high quality, colourful illustrations using a state of the art computer graphics technique. This process allowed images to be easily altered based on feedback from both communities and technical subject experts. Initial drafts of the illustrations were pilot tested in four FGDs composed of mothers and community members in different villages on the outskirts of Moshi town, as well as among pMTCT counsellors working at KCMC. A colour copy of each image was laminated for circulation during FGDs to elicit participants' feedback on the colours and other aspects of the images. FGD participants received black and white photocopies of all images to hold and study during the group session. This field testing process was critical to the finalization of the initial set of materials in that: 1) it provided essential feedback from community members and the counsellors that enhanced the overall quality and acceptability of the images; and 2) underscored the important role of the illustrations in communicating key messages visually. Based on the field test results, adjustments to the illustrations were made, including the relative sizes of the infants, colours and type of clothing, composition of cooking fires and utensils used for preparing replacement feeds.

Simulated counselling sessions

Finally, the research team observed nurse counsellors during simulated counselling sessions with mothers where different infant feeding options were discussed. Simula-

tion was necessary given institutional restrictions on direct observation of counselling and provided important insights into standard client provider interaction and counselling practices.

Data collection and analysis of data

Interviews, FGDs and observations were conducted by the first author (native to the area), with the support of an experienced local female research assistant. A local elder arranged the interviews and FGDs at community level. Great care was taken to ensure that all the information collected remained confidential. The counselling tools were field tested and modified before final production. The analysis was performed using the 'thematic content analysis' frameworks [28,29], consisting of reading and re-reading the field notes and transcribed texts, manual coding in the margins, and synthesizing and grouping data in relatively exhaustive categories.

Ethical permission

National, regional and local authorities in Tanzania, including the Tanzania National AIDS Control Programme, the medical authorities in the Kilimanjaro region and the ethical committee at KCMC provided approval to conduct the research. Each participant provided informed consent to participate.

Results

Perceived risk of mother to child transmission of HIV (MTCT)

Focus group participants understood that infants can be infected with HIV through their mothers during pregnancy, delivery and breastfeeding, but the relative risk of transmission was strongly overestimated. The common belief was that if a mother is HIV positive, her infant will be automatically infected. Although the HIV positive women who had been counselled were generally better informed about MTCT than the focus group participants, they also overestimated the risk and underestimated the potential of prevention through safer infant feeding and safe sex during breastfeeding.

Knowledge, practices and beliefs associated with HIV/IIF options

Exclusive breastfeeding

All focus groups saw breastfeeding as the best way to feed an infant and believed it should preferably be practised into the second or third year of life. Exclusive breastfeeding, however, was not seen as being customary or feasible beyond three months because breast milk was considered insufficient for the child's growth and because mothers generally had to resume activities outside the house (FGDs and interviews). Poor maternal nutrition was also mentioned as an obstacle (interviews). There was a common belief that babies need water in their first month

because they 'feel thirsty', and FGDs reported that sometimes babies were given water even before breastfeeding was established. Boiled water and gripe water were seen as essential for the relief of abdominal colic, and many believed that water should be given at least daily. Complementary foods were usually introduced before the baby reached three months (FGDs and interviews). Interviewed mothers reported that they introduced light porridge mixed with cow's milk at around two months because they believed their milk was not enough to make the baby grow 'fat and shiny' as expected by kin and neighbours. Mothers were generally concerned that exclusive breastfeeding might raise suspicion of HIV positive status.

Cow's milk feeding

Cow's milk, usually diluted with water and sugar, was the feeding method most commonly used as a supplement to breastfeeding (FGDs and interviews). However, it was not generally regarded as an adequate replacement for breast milk unless the mother had died or had very good health reasons for not breastfeeding (all FGDs).

Commercial infant formula

FGDs indicated that infant formula was not considered the best way to feed an infant and was too expensive for most people. Mothers interviewed reported that they were generally uncertain about the use of infant formula, and those who had used it experienced problems calculating the right amounts of formula powder and water. Opinions on the use of leftover formula were divided: many of the FGD participants were concerned that formula should not be discarded, but mothers who had been counselled said that leftover formula should be. Some mothers reported that for convenience they prepared the formula once a day and kept it in a thermos from morning to evening.

Other animal milks

Although the updated international guidelines and generic counselling materials provide guidance on preparing other animal milks as breast milk replacement (e.g. goat, camel, evaporated cow's milk and powdered whole cow's milk), the formative research revealed that these alternatives were generally not available or prohibitively expensive in the Kilimanjaro markets.

Expression and heat treatment of breast milk

The feasibility and acceptability of expressed and heat treated breast milk was also discussed during focus groups and interviews. Community participants stated that this option seemed too time consuming to be a practical alternative to breastfeeding. Several mentioned that expression of breast milk was strongly associated with stillbirths, infant deaths or pre-term births (FGDs and interviews). Nurse counsellor 'informants' mentioned, however, that

hospital staff used to teach hand expression as part of normal breastfeeding counselling under the Baby Friendly Hospital Initiative in the 1990s, and some agreed that it was important to provide information to mothers on this technique. The concept of heating expressed breast milk, however, was strongly rejected by a number of participants.

Wet nursing

Focus group participants reported that wet nursing by a close relative, such as a grandmother or an aunt, used to be an alternative for orphans and infants born to sick mothers. However, due to fear of HIV transmission, wet nursing is no longer considered safe and has been discontinued. Mothers reported that they would not consider wet nursing because it would encourage neighbours and kin to ask questions on ones HIV status.

Perceived disadvantages of replacement feeding and exclusive breastfeeding

Apart from the practical and economic disadvantages of replacement feeding, the focus group participants were concerned that a mother who did not breastfeed her infant would jeopardize her reputation as a 'good mother'. People would suspect that she had a lover or that she was HIV positive. Mothers explained that community commitment to breastfeeding is so culturally embedded that refusal to breastfeed, without a strong reason, could result in loss of respect, rejection and withdrawal of the assets otherwise granted to a woman during postnatal confinement. Both *not* breastfeeding and a baby's failure to thrive are increasingly associated with maternal HIV infection (FGDs). At the same time, exclusive breastfeeding beyond two or three months, the 'normal' period, without giving any supplements could also be interpreted as an indication that the mother might be HIV positive (interviews).

Experiences of social pressure and lack of control

Although all HIV positive mothers who had been counselled perceived replacement feeding as the best option in terms of MTCT risk reduction, most ended up breastfeeding, some after initially opting for and/or initiating replacement feeding. They explained that they could not withstand the social pressure to breastfeed and were concerned about their reputation as good mothers. They were aware that they should either exclusively breastfeed or exclusively replacement feed to reduce the risk of MTCT, but they all perceived these methods as difficult since they could not fully control the feeding situation. FGDs revealed that mothers in law have considerable power in issues related to infant feeding. Women who spent the confinement period in their mother in law's house all felt that they had to breastfeed while also experiencing great problems preventing the mother in law from giving water

and other supplements to the baby, often within the first few days or weeks of birth.

Some mothers reported giving their babies additional fluids and foods to save their own energy. One mother said during an interview: "I would rather mix feed the baby than have people pointing fingers at me, whispering behind my back that my body looks thin and that I was probably HIV infected."

Lack of knowledge and confidence in implementing the recommended feeding options

Mothers who had been counselled reported that it was difficult to understand the advantages of exclusive breastfeeding compared to mixed feeding, and that exclusive breastfeeding was hard to practise. They reported that they did not feel adequately informed about HIV/IF and that the information was often given on the same day that they received their HIV test results. Only two out of ten HIV positive mothers interviewed could recall HIV/IF information from the counselling session. Mothers who chose replacement feeding after being counselled expressed uncertainty about preparing the formula or cow's milk, especially calculating feeding quantities and frequency. None received written instructions to take home. Mothers who chose breastfeeding reported receiving little or no guidance on exclusive breastfeeding or breast care. Problems with breastfeeding included uncertainty about how to manage cracked or bleeding nipples and thrush in the baby's mouth. The experience of painful, hot and engorged breasts was confirmed as a major cause for discontinuing breastfeeding. Poor positioning of the baby during breastfeeding was observed during home visits.

Nurse counsellors' knowledge, practices, perceptions and beliefs

pMTCT nurse counsellors reported that they found it difficult to promote exclusive breastfeeding as an option since they did not believe that mothers could or would adhere to this method, for a variety of reasons, especially for more than two or three months after birth. Many believed that replacement feeding, and in particular infant formula, was the best option for preventing MTCT and generally recommended this feeding method, even if they did not think it was feasible. They reported that the major barrier to commercial formula feeding was cost. Very few referred to gender or other contextual issues such as poor decision making power on the part of the woman, fear of disclosure, or social pressure to breastfeed. Literacy and access to clean water and fuel needed for safe formula feeding were not mentioned as conditions affecting which feeding method(s) to recommend.

The counselling simulation revealed that the counselling session was constructed as a traditional client provider sit-

uation [30], where the nurse counsellor informed the client about the different feeding options but actually gave 'strong advice' on which to choose. A supportive dialogue was not established, practical guidance was absent, and the time spent with each mother was considered inadequate.

The formative research process revealed a high level of consensus among the different stakeholders concerning infant feeding, infant feeding in the context of HIV, and the appropriateness of the various feeding methods.

Discussion

The formative research findings underscore the complexity of HIV/IF and associated pMTCT counselling. Problems include counsellors and the individual clients' knowledge, the mother's decision making power, collective infant feeding norms and beliefs, poor access to information and resources (counselling tools and take home materials), time constraints and limited inter-personal communication and counselling skills.

Dissemination of findings and initial consensus building

In line with the study team's participatory approach, the formative research findings were disseminated and subsequently discussed with different groups of stakeholders at facility, district, regional, national and international level. Both electronic correspondence and face to face meetings were used to achieve the broadest possible participation of various national and international stakeholders and other technical experts. These discussions aimed to disseminate information on the barriers and facilitators of change of infant feeding, to develop a feasible behaviour change *strategy* and to obtain consensus and support for the proposed intervention.

Rationale for the focus on developing an integrated set of job aids

In selecting the intervention strategy, a number of important issues were taken into consideration, including time for developing the intervention, available resources and infrastructure. The study team fully realized that not all aspects of this very complex, multi-dimensional problem could be addressed with just one intervention. Given that the pMTCT programme was already well established at KCMC, that a relatively high level of trust was enjoyed by the pMTCT nurse counsellors and that the government planned to scale up its pMTCT programme, the idea of strengthening pMTCT counselling services was determined to be the most appropriate focus. Although the study team recognized that a health systems approach may have limited impact in a context where infant feeding decisions are traditionally made at home, the formative research confirmed that ideas emanating from the health care system generally reach the larger population. The

pMTCT programme was acknowledged as the major arena for information exchange related to infant feeding in the context of HIV counselling and testing.

Development of performance and learning objectives and key messages

Following dissemination of findings and initial consensus building, performance objectives were identified for the HIV positive mother – to either exclusively breastfeed for up to six months or exclusively replacement feed. Performance objectives were also identified for the counsellors – to practise culturally sensitive counselling based on the updated international HIV/IF guidelines, and to use AFASS criteria for assisting HIV positive mothers in selecting the most appropriate infant feeding method based on their own personal situation. Based on the formative

research and guided by the IM protocol, personal and social determinants of the recommended feeding methods were articulated (e.g., perceived risk, knowledge and beliefs, perceived social and practical disadvantages) and were matched with educational strategies, key messages and visual images. Table 1 and 2 list the learning objectives and their modifiable determinants with related educational strategies for mothers and counsellors that were applied during the development of the intervention. Drafts of WHO and UNICEF generic counselling materials were collected along with other existing infant feeding related counselling and information, education and communication (IEC) materials. Existing materials were reviewed as part of a benchmarking process, and their appropriateness was assessed in light of the formative research findings, the established learning objectives and

Table 1: Selected educational methods and strategies related to learning objectives and modifiable behavioural determinants among breastfeeding mothers

Performance objective: Exclusive breastfeeding		Modifiable behavioural determinants		
Learning objectives	Awareness-attitudes	Preferences	Self efficacy/skills	Social influence
Mothers can explain positive health consequences for the baby following exclusive breastfeeding and giving colostrum	Information transfer, presenting personally relevant information, content and images of breastfeeding brochure	Information transfer, personally relevant information, content and image of brochure		
Mothers have confidence and can practice proper positioning of baby at the breast when breastfeeding	Information transfer, presenting personally relevant information, content and images of breastfeeding brochure		Instruction – presenting topics in recognizable situations, showing techniques, facilitating factors-content and images of brochure	Role modelling, content and images of take home brochures
Mothers can name important persons to consult in case of breast problems	Information transfer, presenting personally relevant information, content of and images of breastfeeding brochure		Encouragement to ask for help and assistance, facilitating factors, content and images of brochure	
Mothers can explain positive health consequences of safe sex	Information transfer, presenting personally relevant information, content and images of brochures, counselling card	Information transfer, linking new information to old		
Mothers will have adequate perception of incidence and prevalence of MTCT	Information transfer, presenting personally relevant information, counselling card			
Mothers can explain what she can do in case of breast problems	Information transfer, presenting personally relevant information, content and images of breastfeeding brochure	Personally relevant information	Instruction-practices, positive reinforcement, discuss how to overcome barriers	Role modelling-image of brochures

Table 2: Selected educational methods and strategies related to learning objectives and modifiable behavioural determinants among pMTCT counsellors

Performance objective: <i>Counselling on infant feeding options</i>	Modifiable behavioural determinants				
	Learning objectives	Awareness-attitudes	Preferences	Self efficacy/skills	Social influence
Good interpersonal relationship with mothers	Information transfer-training, Q&A Guide, content and images of brochures, counselling card			Instruction on how to overcome barriers, training interpersonal communication	
Has confidence with respect to counselling mothers on exclusive breastfeeding in the context of HIV	Information transfer, training, Q&A Guide, content and images of breastfeeding brochure, counselling card			Instruction on how to overcome barriers, facilitating factors, training interpersonal communication	Receive information about family attitude and behaviours
Can explain to the HIV infected mother how to negotiate replacement feeding	Information transfer, training, Q&A Guide, content and images of replacement feeding brochures, counselling card			Training interpersonal communication, feedback, positive reinforcement, role modelling	Information on the attitudes and behaviours at home and in the community

feedback from stakeholders and other technical experts. Local adaptations of the technical content of specific generic infant feeding materials were proposed by the study team based on the key messages that were determined to be culturally and socially acceptable/relevant. Ideas were also identified through the formative research for developing and/or adapting images.

Technical content and illustrations used in the job aids

The job aids developed in this study were designed to support infant feeding counselling in ongoing pMTCT programmes and infant feeding practices by mothers in their home environment. They were meant to be reviewed with clients during a counselling session to strengthen and improve counselling, increase knowledge transfer, encourage informed choice and reinforce positive behaviour change. They were then intended to be given to the client to take home as a personal reference or memory aid to support adherence to the recommended infant feeding methods.

During the development/adaptation process, the study team sought to present the basic, essential information using a logical sequence (flow) of key messages and high quality graphics. The text was developed initially in English to facilitate a broad participatory technical review, and subsequently translated into the local vernacular, Swahili. The content targeted the literacy level and socio-cultural values of the local communities. Since educational levels in the region are relatively high, fairly large amounts of text were allowed. To ensure a minimum comprehension, however, colourful graphic illustrations

reflecting the cultural characteristics and clothing, typical family life and locally available technologies (e.g. utensils and cooking fires) were selected to visually support and communicate the major technical content (key messages). The illustrations, considered an essential element of the job aids, highlight images of mothers safely feeding infants following the recommended HIV/IF guidelines.

Description of each element of the integrated set of job aids

The integrated set of HIV/IF job aids included a Question and Answer Guide (Q&A), infant feeding method brochures, a counselling card on the relative risks of HIV infection and an infant feeding 'tool box'.

The Question & Answer Guide (Q&A)

The Q&A was designed for use during training and as a reference for health care workers to help answer commonly asked questions about HIV and infant feeding. It summarised the current international guidance on HIV/IF in a simple to read and graphically illustrated question and answer format. Questions were divided into four categories: protecting babies from HIV; infant feeding options; advantages and disadvantages of the most popular options; and safer breastfeeding and maternal nutrition. (See Figure 1.)

The exclusive breastfeeding brochure

Current international guidelines promote exclusive breastfeeding for six months by all HIV negative women, women of unknown status and HIV positive women who either choose to breastfeeding and/or do not meet the

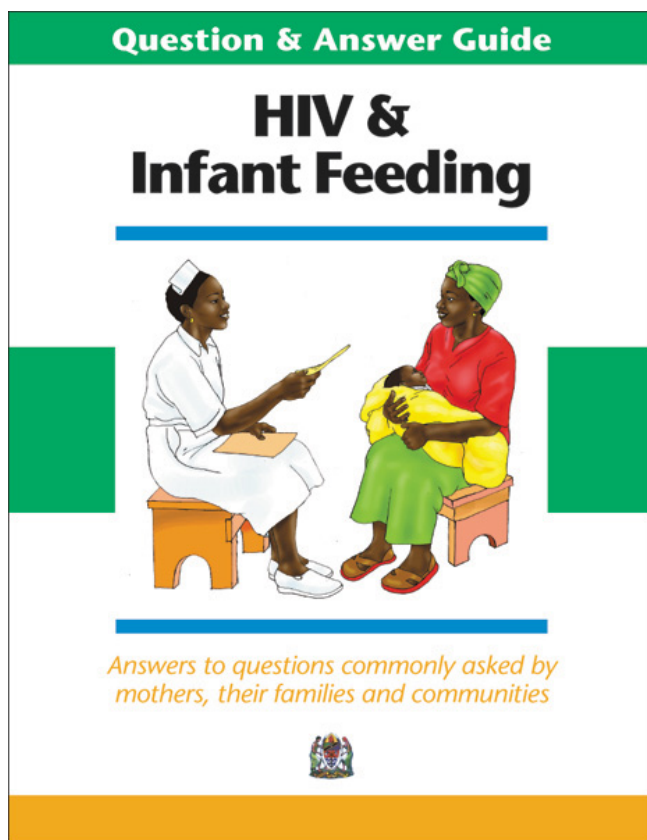


Figure 1
Shows Question & Answer Guide for counsellors on commonly asked questions about HIV and infant feeding.

AFASS criteria for replacement feeding [2]. A major concern in the development of the integrated set of materials was the need for a breastfeeding brochure that was 'universally acceptable', that could be used as an educational and promotional tool with the general population. Consequently, the team took great caution in developing the brochure to: 1) support efforts to promote exclusive breastfeeding for the first six months of age; 2) avoid any association between exclusive breastfeeding and HIV positive status; and 3) ensure that HIV positive mothers using the brochure were not "exposed" or inadvertently put in jeopardy.

Unlike the other materials, the breastfeeding brochure was specifically designed to be used in counselling all prenatal or postpartum women – HIV positive, HIV negative and women of unknown status through pMTCT programmes as well as antenatal, postpartum and well child clinics. Strategically, the brochure does not refer to HIV status. The cover features a culturally sensitive image of a Tanzanian mother breastfeeding her baby. The text and illustrations emphasise the importance of *exclusive* breast-

feeding on demand and the avoidance of water or any other liquids or solid foods during the first six months of life. The images illustrate proper positioning and attachment to reduce breast pathology (such as engorgement, soreness, bleeding and abscesses), how to cope with common *breastfeeding problems* and the importance of practising *safe sex* with emphasis on using a condom, especially while breastfeeding. (See Figures 2 and 3.)

Replacement feeding brochures


Two brochures addressing replacement feeding options (cow's milk, infant formula) each portray an image on the cover of a mother feeding her baby using a cup rather than a bottle. The images and the text of the cow's milk brochure emphasise the use of local resources (utensils and wood fires); safe procedures for the preparation of the milk; and the steps needed to calculate and mix the appropriate quantities of milk, water, sugar and micronutrients for each feed according to the baby's age. Similarly, the brochure on infant formula illustrates safe procedures for preparing utensils, boiling the water; and calculating the right amounts of formula powder and water for each feed, according to the baby's age. Both brochures emphasise using an open cup to feed the baby, avoiding mixed feeding, the importance of safe sex, and the use of family planning to achieve adequate child spacing. (See Figure 4.)

Expression and heat treatment brochure

Given the cost and other AFASS issues associated with replacement feeding, the expression and heat treatment of breast milk was included as a possible feeding option in the updated international guidelines. The effect of heat treatment in reducing the risks associated with breastfeeding related HIV transmission has been documented [31,32], and its feasibility and acceptability, especially during the transition from exclusive breastfeeding to exclusive replacement feeding, have been demonstrated in several settings in sub-Saharan Africa [33,34]. Discussions around expression and heat treatment throughout the present study, however, revealed a split of interests between the international technical actors (WHO, UNICEF and research institutions) and local stakeholders (counsellors, mothers and community members). Because the initial reaction of study participants in Moshi to both expressing and heating breast milk was undeniably negative, the decision to include a brochure on this method as part of the intervention deserves a special note. With the intent of exploring issues related to heat treatment and positioning this method for possible use in the future, formative research findings were used to improve the draft illustrations and ensure that the content was as clear and visually appealing as possible. Due to the underlying client centred philosophy of the intervention, however, this brochure was presented to counsellors during their one day training, but was not actively promoted as a




Breastfeeding

What do I need to know?





- ✦ It is very important to practice exclusive breastfeeding from the moment your baby is born, until your baby is six months old.
- ✦ Colostrum, or the first milk, is very important, because it protects your baby from many diseases. Exclusive breastfeeding continues to protect your baby, especially from diarrhea and pneumonia.
- ✦ Breast milk is the perfect food for babies. It provides all of the nutrients and water that your baby needs to grow during the first six months of life.
- ✦ Exclusive breastfeeding means giving breast milk only, and nothing else, not even sips of water, except for medicines prescribed by a doctor or nurse.
- ✦ Breast milk can contain HIV if the mother is infected. This virus can pass to a baby through breast milk. Exclusive breastfeeding, however, reduces the chances that a baby will become infected.

How should I breastfeed?

- ✦ Start breastfeeding within the first one hour of birth. When you first begin to breastfeed, you may need to help the baby attach well to the breast to avoid hurting your nipples.
- ✦ Your baby's tummy should be facing your tummy. Touch the baby's lips to your nipple. When the baby's mouth is opening wide, move the baby quickly onto the breast, aiming the lower lip below the nipple.
- ✦ Check that your baby is feeding well by seeing that the baby's
 - mouth is wide open
 - lower lip is turned outward
 - chin is touching the breast
 - cheeks are rounded
- ✦ The baby should take most of the dark skin (areola) into its mouth. The baby's tongue should be over the bottom gums. If the baby is in a bad position, or if you feel any pain, then gently take the baby off the breast and start again.
- ✦ Your baby should take slow, deep sucks while breastfeeding, sometimes pausing. You may also hear the baby swallowing.

Continuing to breastfeed

- ✦ Let your baby finish one breast first and come off the breast on his or her own. This is a sign that the baby has gotten most of the milk out of that breast. Then give your baby the other breast. This will ensure that your baby gets the most nutritious and satisfying milk.
- ✦ Feed your baby frequently, day and night, as often and for as long as the baby wants, at least 10 times in 24 hours.
- ✦ Frequent feeding will help your body begin to produce enough milk and keep your breasts from getting engorged (swollen). Let the baby sleep close to you at night to make it easier to feed.
- ✦ You will know that your baby is getting enough milk if the baby urinates at least six times per day. The baby's urine should be light in color and not strong smelling.

Figure 2
Shows how to breastfeed a baby.

feeding option during counselling conducted under the subsequent operations research study at KCMC.

The counselling card on relative risk

The counselling card explains the relative risk of HIV transmission from mother to child, based on a WHO generic counselling material. The card graphically presents the number of babies infected during pregnancy, birth and breastfeeding from among 100 babies born to HIV infected mothers. This graphic design was based on the mothers' level of literacy to communicate at both their emotional and cognitive level using something they can easily identify. (See Figure 5.)

The infant feeding 'tool box'

The infant feeding tool box was designed to be used in counselling sessions and contains basic items such as cups, spoons, sample tin of formula, thermos, pot, sugar and micronutrients needed to demonstrate how to prepare infant formula and cow's milk respectively. It also contained soap for washing hands and cleaning utensils. (See Figure 6.)

The technical review process and incorporation of technical feedback

After field testing the draft illustrations at the community level, the modified illustrations were incorporated into

the layout of key text messages for each material. Electronic versions (PDFs) of the job aids (both in English and Swahili) were widely circulated by email for technical review by local and national stakeholders and other national and international technical experts. Comments were incorporated and adjustments made to the technical content and illustrations prior to producing a limited package of the integrated set for use in a one day training/orientation workshop for 15 nurse counsellors from the KCMC pMTCT Programme. During this event, additional technical comments and corrections to both the English and Swahili translations were received and incorporated. All changes were made prior to printing a sufficient quantity for use during the six month operations research study to assess the strengths and weaknesses of the job aids, to be reported in a forthcoming article. The significance of the one day training/orientation workshop, which focused on interpersonal communication, counselling skills and the effective use of the job aids, is also reported elsewhere.

Conclusion

This study recognizes that infant feeding norms and practices are produced and reproduced or transformed in the encounter between local ideas and customs on the one hand and forces emanating from the larger national and international community on the other. Through partici-

How To Breastfeed Your Baby

How to prevent problems:

- ✦ Check for sores in your baby's mouth often. If you find any, get them treated as soon as possible.
- ✦ If your nipples become cracked or sensitive or if one or both of your breasts become too full, painful, hot to the touch or develop a red streak, this is a sign that something is wrong. Consult a trained counselor or other health care worker immediately for advice or treatment.
- ✦ Try not to miss a feed, or your breasts may become swollen (engorged) with milk which makes it difficult for both you and the baby. If you must miss a feed, you should express some milk to keep your breasts soft. You can also express some milk and store it in a cool place so that someone else can feed your baby while you are away.
- ✦ "Mixed feeding" (which means combining breast milk with other milks, water, liquids or any kind of foods), is not healthy for your baby before six months of age. It can reduce the amount of milk that you produce and can make your baby sick. If you are having trouble practicing exclusive breastfeeding, discuss your situation with a trained counselor.
- ✦ When your baby is six months old, it is time to begin giving other foods that are clean and prepared in a safe way. Talk to a trained counselor about how and when to introduce new foods to your baby.

Things to remember:

- ✦ If your nipples become cracked or painful, your baby may not be attached correctly to your breast. You may need help to position the baby better. Breastfeeding should not hurt.
- ✦ If you develop cracked nipples, put some breast milk on them, and let them air dry. This helps to heal the cracks. Do not use any other types of creams or ointments unless a doctor has diagnosed thrush or candidiasis on the nipples and has given you a special medicine for this.
- ✦ If a woman is HIV-positive, she should not feed her baby from a nipple that is cracked or bleeding. It is best to express and discard the milk from that breast until it has completely healed.
- ✦ To protect your baby from becoming exposed to HIV while you are breastfeeding, you and your partner should practice safe sex. This means that both partners stay faithful to each other, abstain from having sex, or use a condom. Consult a trained counselor about family planning options.









This brochure was adapted from materials developed originally by WHO/UNICEF. Both technical and financial support for the development of this brochure was provided by the Quality Assurance Project (QAP), managed by University Research Co., LLC (URC), under USAID Contract Number GPH-C-00-02-00094-00, March 2005

Figure 3
Shows how to prevent breast problems when breastfeeding.

patory qualitative research, this study aimed to adapt the international WHO/UNICEF guidelines on HIV and infant feeding and related generic counselling tools to the local social and cultural context of infant feeding and HIV in the Kilimanjaro Region of northern Tanzania. Because infant feeding practices are socially and culturally embedded, community norms and the cultural beliefs and practices of mothers and those who influence them must be taken into consideration in designing an intervention. Tailoring the present educational intervention to the specific needs and characteristics of the study participants helped to ensure that this intervention would be socially and culturally acceptable to the targeted study population, and underscores the importance of formative research in the intervention development process.

Although the utility of applying theoretical frameworks to the design and execution of interventions has been questioned [35], IM provided a useful reference to guide the development of the educational material (job aids) presented in this study, through a dual focus on health promotion theory and empirical evidence obtained through formative research. Given restrictions on time and other resources, a modified version of IM was applied, which restricted the complexity of the change objectives. Nonetheless, IM was a valuable tool in the development of objectives, methods, strategies, materials and procedures.

Through the definition of performance objectives, modifiable determinants and specified learning objectives as outlined in Tables 1 and 2, outcome indicators were identified at both the individual and environmental levels.

To ensure "ownership" of or "buy in" to the intervention by key stakeholders and to position this pilot intervention for subsequent scale up, the development process required the active and strategic participation of all relevant stakeholders, including participation in the initial review of the intervention strategy and technical reviews of the related products. Through the participatory approach prescribed, IM facilitated an active and systematic dialogue with all relevant actors.

Through the needs assessment, the intervention planning and the strategy and job aids development process, a number of questions related to potential impact and sustainability of the intervention emerged. As the IM framework underscores, change is very often the result of change in the behaviour of decision makers and key actors on multiple levels. For example, as documented in the current paper, there is no doubt that a woman's husband, her mother in law and her pMTCT counsellor are important actors in her infant feeding environment. pMTCT as a family issue remains tricky, in particular because of challenges related to the issues of confidentiality and dislo-

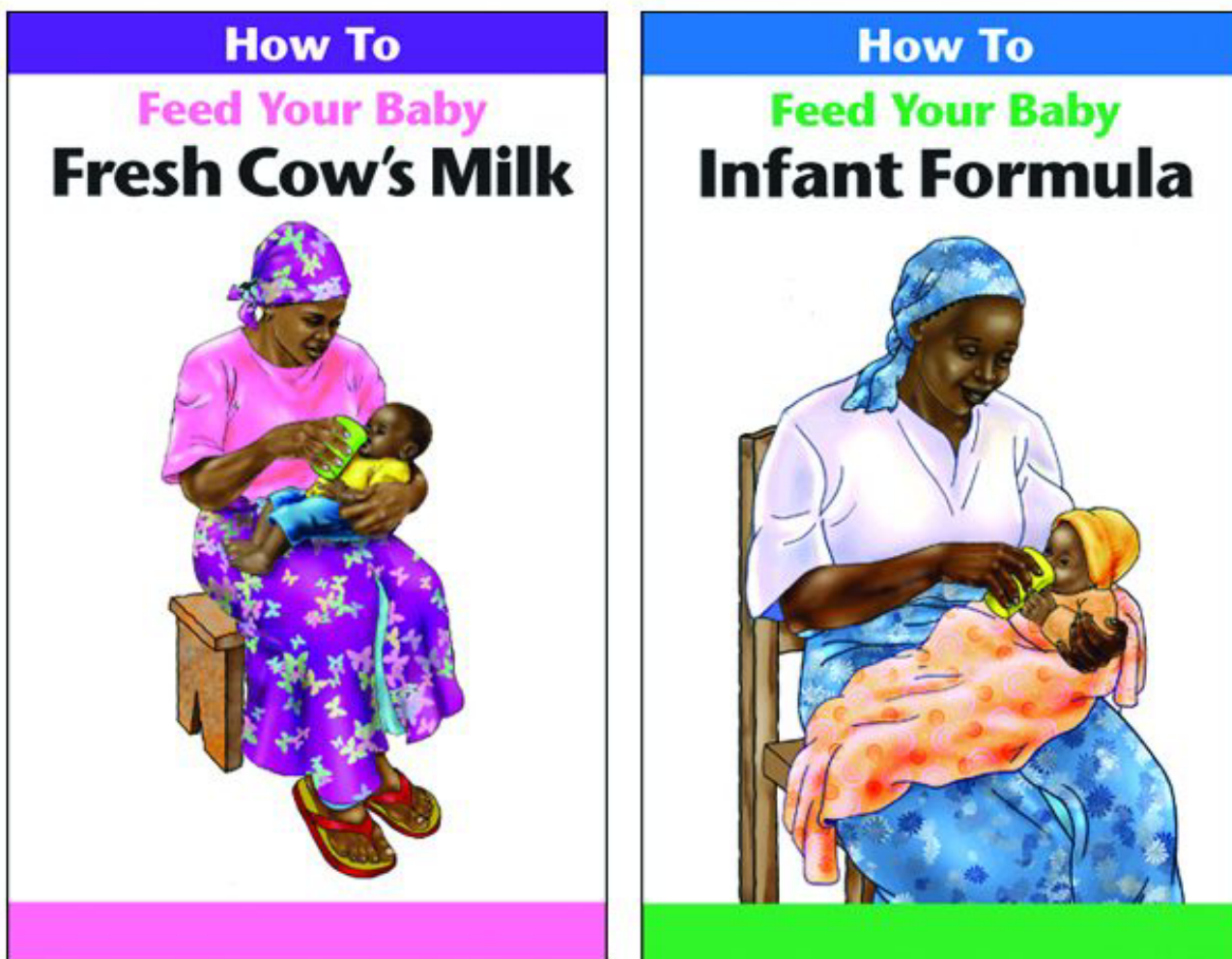


Figure 4
Shows how to feed infant formula and modified cow's milk to the baby.

sure. The framework reported in the current intervention primarily addresses individual motivational factors, i.e. factors internal to the mother herself. Changing knowledge, attitudes and beliefs is critical for behavioural change but may not be sufficient to change mothers' infant feeding practices. There are many factors, barriers and facilitators of change, that contribute to mothers' decisions concerning the feeding of their babies. These factors vary depending on determinants of choice and the individual or group of mothers in question.

In the context of HIV, stigma and the fear of disclosure of positive HIV status is a major concern influencing mothers' infant feeding choice, even though they are highly

committed to preventing the transmission of HIV to their babies. This study underscores the complexity of promoting recommended infant feeding practices and clearly indicates the need for a multi-dimensional behaviour change strategy involving both mothers and counsellors, and if possible significant others who influence decision making processes. In a context where disclosure of status is a major challenge, the participation of partners and other relatives in counselling, although ideal, is seldom realized.

'Informed choice' related to infant feeding in the context of HIV/AIDS is a complex issue. Access to information and improved interpersonal communication and counselling



Figure 5 Shows counselling card on relative risk of HIV transmission from mother to child when there are no preventive measures used.

are among many factors influencing an HIV positive mother's confidence, courage and ability to select and successfully implement the most appropriate feeding option given her own individual situation. This intervention study underscores the importance of providing culturally compatible counselling support that improves self-esteem and confidence and corresponds with the social norms and perceptions of mothers.

Competing interests

The author(s) declare that they have no competing interest.

Authors' contributions

SCL, PKB and KMM contributed to conception and design of the study, analysis and interpretation of data, revised drafts of job aids, illustrations and key messages. Also drafted and revised the manuscript drafts. PKB managed the developed and external technical review of the draft job aids. MDP revised drafts of job aids illustrations and key messages and revised manuscript drafts. ANA critically revised the manuscript drafts and gave advice on the the-



Figure 6 Shows the infant feeding tool box for demonstration during counselling session.

oretical approach. All authors revised and approved the last version of the manuscript.

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Paper IV: “Counselling tools in the promotion of safer infant feeding practices in the context of HIV: An evaluation study from Kilimanjaro region, northern Tanzania”. Submitted to *BMC- Health Services Journal*, July 2007.

**Counselling tools in the promotion of safer infant feeding practices in the context of
HIV: An evaluation study from the Kilimanjaro region, northern Tanzania**

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Abstract

Background

The paper presents and discusses the results of an evaluation of an intervention study aiming to strengthen infant feeding counselling in the context of HIV in the Kilimanjaro region, northern Tanzania. Based on international guidelines, the intervention developed an integrated set of culturally sensitive, infant feeding counselling tools (job aids) and take-home materials. The tools were developed for counsellors and for mothers participating in the prevention of mother to child transmission of HIV (pMTCT) programme in northern Tanzania. The present paper aims at investigating how the intervention affected the quality of the infant feeding counselling and infant feeding practices.

Methods

The study used a qualitative design and compared an intervention group to a comparison group. The intervention group consisted of 30 mothers (20 HIV-positive and 10 HIV-negative) from the pMTCT programme at Kilimanjaro Christian Medical Centre (KCMC). The comparison group consisted of 29 mothers (19 HIV-positive and 10 HIV-negative) from two pMTCT programmes in the same district that were not exposed to the intervention. These programmes were run by government health centres that offered a standard package of VCT, ART prophylaxis and infant feeding counselling. Semi-structured qualitative interviews were conducted with all study participants within the first nine months after delivery to elicit their experiences, knowledge and beliefs about HIV and infant feeding.

Results

The study findings indicate that the intervention increased the knowledge about infant feeding among mothers and strengthened certain aspects of infant feeding counselling compared with the counselling offered in the standard pMTCT programme. For example, the mothers in the intervention group had more knowledge of the definition and benefits of exclusive breastfeeding for six months and were able to cite more ways of protecting their babies from HIV infection. However, some clear limitations and challenges were revealed in the course of the study. These were particularly linked to limited counselling related to the risks involved in mixed feeding and counsellors' bias towards formula feeding among HIV-positive mothers. Further, poor judgement of the 'acceptability, feasibility, affordability, sustainability and safety' criteria (AFASS) of the various feeding methods in the particular infant feeding

situation of each mother, compromised the quality of infant feeding counselling and hence, complicated the process of choice. The study calls for a critical assessment of the concept of informed choice which underlies the international infant feeding guidelines.

Background

Mother to child transmission of HIV (MTCT) through breastfeeding represents one of the most serious public health challenges in sub-Saharan Africa today, where breastfeeding is seen as vital to child survival and where other feeding methods may not be feasible and safe. Mixed feeding, i.e. combining breastfeeding with the feeding of other foods or liquids has been found to transmit the HIV virus more frequently than either exclusive breastfeeding or exclusive replacement feeding [1-3]. Unfortunately, however, it is mixed feeding that is normative in large parts of the world. Moreover, the character of breastfeeding as a culturally deeply entrenched practice makes it a particularly complex issue to address. This paper discusses the results of an evaluation linked to an intervention study aiming to strengthen infant feeding counselling in pMTCT programmes in the Kilimanjaro region, northern Tanzania. The rationale and design of the intervention study reflected a call to action related to the need to improve infant feeding counselling as expressed in international policy documents [4, 5] as well as the specific recommendations on HIV and infant feeding made by the Ministry of Health in Tanzania [6]. Formative research linked to pMTCT programmes in the Kilimanjaro region carried out by the first author of the present paper revealed that HIV-positive mothers felt generally uncertain about how to feed their infants and that the counsellors to some extent shared this uncertainty and lacked relevant and reliable updated information to use during infant feeding counselling [7, 8].

The purpose of the intervention study was to produce a cost-effective, culturally sensitive and technologically appropriate set of counselling tools based on the international guidelines on HIV and infant feeding [5]. The overall objective of the study was to strengthen counsellors' ability to guide HIV-positive mothers to make an informed choice of infant feeding method and to safely practise a feeding method appropriate to their personal situation.

The project involved several steps. The first steps, including the identification of performance and learning objectives, the selection of theory and strategies to achieve these objectives, and

the process of developing and pre-testing the material (job aids), have been presented in an earlier publication [9]. The present article focuses in particular on the evaluation of the intervention.

The international recommended guidelines for infant feeding [5] differentiate between HIV-negative and HIV-positive mothers. The guidelines recommend that HIV-negative mothers initiate breastfeeding within one hour of birth, breastfeed exclusively for the first six months, and then introduce complementary feeding gradually while continuing to breastfeed for up to two years and beyond. For HIV-positive mothers, WHO recommends that if replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), it should be opted for from birth to reduce the risk of mother-to-child transmission of HIV. However, if mothers do not meet the AFASS criteria, the current guidelines encourage the mother to exclusively breastfeed, avoiding all mixed breastfeeding, and then switch to exclusive replacement feeding as soon as the AFASS conditions are met. Replacement feeding includes commercial infant formula and home-modified animal milk. Other recommended breast milk alternatives are expressed and heat-treated breast milk, wet nursing, and breast-milk banks [10].

However, several studies have indicated that a proper assessment of the AFASS criteria is often compromised by time constraints in overburdened pMTCT clinics [8, 11, 12], making the assessment of what option HIV-positive woman should choose somewhat haphazard.

The WHO guidelines also make recommendations about counselling for infant feeding. After discussing the advantages and disadvantages of the various feeding options, the counsellor should guide the mother towards making an *informed* choice of infant feeding method. Thereafter the counsellor should demonstrate positioning and attachment if the mother chooses to breastfeed, and safe and appropriate preparation of infant formula and/or modified animal milk if the mother opts for replacement feeding [10]. She should also talk about breast care since mastitis, cracked nipples and breast lesions increase the risk of HIV transmission to the infant during breastfeeding [13, 14].

Earlier studies have found that written instructions as well as personal encouragement by the service provider exerted a favourable influence on breastfeeding practices [15]. One study that introduced educational materials in counselling documented an increase in the incidence of

breastfeeding from 15% to 56% and exclusive breastfeeding from 0% to 15% [16]. The counselling tools (job aids) have emerged as relevant in these contexts. These are tools developed to improve the performance of service providers, such as nurse counsellors, and are recognised as reducing guesswork, minimising reliance on memory, and promoting compliance with standards in a cost-effective way [17]. Examples of job aids are posters, instructional cards and flow charts.

A review of methods for improving counselling concluded that job aids were effective, but only when used as a component of a multi-faceted intervention that also includes training and possibly other complementary actions such as mass media campaigns, patient take-home materials, and supervision [18]. Client-oriented job aids (also called ‘decision aids’) aim to guide patients through a series of steps, giving them personalised information that helps them clarify their values and risk exposure related to a particular health issue [19, 20]. This article will evaluate an intervention in which job aids were developed for the prevention of mother to child transmission of HIV programmes.

The HIV prevalence for antenatal women in Tanzania was estimated at 12% [21]. In 2000 the Ministry of Health (MoH) in collaboration with UNICEF initiated a pilot programme on pMTCT, and Kilimanjaro Christian Medical Centre (KCMC) was selected as one of five pilot sites [22]. An assessment of this pilot programme in 2002 emphasised the importance of strengthening the training of pMTCT counsellors and of developing appropriate support materials for use in infant feeding counselling (provider job aids) and educational materials (client job aids) for mothers to take home [6]. The intervention/evaluation study described here was designed in response to this challenge.

Formative research findings

Formative research (using a qualitative triangulation design) conducted by the first author of the present paper in 2003 in the KCMC catchment area [9], prior to and during the initial phase of this study highlighted widespread confusion about the risk of HIV transmission in general and through breastfeeding in particular among pMTCT counsellors and in the community at large. A common concept in both groups was that if the mother is HIV-positive the baby will also be so. Only three feeding options emerged as being potentially acceptable

in this region: exclusive breastfeeding, cow milk feeding, and formula feeding. Although once culturally acceptable, wet nursing was considered dangerous in the context of HIV and was therefore discouraged. The concept of heating expressed breast milk was also rejected, partly because the expression of breast milk is associated with the death of an infant. The customary introduction of water and traditional foods soon after birth and the high prevalence of mixed breastfeeding for all infants under six months of age that have also been highlighted in previous studies [23, 24] was also found in the present area. In Kilimanjaro the baby is partly breastfed and partly fed with water, cow's milk or porridge from an early age [11].

Most of the HIV-positive women interviewed during formative research stated that health workers were their most trusted source of information about health issues in general and infant feeding issues in particular. Nevertheless, most of these women could not recall receiving infant feeding information during counselling, most likely because it is during the very same counselling session that they receive the news of their HIV-status for the first time. Mothers who chose exclusive replacement feeding did complain about insufficient information about the required amount, frequency, and preparation of feeds [9]. For their part, counsellors expressed difficulty in assessing individual women's situations and in guiding HIV-positive women in their choice of an appropriate infant feeding method. Other studies have also revealed that many PMTCT counsellors are not well informed about how best to protect the infant from HIV transmission, and they are often given the difficult task of counselling HIV-positive mothers on infant feeding with little or no training [12, 25].

The counsellors interviewed during the formative study complained that their caseloads were very high, leaving little time for individual counselling. Furthermore, they complained that there was no standardised system for providing follow-up support on infant feeding to mothers once they left the health facility after birth [8]. Inaccurate and inconsistent information about HIV and infant feeding among counsellors and lack of adequate time dedicated to counselling have also been documented as major limitations of HIV and infant feeding counselling in Tanzania and other similar settings [11, 26].

Based on these prior research-based findings, and drawing on the international and national guidelines for HIV and infant feeding, the intervention was developed [9] for nurse counsellors to use during infant feeding counselling and to provide take-home material for mothers to refer to during the period of infant feeding. The developed 'job aids' consisted of:

- A question and answer guide on HIV and infant feeding including illustrated answers to 25 questions commonly asked by mothers, their families and community members.
- A counselling card on the risk of HIV passing from HIV-positive mothers to their babies when no preventive action is taken.
- Three counselling/take-home brochures on safer infant feeding options including breastfeeding, formula feeding, cow milk feeding.
- A demonstration box or 'tool kit' (including cups, spoons, sample tin of infant formula, thermos, pan, sugar, micronutrients and soap) for use in the pMTCT clinic.

(See Appendix: Original Integrated Set of Materials)

Study objectives

This study aims to investigate how the present intervention has affected the quality of infant feeding counselling and infant feeding practices. More specifically, the evaluation study addresses the following questions:

1. How does the introduction of counsellor job aids, mother's take-home brochures and specific counsellor training in pMTCT programmes affect the quality and relevance of infant feeding counselling to HIV-positive and HIV-negative mothers in the Kilimanjaro region?
2. How does the use of job aids during infant feeding counselling and the take-home material provided affect the choice of infant feeding method and adherence to this method among HIV-positive and HIV-negative mothers?

Methods

Training of nurse-counsellors

A one-day training session was conducted at KCMC hospital for all 16 KCMC counsellors who were working on pMTCT at the time of the fieldwork. The aims were to provide a technical update on HIV and infant feeding and to teach the essential characteristics of good interpersonal communication and counselling and the effective use of the developed counselling tools. The trainers included the research team and a national trainer from the Tanzania Food and Nutrition Centre (TFNC). Copies of the materials, in English and Swahili, were given to all nurse-counsellors. Participants were divided into groups (five to six nurse-

counsellors) to review and discuss the content of each item in order to ensure that everyone was familiar with the technical recommendations. Role plays using the various counselling materials were conducted to reinforce the interpersonal communication and counselling skills and to provide an opportunity for participants to discuss different case scenarios.

Four of the 16 counsellors who participated in the one-day training course were recruited as participants in the intervention study. The criteria used for recruitment were reports of good rapport with clients and an expressed interest in the study.

The evaluation study employed a qualitative design, although parts of the findings were converted to numerical figures in the analysis phase to ease the comparative aspect (see below). The study participants were divided into two groups: an 'intervention group' and a 'comparison group'. The intervention group consisted of 30 mothers (20 HIV-positive and 10 HIV-negative) from the pMTCT programme at KCMC. These mothers were recruited and served by four counsellors who had participated in the one-day training session at KCMC and who had the counselling and take-home materials available. The comparison group consisted of 29 mothers (19 HIV-positive and 10 HIV-negative) from two pMTCT programmes within the same district. These pMTCT programmes were not exposed to the present intervention but were run by government health centres offering a standard package of VCT, ART prophylaxis and infant feeding counselling. The only two trained counsellors who were working on this project were recruited as research assistants for the present study. These two counsellors received individual orientation about the general purpose of the study and their role in recruiting the mothers. Neither of them received additional training, nor were they exposed to any of the counselling materials, or to the WHO HIV and infant feeding guidelines.

Recruitment of mothers

The intervention group was counselled, tested and recruited to the study by the four intervention counsellors. The criteria for selection were willingness to participate and to be interviewed at home after delivery. Similarly, the comparison group was identified and consulted by the two counsellors at the comparison pMTCT sites, and the members were subsequently recruited into the study. One HIV-positive mother selected for the comparison group was excluded from the study after she travelled to the intervention site for a postpartum

follow-up visit and received the take-home materials there. Hence, the comparison group was left with 29 participants.

The only feasible comparison group that could be accessed outside the intervention site was in fact part of another on-going pMTCT cohort study that had been monitored for some time. This had implications for the present study in that the majority of the mothers had already completed the first critical phase of infant feeding. Hence, the infants in the comparison group were substantially older than the infants in the intervention group at the time of the interview, and the study team had to depend on recall of infant feeding among the mothers in the comparison group. The possible effect of this discrepancy is discussed in the section on methodological reflections.

Individual in-depth interviews

A semi-structured interview guide (developed in Swahili) with a set of questions was employed during the study. The majority of the questions were open ended with potential for probing. The questions focused on the mother's knowledge and beliefs about HIV and infant feeding, intended infant feeding practices, problems encountered, the nature of the infant feeding counselling they received, and feedback from the mothers in the intervention group on the take-home materials. All the 59 mothers in the two groups were interviewed at home using this same interview guide/flexible list of questions. Whenever possible, additional observations related to infant feeding were noted on the interview form.

A research assistant with substantial prior training in interviewing was introduced to the mothers by their respective nurse-counsellors, and later carried out all the in-depth interviews. She was accompanied by the main researcher during the first twelve and during the two final interviews. Otherwise, she reported to the researcher in-charge on a daily basis about the interviews as well as potential daily experiences.

Follow-up interviews were carried out with 13 mothers in the intervention group and with seven mothers in the comparison group between four to six weeks after the first interview. It was not possible to follow up all mothers given the limited time and resources. The criteria for the selection of these mothers included feeding method practised, counselling site and

willingness to be home visited a second time. The follow-up interviews were conducted by the same research assistant. These interviews investigated potential changes in knowledge and practice related to infant feeding since the first interview, as well as thoughts and experiences related to the take-home materials.

At the end of the study, the four nurse-counsellors in the intervention group participated in a group discussion with the research team that focused on their experiences of using the counselling tools. They also presented recommendations for improving the tools.

Data analysis

All the information collected was translated from Swahili into English by the first author. The collected narratives were reviewed by three of the authors (SL, PKB, BB) who independently read through the entire set of narratives several times. Each one coded/sought for the emerging themes from the text. Thereafter the themes were presented and discussed in the group. The authors then condensed part of the material by defining the research questions that the themes were attempting to answer. The next step transformed the unstructured responses to structured data by defining categories of answers to each question in both the first and the second interviews. The answers were then coded under each research question and entered into an electronic file. Analysis was performed using SPSS programme.

Ethical considerations

Approval to conduct the research was obtained from national, regional and local authorities including the medical authorities in Kilimanjaro region and the ethics committee of the KCMC and Muhimbili University College of Health Sciences. Confidentiality issues were carefully considered during the research, and the participants were assured that the information from the collected data would be employed only for research purposes. Informed consent to participate was obtained before each interview. The home visits were carried out as anonymously as possible; the inclusion of both HIV-negative and HIV-positive mothers in the study became the key to avoiding possible suspicion and rumours associated with postpartum home visits.

Results

The presentation of the findings includes both narratives and numerical material developed from the research questions/replies.

Characteristics of the informants

There was no significant difference between the intervention and the comparison groups in terms of socio-demographic characteristics or the sex of the child. Most of the mothers in both groups were in their twenties and had completed primary school education. A higher proportion of the mothers in the intervention group than those in the comparison group were married (77% and 55% respectively). Most of the babies in the intervention group were however much younger than the babies in the comparison group. At the time of the first interview, the babies in the intervention group were on average one month old, whereas the babies in the comparison group were on average nine months old. In addition, within the comparison group, babies born to the HIV-positive mothers were on average older than babies born to HIV-negative mothers (ten months and six months respectively at the first interview).

The take-home material

Use and usefulness of the infant feeding brochures

All the mothers in the intervention group reported that they were shown the newly developed job aids on infant feeding during counselling, and everyone was able to describe the materials. All but one reported that the counsellor had read the text of the materials to them; the exception was a teacher who said there was no need as she could read it herself. Moreover, all mothers in the intervention group reported they had been given the take-home brochure on the feeding method they had chosen. During the first interviews five mothers in the intervention group showed the interviewer the brochure spontaneously, and the rest were able to produce the brochure on request. During the follow-up interviews most mothers said they were still using the take-home brochures.

When they were asked: “*Are you still using the brochure?*” their responses were generally positive:

“Yes, I just like to read it to remind myself what I was told about positioning the baby when breastfeeding. ...My husband always reads it and reminds me of what I should

do in case I do anything different. Also my friends like the colours and the content and want to have their own copy” (HIV-positive breastfeeding mother).

“I read the brochure whenever I feel like reading it. When I discuss breastfeeding with my friends I usually show them what is written in that brochure because most people believe in giving water to the baby from a very early age, even from the second week after birth” (HIV-negative breastfeeding mother).

“Yes, I’m still using the brochure to remind myself how much the baby needs as he grows. ... Only my husband reads it because I don’t like other people to know that I’m not breastfeeding the baby” (HIV-positive mother replacement feeding).

The appropriateness of the text and images

During the first interview, mothers were asked if they had met any challenges reading the information in the brochure, what they thought about the illustrations and what they liked or disliked about the brochure. Almost all mothers (29) said that in general the brochure was clear and understandable. All of them thought the illustrations reflected their own community, and none expressed difficulty understanding the language.

Some of the responses to the question, *“What do you like most about the brochures?”* are exemplified below:

“The illustrations and writing teach not only me but everyone who reads it. A good example is my husband. After reading it he always refers to what is written there whenever he wants to tell me what I should do. It gives me a sense of confidence that what I’m doing is the right thing.”

“The illustrations are simple and clear. They don’t target a few rich women, like showing an electric cooker, which is not common in this village. Most mothers will be attracted to reading them because of their nice colours, and they show the real dressing of most mothers such as wearing ‘khanga’ and using firewood.”

“I like the pictures because even without the words you can figure out what is being done. Even the people who cannot read can follow the pictures very well to understand what is written.”

Although most mothers said they liked the images in the brochure and said that the women could have come from their own community, some of the informants mentioned aspects of several images that they did not like: the breastfeeding mothers’ breasts should be “covered more,” the image of money in the infant formula brochure would discourage mothers from using formula, and breastfeeding woman lying on the mat would imply that is the recommended position when breastfeeding the baby were brought up by several informants.

Counselling on infant feeding

The four counsellors in the intervention group agreed during the follow-up discussion that having the job aids and being trained in how to review the content with mothers during counselling both enabled and encouraged them to follow a logical, sequential flow of the key counselling messages. How the intervention in sum affected the counselling advice is however a different question. The findings below are based on reports from mothers, and reflect their perceptions and experiences of the infant feeding advice of the counsellors.

Breastfeeding versus replacement feeding

All HIV-negative mothers included in the study said they were advised by the counsellor to breastfeed their infants. A majority of the HIV-positive mothers (27) however said they were advised to replacement feed. To what extent the AFASS criteria were used to guide the counsellors’ advice remained unclear. Twelve of the mothers who were advised to breastfeed belonged to the intervention group, while 19 belonged to the comparison group. Thus, according to the reports from the mothers, there was a significant bias towards counselling in the direction of replacement feeding in the intervention group. The possible basis for and implications of this bias are discussed below.

Regarding the duration of exclusive breastfeeding, the advice given to the mothers in the intervention group differed from that given to the mothers in the comparison group. All mothers in the intervention group were advised to breastfeed exclusively for six months, but only three of the 19 mothers in the comparison group were advised to breastfeed exclusively for six months. The rest were advised to breastfeed exclusively for three to four months.

When it comes to the counselling on the duration of exclusive breastfeeding, the recommended guidelines were hence followed much more closely in the intervention group than in the comparison group.

Mixed feeding, safe sex and breast care

Three additional messages were used to address/assess the quality of the counselling in terms of raising issues with impact on HIV transmission risks: the risks of mixed feeding, the importance of safe sex, and appropriate breast care. Surprisingly, according to the reports of the mothers the dangers of mixed feeding were discussed with only five of the mothers in the intervention group and with only three mothers in the comparison group. The importance of safe sex was on the other hand discussed with a large majority (25) of the mothers in the intervention group, as well as most (19) of the mothers in the comparison group. Appropriate breast care was also discussed with a large majority (26) of the mothers in the intervention group, but with only two mothers in the comparison group. The mothers in the intervention group who did not receive breast care counselling were those who were not breastfeeding.

Demonstrations by counsellors

Participation in the intervention group strongly increased the likelihood of the women (both positive and negative) receiving a demonstration of breastfeeding positioning and preparation of replacement feeds. Proper breastfeeding as well as proper positioning was reported to have been demonstrated to almost all (26) mothers in the intervention group.

The tool kit provided to the counsellors in the intervention group appeared to be routinely used during counselling. In the intervention group, all mothers except one reported having received some kind of infant feeding demonstration from the counsellor compared to none in the comparison group.

Mothers' knowledge and beliefs about infant feeding methods

The mothers were asked which feeding method is best for most babies in their community. All the mothers in both the intervention and the comparison groups responded that breastfeeding is best, but only four women (from the intervention group) still held this view when asked about infant feeding for babies born to HIV-positive mothers. In contrast, a great majority (46) answered that because of the risk of HIV transmission through breast milk,

replacement feeding is best for babies born to HIV-positive mothers. Nine mothers said they did not know what would be the best feeding method to use.

The mothers were also asked what it means to “exclusively breastfeed.” Their answers were classified into four categories, ranging from ‘good’ to ‘no knowledge’ according to the WHO definition of exclusive breastfeeding. Almost all the mothers in the intervention group (28) were able to give a good definition compared to only four in the comparison group.

According to the International Guidelines, mothers *‘should ideally’* exclusively breastfeed for six months. The mothers were asked for how long they *should* exclusively breastfeed. The answers given by the mothers differed between the intervention and the comparison group. A large majority of the mothers in the intervention group (25) said that mothers *should* exclusively breastfeed for six months compared to only two mothers in the comparison group.

Mothers’ choice of infant feeding method

During the first interview, all mothers were asked about the infant feeding method they chose before or at the time of delivery, the reason for their choice and what feeding method they eventually decided upon. All HIV-negative mothers in both the comparison and intervention groups said they chose exclusive breastfeeding. One of the HIV-positive mothers in the comparison group chose replacement feeding. It is important to note that almost all (18) HIV-positive mothers in the intervention group said they were initially advised to replacement feed. They reported, however, that even though their counsellor originally recommended replacement feeding, almost all mothers nonetheless decided to breastfeed because they could not afford replacement milk or feared disclosing their HIV status. In fact, only four of the HIV-positive mothers in the intervention group ended up replacement feeding their babies.

The reasons given by HIV-positive mothers for choosing breastfeeding were in both study groups primarily fear of disclosure to close kin and neighbours and the cost of replacement feeding. Disclosure was a major concern for all the women who ended up choosing replacement feeding.

An HIV-positive mother practising replacement feeding said:

“I only shared it (the formula brochure) with my mother as I don’t want other people to know that I’m not breastfeeding the baby. I even lied to the father of this child that I don’t have enough breast milk for the baby because of the operation.”

Discussion

The general objective of the intervention study was to improve infant feeding knowledge and practices of both HIV-positive and HIV-negative mothers. The findings from the present intervention/evaluation study indicate that the intervention did increase some aspects of the knowledge of infant feeding among mothers and strengthened certain aspects of infant feeding counselling compared to the counselling offered in standard pMTCT programmes. However, some clear limitations and challenges were revealed during the evaluation process. The challenges were particularly linked to lack of counselling on the risks involved in mixed feeding, counsellors' bias towards formula feeding for HIV-positive mothers, and poor judgement of the AFASS condition of HIV-positive mothers' individual infant feeding situation – key aspects of the pMTCT concept that aims to reduce the risk of HIV infection of the infants. We shall review each of these points in the discussion.

Strengths

Knowledge

As documented in the formative research preceding the intervention, the counsellors lacked confidence in both their own knowledge and in their new role as counsellors [8]. According to the findings of the present study, the counsellors themselves see the counselling tools, including the question and answer guide, the infant feeding brochures and the counselling card on the risk of HIV transmission, as useful tools with which to guide and structure the counselling session. The use of job aids during counselling has been shown in other studies to reduce the need to memorise and thus the possibility of forgetting or omitting important information. It has also been shown to increase the probability that the technical information, or educational messages, given during counselling will be standardised and uniform [27]. However, the job aids do not change the fact that only a few counsellors believe that all the suggested infant feeding methods are feasible and acceptable in the Kilimanjaro region [8]. This is a challenge that needs to be seriously addressed through more comprehensive approaches, but which was addressed in the revision of nurse-counsellors' training as described in *Expanding the job aids and training package* below.

While provider-oriented counselling job aids aim to improve the communication between the counsellor and the client during the physical encounter in the counselling room, the take-home material for mothers is intended as a reminder (or personal job aid) for use by the client after the counselling session. The value of giving the mother take-home material is underscored by the fact that many women participating in pMTCT programmes are routinely counselled on their infant feeding options on the very same day that they receive their HIV test results, at a moment when they are confused, upset and distraught. Moreover, in the vacuum of secrecy, that surrounds HIV in the study area, in their capacity as mothers and mothers-in-law women may no longer fill the role as infant feeding advisors. The absence of follow-up from health workers during the infant feeding period adds to the problem, and HIV-positive mothers are often left to themselves without knowledge and sources of knowledge about infant feeding. In this context, the brochures may play an important gap-filling role. Furthermore, in some cases the brochure appears to have encouraged dialogues about infant feeding with husbands or partners. Whether a brochure can also be used as an entry point to disclose positive HIV-status to partners is not indicated on the basis of the present study but should be further investigated.

Demonstrations

A much underestimated factor that increases the risk of the transmission of HIV through breastfeeding is improper breast care and poor positioning of the baby during breastfeeding. When it comes to these technicalities of breastfeeding, the mothers reported that the quality of counselling was superior in the intervention group compared to the comparison group. The various aspects of breast care as well as positioning are important preventive measures that can easily be ensured without the support of experts and without particular resources. When it comes to replacement feeding, safe preparation is known to be one of the greatest obstacles. Instructions are often complicated, resources scarce, and the level of literacy commonly varies more than in Kilimanjaro where the large majority of women have primary school education. In this context, the job aids emerge as important.

Another aspect of the demonstration is that the exercise in itself takes time and works to extend the duration of the counselling encounter which is otherwise often rather brief. Hence, there is no doubt that the infant feeding demonstrations carried out in the intervention group added considerable value to the counselling sessions.

Weaknesses

Mixed feeding

Although exclusive breastfeeding was emphasised as the preferred method of infant feeding among both HIV-positive and HIV-negative mothers, the risks associated with failing to breastfeed exclusively, i.e. with mixed feeding, were not paid much attention during counselling. It was surprising to find that counselling advice on mixed feeding did not seem to differ significantly between the intervention group and the comparison group.

According to the findings, counselling on the dangers associated with mixed feeding was largely lacking also to the group of HIV-positive mothers. This is rather alarming considering the strong evidence of the increased risk of HIV transmission involved in combining breastfeeding with other fluids and solids [3, 28] which is customarily practised in the study area [7, 23]. The impact of the limited attention paid to mixed feeding during counselling on infant feeding practices in the two groups is an important question that this study cannot fully answer since the data on actual feeding practices is inconclusive. Although the mothers in the intervention group appeared to be more consistent than the mothers in the comparison group in adhering to their chosen feeding method (exclusive breastfeeding or exclusive replacement feeding respectively) through the first and second home interviews, the higher age of the babies in the comparison group at the time of the interviews makes the two groups difficult to compare.

AFASS and informed choice

An assessment of the AFASS criteria may be a challenging exercise but is undoubtedly fundamental to infant feeding counselling. Without a proper AFASS assessment, counsellors may end up guiding women according to their own preferences and beliefs rather than according to the individual woman's possibilities to succeed with exclusive replacement feeding or exclusive breastfeeding. The findings that replacement feeding was favoured more by mothers in the intervention group than in the comparison group and that most of the mothers reported that the counsellors had initially advised them to replacement feed raise questions about the counsellors' judgement of the AFASS criteria for each individual woman. The question of whether the counsellor mis-interpreted or neglected to pay attention to the AFASS conditions of each mother is not answered in the present study.

The replacement feeding bias in the intervention group may be connected to increased exposure to the *International Guidelines on HIV and Infant Feeding* through the training organised as part of the intervention. In her pMTCT study from the same area, Marina de Paoli [11] found that most counsellors whom she interviewed at KCMC (the intervention site of the present study) thought exclusive breastfeeding was the only feasible option in the Kilimanjaro region. After being trained in infant feeding counselling as part of the present study, however, the counsellors may have felt prepared and motivated to promote replacement feeding because they now had tools that included counselling job aids, mothers' take-home materials and the demonstration box of replacement feeding utensils. Alternatively, the counsellors did not believe that women could adhere to exclusive breastfeeding and that mixed feeding would be the inevitable outcome. In contrast, the counsellors in the comparison group had not been trained for the intervention and were probably less confident about promoting replacement feeding.

The problem of assessing AFASS and guiding an HIV-positive mother to choose between the recommended infant feeding options may be linked to more fundamental problems associated with the principle of 'informed choice'. The current international guidelines unequivocally recommend 'informed choice', stating that all HIV-positive mothers should be counselled on the advantages and disadvantages of all infant feeding options and then, assisted by the counsellor, the *mother* should select the best option given her own individual circumstances (AFASS conditions). The mother should make the final 'informed choice' on how to feed her child, and she should be supported in whatever method she chooses [10]. However, in a context where information is scarce [10], where breastfeeding is normative, where the economic status of families is commonly very marginal, and where choice of infant feeding method does not commonly rest with the mother alone [7], the concept of informed choice may not be of much use. In fact, it could indeed cause more harm than good in light of the fact that mortality is much higher for replacement and mix-fed infants than for exclusively breastfed infants. The fact that mortality in these groups is also higher than the rate of HIV transmission in exclusively breastfed infants of HIV-positive mothers could put the entire AFASS recommendation in question. With its focus on the individual mother as the decision maker and the role of the counsellor as a neutral facilitator rather than an active partner in the decision-making process, the concept of informed choice may even represent a barrier to a constructive problem-solving dialogue based on well established norms and role expectations.

It concerns us that several mothers who chose to breastfeed said that they did so because they could not afford to replacement feed or because they feared discrimination if they did not breastfeed. Nevertheless, they said they felt guilty breastfeeding their baby because it was not recommended and could transmit the HIV virus. Moreover, they expressed no understanding of the risks associated with replacement feeding. Although informed choice based on a thorough AFASS assessment is an important counselling goal, it may not work in practice and may in fact have the adverse effect of causing more rather than less risk of HIV transmission to the baby as well as more uncertainty for the mother.

These research findings promoted the subsequent development of counselling tools to specifically support the assessment of AFASS, which were not part of the initial job aids package. The findings also encouraged greater focus on AFASS in the updated and expanded training component of the integrated package as discussed below.

Expanding the job aids and training package

Based on a presentation of the initial analysis of results of the evaluation of the job aids and training package and on discussions with local and national stakeholders (KCMC, the Ministry of Health), a scale-up of the intervention to other regions of the country was planned. Under the President's Emergency Plan for AIDS Relief (PEPFAR), the United States Agency for International Development (USAID) in Tanzania committed funds for improving and expanding the initial job aids and training package described above. Improvements in the counselling materials included new and altered illustrations, the addition and clarification of key messages, re-editing the Swahili translations, and the addition of several new materials – either specifically suggested by the counsellors and mothers or indirectly suggested by the research findings. The new material developed included an AFASS counselling card that visually depicts the conditions required for acceptable, feasible, affordable, sustainable and safe replacement feeding. An expanded whole-facility training programme was developed including a six-day training of trainers and a four-day training of infant feeding counsellors as well as a shorter training/sensitisation programme for other healthcare workers and administrators.

Expanding the integrated systems approach

The integrated set of job aids and training developed and tested during this intervention study and subsequently expanded is clearly only one of many potential approaches to address the problem of infant feeding in the context of HIV in Tanzania. Complementary programmes and materials are obviously needed to address this complex behavioural and social issue. For example, supportive supervision of pMTCT counsellors and on-the-job training could encourage on-going improvements and more consistency in counselling. Mass media, especially radio, could be utilised to disseminate universal messages about optimal infant feeding practices. Individualised follow-up infant feeding counselling, home visits and mother support groups should be encouraged, regardless of HIV status. Programmes to promote male involvement and the design and dissemination of materials and supportive messages directed to other influential family members such as mothers-in-law have had demonstrable impact in other settings and deserve serious also consideration in Tanzania.

Methodological limitations

The study is based on a small sample of counsellors and mothers from only one district of Tanzania (four intervention and two comparison counsellors, 30 intervention and 29 comparison mothers). The timeframe for the research was short, approximately four months from the training session held at the KCMC on February 2003 to the final follow-up interview held at the end of June 2003.

The physician and two counsellors facilitating the identification of women for the comparison group ultimately recruited the required number of HIV-positive women, but to do this they had to draw on past clientele with whom they had a prior follow-up which resulted in much older babies in the comparison group. This created two limitations.

Firstly the mothers in the comparison group were possibly selected on the basis of a positive relationship with the facilitating physician or counsellor. This category of women probably had a more positive counselling experience than women who felt negative towards their counsellor. This may cause an under-reporting of differences between the programme and comparison groups. Secondly, the babies in the comparison group were considerably older at the time of the interview than the babies in the intervention group (nine months versus one month). The longer recall period of the comparison group mothers compared to the intervention group mothers raises questions about the comparability of the mothers' responses on their counselling experience and early practices.

Given these limitations, the relevance or broad application of some of the study findings in other regions across the country may be questionable. Although most of the results are useful, they should be applied with some caution.

Conclusion

The findings of this study add to our understanding of the experiences of both counsellors and mothers related to counselling in the context of HIV/AIDS, and demonstrate the need for and value of job aids and counsellors training to improve infant feeding practices. The results suggest that focusing provider training on the effective use of counselling job aids and take-home materials may increase counsellors' and mothers' knowledge and may contribute to improving infant feeding-related behaviours and safer sex during the breastfeeding period. To what extent these factors lead to improved health outcomes for children born to HIV-positive mothers cannot be established on the basis of the present study.

This intervention study underscores the complexity of translating global recommendations on HIV and infant feeding to the local context and of developing culturally appropriate counselling tools. Issues surrounding informed choice and counsellors' ability to evaluate the AFASS conditions of individual mothers require additional thought and consultation at national and international level. The impact of this small intervention indicates the need for greater investments in integrated counselling interventions that include counsellor job aids, mother take-home brochures, and counsellor training by national programmes. The limitations of this study argue for expanded, multi-dimensional strategies that systematically address the underlying issues surrounding infant feeding in the context of HIV, including education and training, gender and power relations, and issues related to stigma and discrimination.

Acknowledgements

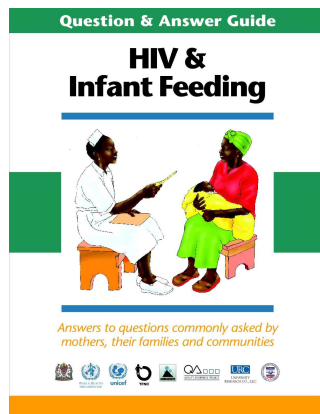
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Breastfeeding

What do I need to know?



- ✦ It is very important to practice exclusive breastfeeding from the moment your baby is born, until your baby is six months old.
- ✦ Colostrum, or the first milk, is very important, because it protects your baby from many diseases. Exclusive breastfeeding continues to protect your baby, especially from diarrhea and pneumonia.
- ✦ Breast milk is the perfect food for babies. It provides all of the nutrients and water that your baby needs to grow during the first six months of life.
- ✦ Exclusive breastfeeding means giving breast milk only, and nothing else, not even sips of water, except for medicines prescribed by a doctor or nurse.
- ✦ Breast milk can contain HIV if the mother is infected. This virus can pass to a baby through breast milk. Exclusive breastfeeding, however, reduces the chances that a baby will become infected.

How should I breastfeed?



- ✦ Start breastfeeding within the first one hour of birth. When you first begin to breastfeed, you may need to help the baby attach well to the breast to avoid hurting your nipples.



- ✦ Your baby's tummy should be facing your tummy. Touch the baby's lips to your nipple. When the baby's mouth is opening wide, move the baby quickly onto the breast, aiming the lower lip below the nipple.



- ✦ Check that your baby is feeding well by seeing that the baby's
 - mouth is wide open
 - lower lip is turned outward
 - chin is touching the breast
 - cheeks are rounded
- ✦ The baby should take most of the dark skin (areola) into its mouth. The baby's tongue should be over the bottom gums. If the baby is in a bad position, or if you feel any pain, then gently take the baby off the breast and start again.
- ✦ Your baby should take slow, deep sucks while breastfeeding, sometimes pausing. You may also hear the baby swallowing.

Continuing to breastfeed



- ✦ Let your baby finish one breast first and come off the breast on his or her own. This is a sign that the baby has gotten most of the milk out of that breast. Then give your baby the other breast. This will ensure that your baby gets the most nutritious and satisfying milk.
- ✦ Feed your baby frequently, day and night, as often and for as long as the baby wants, at least 10 times in 24 hours.

- ✦ Frequent feeding will help your body begin to produce enough milk and keep your breasts from getting engorged (swollen). Let the baby sleep close to you at night to make it easier to feed.
- ✦ You will know that your baby is getting enough milk if the baby urinates at least six times per day. The baby's urine should be light in color and not strong smelling.



How To Breastfeed Your Baby

How to prevent problems:

- ✦ Check for sores in your baby's mouth often. If you find any, get them treated as soon as possible.
- ✦ If your nipples become cracked or sensitive or if one or both of your breasts become too full, painful, hot to the touch or develop a red streak, this is a sign that something is wrong. Consult a trained counselor or other health care worker immediately for advice or treatment.
- ✦ Try not to miss a feed, or your breasts may become swollen (engorged) with milk which makes it difficult for both you and the baby. If you must miss a feed, you should express some milk to keep your breasts soft. You can also express some milk and store it in a cool place so that someone else can feed your baby while you are away.
- ✦ "Mixed feeding" (which means combining breast milk with other milks, water, liquids or any kind of foods), is not healthy for your baby before six months of age. It can reduce the amount of milk that you produce and can make your baby sick. If you are having trouble practicing exclusive breastfeeding, discuss your situation with a trained counselor.
- ✦ When your baby is six months old, it is time to begin giving other foods that are clean and prepared in a safe way. Talk to a trained counselor about how and when to introduce new foods to your baby.



Things to remember:

- ✦ If your nipples become cracked or painful, your baby may not be attached correctly to your breast. You may need help to position the baby better. Breastfeeding should not hurt.
- ✦ If you develop cracked nipples, put some breast milk on them, and let them air dry. This helps to heal the cracks. Do not use any other types of creams or ointments unless a doctor has diagnosed thrush or candidiasis on the nipples and has given you a special medicine for this.
- ✦ If a woman is HIV-positive, she should not feed her baby from a nipple that is cracked or bleeding. It is best to express and discard the milk from that breast until it has completely healed.
- ✦ To protect your baby from becoming exposed to HIV while you are breastfeeding, you and your partner should practice safe sex. This means that both partners stay faithful to each other, abstain from having sex, or use a condom. Consult a trained counselor about family planning options.

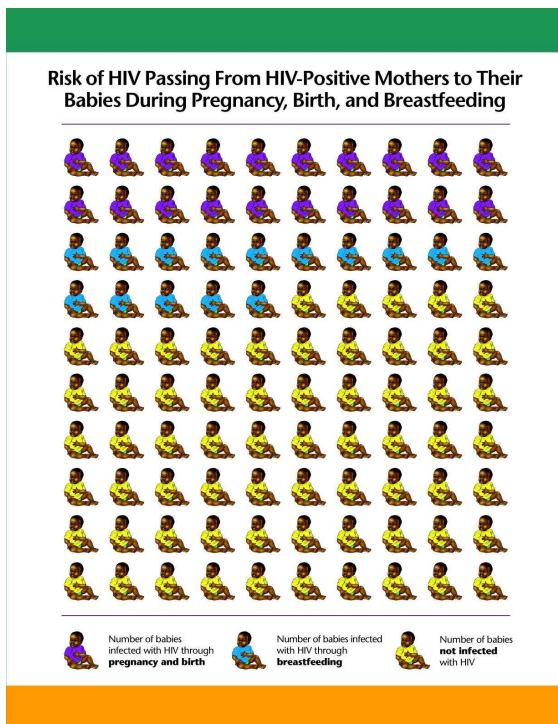
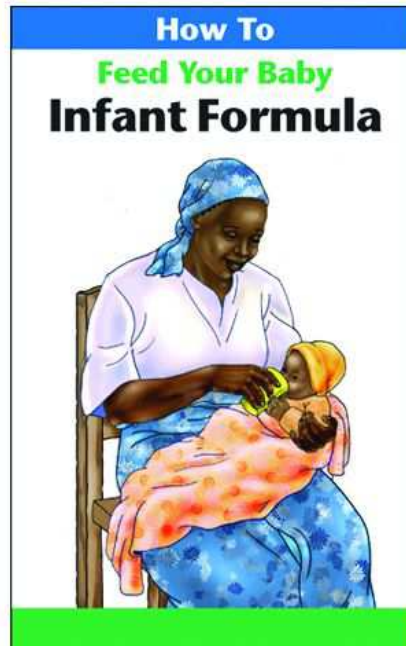


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How To Breastfeed Your Baby



Job Aids



Infant feeding tool kit for demonstration



APPENDICES 1 – 8b

Appendix 1: International guidelines on infant feeding 1992-2000

1992 statement by WHO, UNICEF and UNAIDS

“Where infectious diseases and malnutrition are the main cause of infant deaths and the infant mortality rate is high, breastfeeding should be the usual advice given to pregnant women including those who are HIV infected. This is because their baby’s risk of HIV infection through breast milk is likely to be lower than the risk of death from other causes if it is not breastfed”.

1997 statement by WHO, UNICEF and UNAIDS

“When children born to HIV infected women can be assured of uninterrupted access to nutritionally adequate breast milk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breastfed. However, when these conditions cannot be met – in particular in environments where infectious diseases and malnutrition are the primary causes of death during infancy – then artificial feeding substantially increases children’s risk of illness and death. The policy objective must be to minimize all infant feeding risks and to urgently expand access to adequate alternatives so that HIV infected women have a range of choices. The policy should stipulate what measures are being taken to make breast milk substitutes available and affordable; to teach the safest means of feeding them to infants; and to provide the conditions which will diminish the risks of using them”.

1998 statement by WHO, UNICEF and UNAIDS

“The principle recommendation is for mothers to receive counselling that will enable them to make a fully informed decision appropriate to their situation and resources. The responsibility of the policy-maker and health care manager is to provide the necessary support to enable mothers to make and carry out their choices, whether to breastfeed or to use replacement feeds. The guidelines accommodate all reasonable infant feeding options for mothers with HIV, and support a fully informed choice, which will allow mothers to be provided with better information as it becomes available”.

2000 statement by WHO Technical Consultation on behalf of the UNICEF/WHO/UNAIDS Interagency task Team on Mother-to-Child Transmission of HIV – (WHO, 2001)

“When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV infected mothers is recommended. 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”.

Appendix 2:

Table 2: - WHO/UNICEF/UNAIDS (2003) definitions of infant feeding patterns.

Infant feeding pattern	Definition
Breastfeeding (any)	An infant who receives breast milk, either directly from the breast or expressed is considered to be breastfed. Breastfeeding is recommended to be 'on demand' by the infant.
Exclusive breastfeeding (EBF)	Giving the infant no other food or drink, not even water, apart from breast milk (including expressed breast milk), with the exception of drops or syrups consisting of vitamins, mineral supplements or prescribed medicines.
Mixed (partial) breastfeeding	Giving a baby some breast milk and some artificial feeds, either milk or cereal also any other fluid or feeds.
Replacement feeding	The process of feeding infants who are receiving no breast milk with a diet that provides the nutrients infants need until the age at which they can be fully fed on family foods. During the first six months of life, replacement feeding should be with a suitable breast-milk substitute.
Breast milk substitute	Any food being marketed or otherwise presented as a partial or total replacement for breast milk, whether or not suitable for that purpose.
Complementary feeding	Giving other foods in addition to breast milk. These other foods are called complementary foods.
Predominant breastfeeding	When an infant's predominant source of nourishment is breast milk, but the infant receives water or water-based drinks (e.g. sweetened or flavoured water, teas and infusions), fruit juice, folk fluids. With the exception of fruit juice and sugar water, no food-based fluids are allowed under this definition. Folk fluids are defined as liquids used for non-nutritional purposes such as oil to relieve constipation or gripe water to relieve colic.
Cessation of breastfeeding	Completely stopping breastfeeding, including suckling.

Appendix – 3

Guidelines for in-depth interviews (community key informants)

Introduction

I am a student at the Centre for International Health, University of Bergen, Norway, and I am currently conducting fieldwork in connection with my PhD study on maternal and infant nutrition including breastfeeding. The purpose of the study is to generate knowledge on the dilemmas of maternal and infant feeding that can be utilised to improve existing nutritional intervention programmes according to the social, economic and cultural context of Tanzanian communities.

In this connection I would like to ask you for an interview at which I will ask about your particular experiences. The interview will last for half an hour or more.

I would like to emphasise that participation in the study is voluntary and that you can agree or disagree without any consequences for you whatsoever. Any information you give will be confidential, and you will remain anonymous throughout the study.

Thank you for your co-operation.

Interview no. -----

Date of interview. -----

Brief socio-demographic data

Age. -----

Sex -----

Marital Status -----

Religion -----

Level of education -----

No. of children -----

Place of residence – a) Rural -----

a) Urban -----

Themes

1. Explore the social and cultural issues pertaining to breastfeeding and infant feeding in general
 - a) What is the role of cultural beliefs and practices on infant feeding options amongst Chagga communities?
 - b) How are mothers fed during pregnancy and after delivery?
 - c) What are the perceptions of the community concerning exclusive breastfeeding and the act of breastfeeding?
 - d) What are the cultural beliefs and rituals surrounding breastfeeding and infant feeding practices?
 - e) What are alternative infant feeding methods if the mother is sick? Or for orphans?
 - f) What are the attitudes and awareness towards these other infant feeding options in the community?
 - g) How is the mother who just decides not to breastfeed her baby seen in this community?
 - h) Who decides about infant feeding in general?
 - i) What are the attitudes of husband/partner/community to a mother who does not breastfeed the baby?
 - j) How are men and other family members involved in feeding the baby?
 - k) What are the perceptions of HIV transmission, explanatory models of the HIV disease, perceptions of the risk involved, perceptions of the accessibility and acceptability of the feeding options proposed to women? Source of information?
 - l) Any other information you would like to share about infant feeding and maternal nutrition?

Appendix – 4a

Recruitment talks with women during pregnancy (hospital-based)

Introduction

Thank you again for agreeing to participate in this study. I would still like to emphasise that your participation in this study is completely voluntary and that you can agree or disagree to participate at any time during the interview without any consequences for you whatsoever. Any information you give will be confidential, and you will remain anonymous throughout the study.

Participant no. -----

Date of recruitment. -----

Brief Socio-demographic Data

Age -----

Marital Status -----

Religion -----

Level of education -----

No. of children -----

Full address -----

Place of residence – a) Rural -----

a) Urban -----

Discussion

1. Views about the counselling services

- Please explain how you feel about the counselling services.
- Will you make your own decision regarding infant feeding?
- Can you please explain about your plans for infant feeding?
- What kind of challenges do you expect in implementing your choice?

- How are you going to deal with any reaction from people close to you?

2. Women's experiences

Can you please share with me your experience of living with HIV:

- Physically
- Psychologically
- Socially

What do you know about breastfeeding and mother-to-child transmission of HIV?

3. Knowledge of HIV Status

- When were you told about your test results?
- Were you counselled before?
- What were you told?
- How were you told?
- Where were you counselled?
- What was the immediate reaction?

4. Thoughts about the future

- Own health
- Partner's health
- Children's health

5. Social network support

- Relationship with partner
- Family support
- Neighbours
- Any other support (e.g. govt. assistance etc.)
- Financial situation

6. Infant feeding

- In a normal situation, how long would you breastfeed?
- How do you perceive the option of exclusive breastfeeding?
- How do you perceive formula feeding – Socially
 - Psychologically
 - Economically

Thank you for your cooperation.

Appendix – 4 (b)

Guidelines for in-depth interview (community-based: HIV-positive mothers)

Introduction

Thank you again for agreeing to participate in this study. I would still like to emphasise that your participation in this study is completely voluntary and that you can agree or disagree to participate at any time during the interview without any consequences for you whatsoever. Any information you give will be confidential, and you will remain anonymous throughout the study.

Thank you for your co-operation.

Interview no. -----

Date of interview. -----

Brief socio-demographic data

Age -----

Marital Status -----

Religion -----

Level of education -----

No. of children -----

Place of residence – a) Rural -----

a) Urban -----

Themes

- Knowledge about mother-to-child transmission of HIV
- Common feeding practices for babies in this community
- Opinions about HIV-positive women who breastfeed
- Opinions about HIV-positive women who do not breastfeed

- Current infant feeding method
- Any changes after delivery----, going home-----
- Challenges and successes of implementing the feeding method
- How do you cope with problems and challenges within the extended family network?
- What support do you get from your husband/partner, family and community members?
- Are women who choose not to breastfeeding because of their HIV status provided with adequate support?
- What is your view about confidentiality and partner involvement?
- How do you take care of yourselves?
- Views about the other infant feeding options recommended for HIV-positive mothers
- Views concerning adherence to the infant feeding methods chosen during counselling sessions at the PMTCT clinic
- Any other information regarding your experience that you think would be useful for me to know or discuss with you

Thank you for your cooperation.

Appendix – 5

Guidelines for focus group discussions “FGDs” (Community key informants)

Introduction

I am a student at the Centre for International Health, University of Bergen, Norway, and I am currently carrying out fieldwork in connection with my PhD study on maternal and infant nutrition including breastfeeding. The purpose of the study is to generate knowledge on the dilemmas of maternal and infant feeding that can be utilised to improve existing nutritional intervention programmes according to the social, economic and cultural context of Tanzanian communities.

In this connection I would like to ask you for an interview at which I will ask about your particular experiences. The interview will last for one to two hours.

I would like to emphasise that participation in the study is voluntary and that you can agree or disagree without any consequences for you whatsoever. Feel very free to give your views. Any information you give will be confidential, and you will remain anonymous throughout the study.

Group no. -----

Date of interview. -----

Brief socio-demographic data

Group description (write a list of each group member)

Age -----

Sex -----

Marital Status -----

Religion -----

Level of education -----

No. of children -----

Place of residence – a) Rural -----

a) Urban -----

Discussions

1. Explore the social and cultural issues pertaining to breastfeeding.

a) What is the role of cultural beliefs and practices on infant feeding options amongst Chagga communities?

b) How are mothers fed during pregnancy and after delivery?

a) What are the perceptions of the community concerning exclusive breastfeeding and the act of breastfeeding?

b) What are the cultural beliefs and rituals surrounding breastfeeding and infant feeding practices?

c) What are alternative infant feeding methods if the mother is sick? Or for orphans?

d) What are the attitudes and awareness towards these other infant feeding options in the community?

e) How is the mother who just decides not to breastfeed her baby seen in this community?

f) Who decides about infant feeding in general?

- g) What are the attitudes of husband/partner/community to a mother who does not breastfeed the baby?
- h) How are men and other family members involved in feeding the baby?
- i) What are the perceptions of HIV transmission, explanatory models of the disease, perceptions of the risk involved, perceptions of accessibility and acceptability of the feeding options proposed to women? Source of information?
- j) Any other information you would like to share about infant feeding and maternal nutrition?

Appendix – 6

In-depth interview guide with nurse-counsellors during formative research study

Introduction

Thank you again for agreeing to participate in this study. I would still like to emphasise that your participation in this study is completely voluntary and that you can agree or disagree to participate at any time during the interview without any consequences for you whatsoever. Any information you give will be confidential, and you will remain anonymous throughout the study.

Socio-demographic characteristics

Interview no: Date..... Start time..... End time.....

Name of her health facility..... Type of health facility.....

Participant's designation..... Level of education.....

Age..... Sex..... Religion..... Marital status.....

Have you trained in HIV and infant feeding counselling?

If yes, for how long? (wks/months/hrs)..... When was it conducted?

.....

Who organised the training?

Have you trained in breastfeeding counselling?

If yes, for how long? (wks/months/hrs)..... When was it conducted?

.....

Who organised the training?

How long is it since you became a pMTCT counsellor?
(wks/months/yrs).....

Interview questions

1. What are the common feeding practices for babies in this community?
.....

Probe: *Are they according to different age groups of babies?*.....

2. What are your opinions about HIV-positive women who breastfeed?.....

Probe: *What do you think? Is it a right or wrong decision?*.....

3. What are your opinions about HIV-positive women who do not breastfeed?.....

Probe: *What do you think? Is it a right or wrong decision?*

4. Do you think there is one best infant feeding method for HIV-positive women?.....

Probe: *What is it? And why do you think so?*

5. If someone talks about exclusive breastfeeding and exclusive replacement feeding, do you know what each concept means? ...

Probe: *What do they mean?*

6. What are the infant feeding options recommended for HIV-positive mothers?

Probe: *How did you know them?*

Have you seen the international and national guidelines for HIV and infant feeding?

How and where did you get to see these guidelines?

7. What are your views concerning adherence to the infant feeding methods chosen during counselling sessions at the pMTCT clinic. Do you think mothers in this community will be able to adhere?

Probe to clarify adherence to exclusive breastfeeding:

Is EBF acceptable? *Is there any barrier to EBF? Is there any perceived stigma in the community about EBF? Who decides how to feed the baby? Will the mother be supported by significant others if she decides to exclusive breastfeed her baby? Will she be supported by the community members?*

Is EBF feasible? *How is breastfeeding done in this community? Do mothers have enough time to EBF the babies? Do they have enough knowledge and skills on the frequency and how to position and attach the baby properly to the breast?*

Is it affordable? - *Probe for how long they think mothers in this community are able to breastfeed exclusively without compromising the health and nutrition of both the mother and the baby. Is access to medical care available and affordable to the mother in case of any breastfeeding problems?*

Is it sustainable? - *Probe whether they think that mothers would be able to EBF the baby continuously and uninterrupted up to the opted time for replacement feeding. What are the reasons for the responses?*

Is it safe? - *Probe to learn the pattern of breastfeeding for most women in the community: is it on demand or timed? Why is it so?*

b) Again - probe to clarify adherence to replacement feeding (exclusive formula feeding/cow's milk feeding):

Is it acceptable? - *Probe for any barrier to formula feeding/cow's milk feeding, any perceived stigma or discrimination in the community about these methods. Who decides how to feed the baby? Would the mother be supported by significant others when using formula feeding/cow's milk feeding? Would she be supported by the community members? Would most mothers be able to cope with pressure from family and friends to breastfeed? Would it be possible for them to deal with the stigma attached to being seen feeding the baby milk rather than breastfeeding?*

Is it feasible? – *Do mothers or carers of the babies in this community have adequate time, knowledge, skills and other resources to prepare formula/cow's milk? And feed*

the baby up to 12 times in 24 hours? Do you think mothers can understand and follow the instructions for preparing formula/cow's milk correctly? And sufficiently during the day and at night despite disruptions for the preparation of family food or other work? Will she be supported by the family members?

Is it affordable? – Probe - can most families in the community afford to buy sufficient milk for the baby throughout without compromising the health and nutrition of the family? Do most families have access to fuel, clean water, other items, e.g. soap? Is medical care accessible and affordable in case of health problems, e.g. diarrhoea?

Is it sustainable? – Probe - is there a possibility of having a continuous and uninterrupted supply? And a dependable system of distribution for all ingredients and products needed for safe replacement feeding for as long as the infant needs it, up to one year of age or longer? In the mother's absence, is there a possibility of having some other trustworthy family members who can safely prepare and give replacement feeds? Why is it so?

Is it safe? - Probe by asking – do you think most people in this community can prepare and store formula/cow's milk correctly and hygienically? Why do you think so?

c) Wet-nursing - probe to clarify adherence:

Is wet-nursing acceptable? Is it practised in this community? Why is it done? Is there any barrier to wet-nursing? Is there any perceived stigma in the community about wet-nursing? Who decides who should wet-nurse the baby? How is the person to wet-nurse the baby chosen? What support does the person who wet-nurses the baby get from significant others? What does she get from the community members?

Is EBF feasible? How is wet-nursing done in this community? Do mothers have enough time to wet-nurse the babies of others? Do they have enough knowledge and skills on the frequency and how to position and attach the baby properly to the breast?

Is it affordable? - For how long do they think mothers in this community are able to wet-nurse without compromising the health and nutrition of both the carer and the baby? Is access to medical care available and affordable to the carer in case of any breastfeeding problems?

Is it sustainable? – Do you think that mothers would be able to wet-nurse the baby continuously and uninterrupted up to the opted time for replacement feeding? What are the reasons for the responses?

Is it safe? - Probe to learn the pattern of wet-nursing for most women in the community: is it on demand or timed? Why is it so?

Do you discuss and recommend wet-nursing to your clients? Why?

d) Expressing and heat-treating breast milk - probe to clarify adherence:

Is expressing and heat-treating breast milk acceptable in this community? Is it practised in this community? Why is it done? Is there any barrier to this method? Is there any perceived stigma in the community about expressing and heat-treating breast milk? Would the mother be supported by significant others when she decides to practise this method? Would she be supported by the community members? Would most mothers be able to cope with pressure from family and friends to put the baby to the breast? Would it be possible for them to deal with stigma attached to being seen expressing the milk instead of breastfeeding?

Is it feasible? – Do mothers or carers of the babies in this community have adequate time, knowledge, skills and other resources to heat-treat breast milk? And feed the baby on demand? Do you think mothers can understand and follow the instructions for heat-treating breast milk correctly? And sufficiently during the day and at night despite disruptions for the preparation of family food or other work? Will she be supported by the family members?

Is it affordable? – Probe for how long they think mothers in this community are able to express and heat-treat breast milk without compromising the health and nutrition of both the mother and the baby. Is access to medical care available and affordable to

the mother in case of any breastfeeding problems? Do most families have access to fuel, clean water, other items, e.g. soap? Is medical care accessible and affordable in case of health problems, e.g. diarrhoea? Is access to medical care available and affordable to the carer in case of any breastfeeding problems?
.....

Is it sustainable? - Probe if they think that mothers would be able to express and heat-treat the breast milk continuously and uninterrupted up to the opted time for replacement feeding. What are the reasons for the responses?

Is it safe? - Probe by asking – do you think most mothers in this community store the heat-treated breast milk correctly and hygienically for the baby’s next feed? Why do you think so?.....

Do you discuss and recommend expressing and heat-treating breast milk to your clients? Why?

8. Can you explain to your clients the advantages and disadvantages of each infant feeding method recommended?
.....

9. Does HIV transmit from mother-to-child? If yes, when does it occur?

10. Do you know the estimated risks of MTCT of HIV in the absence of any intervention?

Probe: a) *How much risk during pregnancy?* b) *How much risk during labour and delivery?* c) *How much risk during breastfeeding?* d) *How much is the overall risk without breastfeeding?* e) *How much is the overall risk with breastfeeding to six months?* f) *How much is the overall risk with breastfeeding to 18 to 24 months?*.....

11. How do you feel being a counsellor for counselling HIV-positive mothers on infant feeding besides your role as a nurse?

12. What are the problems or challenges you are facing when counselling HIV-positive mothers on how to safely feed their babies?

13. What do you think are the reasons behind the problems or challenges you are facing when counselling mothers?

Probe: What are the reasons for each problem or challenge given? What are the perceived solutions for each problem or challenge?

Is there any other information regarding your experience with counselling HIV-positive mothers on infant feeding, that you think would be useful for me to know?

Thank you very much for your cooperation and your time. Your responses about your experiences and views have been very helpful.

Appendix – 7

FGDs topic guide with nurse-counsellors during formative research study

Brief socio-demographic data will be registered on a separate sheet of paper as the participants come in. The group description will include focus on group no., date of the meeting, and on each participant's designation, age, sex, level of education, religion, marital status, name of her health facility, type of the health facility, years of experience as a pMTCT counsellor, training in HIV and infant feeding and/or breastfeeding.

Introduction

Good morning/afternoon/evening. My name is Sebalda Leshabari, a student at the Centre for International Health, University of Bergen, Norway, and I am currently doing fieldwork in connection with my PhD research on infant feeding in the context of HIV/AIDS.

And this is my colleague-----.

Thank you for coming and for your time. Let us all relax as a focus group is a relaxed discussion!

Purpose

We are here today to talk about your experiences and the challenges you are facing when counselling HIV-positive mothers on how to feed their babies. The purpose is to get information that will inform future infant feeding counselling policy development and pMTCT programme interventions. I'm not here to share information or to give you my opinions. Your feelings, opinions and perceptions are what matter. There are no right or wrong or desirable or undesirable answers. You can disagree with each other and you can change your mind. I would like you to feel comfortable to say how you really feel and what you really think about your experience.

Procedure

We have discussed most of what we are going to do when we set up this meeting. My colleague (name--) will be taking notes and tape recording the discussion so that I do not miss anything you have to say. Everything will be confidential as we agreed. No one will know who said what, and you will remain anonymous throughout the study. Please make this a very open group discussion, so feel free to respond to anyone in this group without waiting to be called on. However, I'd very much appreciate it if only one person talks at a time for everyone of us to hear the views of everyone in this discussion. There is a lot to discuss, so

bear with me if I sometimes move the discussion on to focus more on our issues of concern for this meeting. The discussion will last for about one to one and a half hours depending on our discussions.

Introduction (participants)

Now, let us start with a brief introduction by mentioning your name, the name of your health facility and how long you have been counselling mothers on infant feeding.

Building rapport

Can you quickly tell us your expectations from this meeting? Anything of interest you would like us to discuss before we start our discussion?

Themes for discussion

1. What are the common feeding practices for babies in this community?

Probe: Are they according to different age groups of babies?

2. What are your opinions about HIV-positive women who breastfeed?

Probe: What do you think? Is it a right or wrong decision?

3. What are your opinions about HIV-positive women who do not breastfeed?

Probe: What do you think? Is it a right or wrong decision?

4. Do you think there is one best infant feeding method for HIV-positive women?

Probe: What is it? And why do you think so?

5. If someone talks about exclusive breastfeeding and exclusive replacement feeding, do you know what each concept means?

Probe: What do they mean?

6. What are the infant feeding options recommended for HIV-positive mothers?

Probe: *What are they? How did you know them? Have you seen the international and national guidelines for HIV and infant feeding? How and where did you get to see these guidelines?*

7. What are your views concerning adherence to the infant feeding methods chosen during counselling sessions at the pMTCT clinic? Do you think mothers in this community will be able to adhere?

Probe to clarify adherence to exclusive breastfeeding:

***Is EBF acceptable?** Is there any barrier to EBF? Is there any perceived stigma in the community about EBF? Who decides how to feed the baby? Will the mother be supported by significant others if she decides to exclusive breastfeed her baby? Will she be supported by the community members?*

***Is EBF feasible?** How is breastfeeding done in this community? Do mothers have enough time to EBF the babies? Do they have enough knowledge and skills about the frequency and how to position and attach the baby to the breast properly?*

***Is it affordable?** - Probe for how long they think mothers in this community are able to breastfeed exclusively without compromising the health and nutrition of both the mother and the baby. Is access to medical care available and affordable to the mother in case of any breastfeeding problems?*

***Is it sustainable?** - Probe whether they think that mothers would be able to EBF the baby continuously and uninterrupted up to the opted time for replacement feeding. What are the reasons for the responses?*

***Is it safe?** - Probe to learn the pattern of breastfeeding for most women in the community: is it on demand or timed? Why is it so?*

b) Again - probe to clarify adherence to replacement feeding (exclusive formula feeding/cow's milk feeding):

***Is it acceptable?** - Probe for any barrier to formula feeding/cow's milk feeding, any perceived stigma or discrimination in the community about these methods. Who*

decides how to feed the baby? Would the mother be supported by significant others when using formula feeding/cow's milk feeding? Would she be supported by the community members? Would most mothers be able to cope with pressure from family and friends to breastfeed? Would it be possible for them to deal with the stigma attached to being seen feeding the baby milk rather than breastfeeding?

Is it feasible? – *Do mothers or carers of the babies in this community have adequate time, knowledge, skills and other resources to prepare formula/cow's milk? And feed the baby up to 12 times in 24 hours? Do you think mothers can understand and follow the instructions for preparing formula/cow's milk correctly? And sufficiently during the day and at night despite disruptions for the preparation of family food or other work? Will she be supported by the family members?*

Is it affordable? – *Probe - can most families in the community afford to buy sufficient milk for the baby throughout without compromising the health and nutrition of the family? Do most families have access to fuel, clean water, and other items, e.g. soap? Is the medical care accessible and affordable in case of health problems, e.g. diarrhoea?*

Is it sustainable? – *Probe - is there a possibility of having a continuous and uninterrupted supply? And a dependable system of distribution for all ingredients and products needed for safe replacement feeding for as long as the infant needs it, up to one year of age or longer? In the mother's absence, is there a possibility of having some other trustworthy family members who can safely prepare and give replacement feeds? Why is it so?*

Is it safe? - *Probe by asking – do you think most people in this community can prepare and store formula/cow's milk correctly and hygienically? Why do you think so?*

c) Wet-nursing - probe to clarify adherence:

Is wet-nursing acceptable? *Is it practised in this community? Why is it done? Is there any barrier to wet-nursing? Is there any perceived stigma in the community about wet-nursing? Who decides who should wet-nurse the baby? How is the person to wet-*

nurse the baby chosen? What support does the person who wet-nurses the baby get from significant others? What does she get from the community members?

Is EBF feasible? *How is wet-nursing done in this community? Do mothers have enough time to wet-nurse the babies of others? Do they have enough knowledge and skills on the frequency and how to position and attach the baby properly to the breast?*

Is it affordable? - *For how long do they think mothers in this community are able to wet-nurse without compromising the health and nutrition of both the carer and the baby? Is access to medical care available and affordable to the carer in case of any breastfeeding problems?*

Is it sustainable? – *Do you think that mothers would be able to wet-nurse the baby continuously and uninterruptedly up to the opted time for replacement feeding? What are the reasons for the responses?*

Is it safe? - *Probe to learn the pattern of wet-nursing for most women in the community: is it on demand or timed? Why is it so?*

Do you discuss and recommend wet-nursing to your clients? Why?

d) Expressing and heat-treating breast milk - probe to clarify adherence:

Is expressing and heat-treating breast milk acceptable in this community? *Is it practised in this community? Why is it done? Is there any barrier to this method? Is there any perceived stigma in the community about expressing and heat-treating breast milk? Would the mother be supported by significant others when she decides to practise this method? Would she be supported by the community members? Would most mothers be able to cope with pressure from family and friends to put the baby to the breast? Would it be possible for them to deal with the stigma attached to being seen expressing the milk instead of breastfeeding?*

Is it feasible? – *Do mothers or carers of the babies in this community have adequate time, knowledge, skills and other resources to heat-treat breast milk? And feed the*

baby on demand? Do you think mothers can understand and follow the instructions for heat-treating breast milk correctly? And sufficiently during the day and at night despite disruptions for the preparation of family food or other work? Will she be supported by the family members?

Is it affordable? – Probe for how long they think mothers in this community are able to express and heat-treat breast milk without compromising the health and nutrition of both the mother and the baby. Is access to medical care available and affordable to the mother in case of any breastfeeding problems? Do most families have access to fuel, clean water, other items, e.g. soap? Is medical care accessible and affordable in case of health problems e.g. diarrhoea? Is access to medical care available and affordable to the carer in case of any breastfeeding problems?

Is it sustainable? – Probe whether they think that mothers would be able to express and heat-treat the breast milk continuously and uninterrupted up to the opted time for replacement feeding? What are the reasons for the responses?

Is it safe? - Probe by asking – do you think most mothers in this community store the heat-treated breast milk correctly and hygienically for the baby's next feed? Why do you think so?

Do you discuss and recommend expressing and heat-treating breast milk to your clients? Why?

8. Can you explain to your clients the advantages and disadvantages of each infant feeding method recommended?

9. Does HIV transmit from mother-to-child? If yes, when does it occur?

10. Do you know the estimated risks of MTCT of HIV in the absence of any intervention?

Probe: a) *How much risk during pregnancy?* b) *How much risk during labour and delivery?* c) *How much risk during breastfeeding?* d) *How much is the overall risk without breastfeeding?* e) *How much is the overall risk with breastfeeding to six months?* f) *How much is the overall risk with breastfeeding to 18 to 24 months.*

11. How do you feel being a counsellor for counselling HIV-positive mothers on infant feeding besides your role as a nurse?
12. Do you use any guidance to determine which infant feeding option is best for specific woman (AFASS) during counselling?
14. Are there some counselling materials for you to use during counselling?
13. Do you do any demonstration to the mothers when counselling about breastfeeding, e.g. position and attachment?
14. Do you demonstrate how to prepare replacement feeding during counselling?
15. Do you do follow-up or make home visits to your clients after counselling?
12. What are the problems or challenges you are facing when counselling HIV-positive mothers on how to safely feed their babies?
13. What do you think are the reasons behind the problems or challenges you are facing when counselling mothers?

Probe: What are the reasons for each problem or challenge given? What are the perceived solutions for each problem or challenge?

Closing (moderator)

Discussion of the different opinion rose-----

Summary of the consensus from the discussion-----

Ask if anyone sees it differently-----

Ask for any addition or clarification-----

Is there any other information regarding your experience with counselling HIV-positive mothers on infant feeding that you think would be useful for us to know?

Thank you very much for coming. Your time is very much appreciated and your comments/views have been very helpful.

APPENDIX 8 (a)

Research Instrument #1
In-depth Interview Guide with Mothers

Interview #: _____ Visit # _____ Status _____ Date of interview: _____

Time home visit begins: _____ Time home visit ends: _____

Time interview starts: _____ Time interview ends: _____

Place of interview (name of community): _____

Location of interview (outside home, living room, kitchen, etc): _____

Socio-demographic Questions

Age of mother: _____ Marital status of mother: _____

Religion of the mother: _____

Level of education of the mother (number of years completed): _____

Occupation of the mother (if working outside the home): _____

Date of birth of infant: _____ Sex of infant: _____

Where was the infant born: _____

Weight of infant at birth (if known): _____

Anything of note concerning health of the child: _____

Total number of living children: _____ Ages of other children: _____

Total number of people living in the home (compound) in addition to herself: _____

Description of their relationships to the mother (for example: husband/father of infant, siblings, grandmother, grandfather): _____

(NOTE: If the answers to the following questions do not fit in the space provided below, note the number of the question on another sheet of paper and continue the answer.)

General Questions About Counseling Experience and Exposure to Counseling Materials

1. During your pregnancy, how many times, or how often did you go to a counsellor at the clinic for testing and/or counselling?
2. Were you ever counseled by one of the counsellors at the clinic about feeding your baby? _____
If yes: Can you tell me in your own words what the nurse told you about feeding your baby?
3. Is there anything else the counsellor told you about feeding or taking care of your baby? _____
(PROBE if necessary: Is there anything you can do to keep you baby healthy and protect your baby from becoming sick or infected with HIV?)
4. Did the counsellor show you any educational or reference materials about feeding your baby? _____
(PROBE: If yes, can you describe the educational or reference materials that she showed you and can you remember if she read them to you?)
5. Did the counsellor give you any educational or reference materials to take home? _____ If yes, can you show me what she gave you? (Note: If the mother cannot show you the materials, ask her what happened to them.)
6. Do you remember seeing any other educational or reference materials at the clinic about feeding or taking care of babies? _____ If yes, can you describe those educational materials to me?

General Questions About Chosen Infant Feeding Method (Ask all mothers)

7. What method of infant feeding do you think is best for most babies in your community and why?
8. What method or methods of infant feeding do you think is/are best for babies of mothers who are HIV-positive and why?

9. What infant feeding method did you choose for your baby and why?
10. Did the counsellor tell you what she thought was the best method for you to use? ____ If so, what method did she recommend?
11. Did you tell the counsellor what your decision was about how to feed your baby? ____ If yes, what you tell her and what did the nurse say or do when you told her?
12. Did the counsellor demonstrate anything to you about how best to feed your baby? ____ (PROBE if necessary- depending on the method: For example, did the nurse show you how to position the baby at the breast, what utensils to use [cup vs bottle], quantities of milk, how to mix or prepare, etc.?)
13. Can you describe in your own words how you fed your baby the day he/she was born and what your experience was?
14. How are you feeding your baby today (method)? _____ (PROBE if the mother indicates that she has changed methods: Can you explain to me when exactly you changed feeding methods, why you have changed feeding methods and what your experience has been so far?)
15. Does anyone else regularly help you feed your baby during the day or night? ____ If yes: Who, when, why?
16. Can you describe to me what you (or others) do each day to feed your baby? (PROBE: Does anything change about the way you feed your baby during the morning, afternoon, evenings or at night?)
17. What would you do if you had to leave the baby unexpectedly for a number of hours with someone else? (PROBE: Ask the mother who she would leave the baby with, and what she would ask them to do if the baby becomes hungry while she is gone?)
18. Is the baby receiving anything other than _____ milk (say - breast milk, cow's milk or infant formula depending on what method the mother says she is using)? ____ (PROBE if necessary: Any vitamins, water, tea, juice or other liquids? Any foods yet?)
19. If yes, how often he/she has received this? (PROBE concerning frequency: Do you give this to the baby once a week, once a day, several times a day, only at night, only when the mother is away from the house?)
20. If yes, how are you giving this (specify liquid or food) to the baby? (PROBE if necessary: What do you use to feed the baby: a cup, bottle, spoon?)
21. In your own words, what does it mean to "exclusively breastfeed" your baby?
22. **(IF MOTHER IS BREASTFEEDING AND SAYS THAT SHE DOES NOT KNOW THE DEFINITION OF "EXCLUSIVE" OR GIVES THE WRONG ANSWER, EXPLAIN TO HER WHAT THE CORRECT DEFINITION IS – "only giving breast milk to the baby, except for medicines prescribed by a health worker")** Did you start off exclusively breastfeeding your baby?

23. How long do you think a mother who breastfeeds should “exclusively breastfeed” her baby and why?
24. How long do you think most mothers in this community CAN exclusively breastfeed their babies and why? (PROBE to see if the mother thinks it is feasible to exclusive breastfeed past a few weeks or months – how many?)
25. Is there anything a breastfeeding mother can do to help protect her baby from getting HIV? (PROBE to find out what the mother knows about having safe sex, regardless of whether she is HIV-positive or negative and about avoiding mixed feeding if she is HIV-positive.)
26. How long do you plan (or did you) “exclusively _____feed” your baby and why – in days, weeks or months? (ask according to the method used).
27. What will you feed your baby (did you start to feed) when you are no longer giving your baby ONLY _____ milk? (ask according to the method used).
28. ASK ONLY IF MOTHER IS BREASTFEEDING: Did the nurse tell you anything about the importance of breast care and what to do if you had problems with your breasts? ____ (PROBE to find out what advise the nurse gave to the mother.)
29. ASK ONLY IF THE MOTHER IS HIV-POSITIVE: Did the nurse tell you anything about the possibility of expressing and heat treating your breast milk to give to the baby, and if so, what did she tell you and what do you think of this idea?

Specific Questions For Mothers Using Modified Cow’s Milk

30. Where do you obtain your cow’s milk from (and if you have to buy it, about how much do you spend on milk for the baby on a daily basis)?
31. Can you explain to me how often you prepare the cow’s milk for your baby and where you store the cow’s milk during the day and at night? (PROBE if necessary to clarify if she prepares the cow’s milk for use for a whole day and where she stores it.
32. Can you tell me how much cow’s milk your baby drinks everyday?
33. Can you please show me how you prepare cow’s milk for your baby? (PROBE if mother does not want to actually prepare the cow’s milk at that time: Can you show me the steps you would take and the ingredients you use to prepare cow’s milk for your baby? [Demonstration: Note each step that the mother takes or describes].)

Specific Questions For Mothers Using Commercial Infant Formula

34. Where do you obtain your infant formula and how much does it cost per can? (PROBE to specify the size of the can).

35. Can you explain to me how often you prepare the infant formula for your baby?(PROBE if necessary to clarify if the mother makes the formula up for each feed. If she indicates that she makes a larger quantity for all or part of each day or night, ask if she stores it in a thermos or where?)
36. Can you tell me how much infant formula you prepare at a time for your baby and how much he/she
37. will drink everyday?
38. Can you please show me how you prepare infant formula for your baby? (PROBE if mother does not want to actually prepare the infant formula at that time: Can you show me the steps you would take and the ingredients you use to prepare the infant formula for your baby? [Note each step that the mother takes or describes.])

Specific Demonstration Questions For Breastfeeding Mothers

(Note each step that the mother takes or describes)

39. Can you please show me how you put the baby to the breast? (DESCRIBE in detail how the mother positions the baby, initiates breastfeeding, interacts with the baby, stops breastfeeding.)
40. ASK ONLY IF THE MOTHER IS BREASTFEEDING TO LEARN IF SHE KNOWS ANYTHING ABOUT EXPRESSING HER BREAST MILK AND HEAT-TREATING BREAST MILK: Can you please show me how you express breast milk? Can you show me how you would heat treat the breast milk for your baby? (PROBE if mother does not want to actually express and heat-treat the breast milk at that time: Can you tell me the steps you would take to express and heat treat breast milk for your baby?)

General Questions About Counselling Job Aids (brochures)

41. Do you have trouble reading the information in the brochures? (PROBE: Is it too much text? Etc.)
42. What do you think of the illustrations – could the mothers in the images be someone from this community? (PROBE: how she would like them corrected)
43. What do you like most about the brochures?
44. What do you like least about the brochures?

Questions that the mother has about infant feeding (answer only at the end of the survey)

45. Do you have any questions about feeding your baby? (NOTE EACH QUESTION. If the answer is in one of the infant feeding brochures, answer the question and give her that brochure if she

does not seem to have a copy. If the mother has a difficult question or problem, encourage the mother to return to the clinic to talk to the nurse.)

Observations

46. Please note (during the home visit or as soon as possible following the home visit) any relevant observations that you make during the actual interview, during the demonstration or while you are visiting in the mother's home. Things of interest include whether or not the mother: has a copy of the brochure or brochures given to her by the nurse; the mother refers to the brochure for guidance without be prompted by the interviewer; has the utensils needed and the ingredients needed to prepare replacement feed; says that she is using replacement feeding but breastfeeds child during the interview; says she is exclusively breastfeeding, but you see evidence of bottles or feeding cups used for that baby; seems confused or worried about the instructions that she has been given by the nurse, etc. Please be as complete and specific as possible in your notes.

APPENDIX 8 (b)

Research Instrument #2

Follow-up In-depth Interview Guide with Mothers

Counseled at _____ (circle: with brochures / without brochures)

Date of first interview: _____ First Interview #: _____

Date of follow-up Interview: _____ Interview # _____ Status _____

Time home visit begins: _____ Time home visit ends: _____

Place of interview (name of community): _____

Location of interview (outside home, living room, kitchen, etc): _____

Socio-demographic Questions (use previous data, but confirm with mother)

Age of mother: _____ Marital status of mother: _____

Religion of the mother: _____

Level of education of the mother (number of years completed): _____

Occupation of the mother (if working outside the home): _____

Date of birth of infant: _____ Sex of infant: _____

Where was the infant born: _____

Weight of infant at birth (if known): _____

Total number of living children: _____ Ages of other children: _____

Total number of people living in the home (compound) in addition to herself: _____

Description of their relationships to the mother (for example: husband/father of infant, siblings, grandmother, grandfather): _____

Current health status of the child Anything of note concerning health of the child:

(NOTE: If the answers to the following questions do not fit in the space provided below, note the number of the question on another sheet of paper and continue the answer.)

General Questions About Chosen Infant Feeding Method (Ask all mothers)

1. How do you feel about the method that you are using now to feed your baby (Probe to know whether it was her own choice or counsellor's choice?) Why do you think so?
2. Does anyone else regularly help you feed your baby during the day or night? If yes: Who, when, why?
3. Can you describe to me what you (or others) do each day to feed your baby? (PROBE: Does anything change about the way you feed your baby during the morning, afternoon, evenings or at night?)
4. Is the baby receiving anything other than milk: (say - breast milk, cow's milk or infant formula depending on what method the mother says she is using)? (PROBE if necessary: Any vitamins, water, tea, juice or other liquids? Any foods yet?)

5. If yes, how often he/she has received this? (PROBE concerning frequency: Do you give this to the baby once a week, once a day, several times a day, only at night, only when the mother is away from the house?)
6. If yes, how are you giving this (specify liquid or food) to the baby? (PROBE if necessary: What do you use to feed the baby: a cup, bottle, spoon?)
7. What are you doing to protect your baby from getting HIV? (PROBE to find out whether the mother is practising safe sex, regardless of whether she is HIV-positive or negative and about avoiding mixed feeding if she is HIV-positive.)

ASK ONLY IF MOTHER IS BREASTFEEDING:

8. How long do you intend to exclusive breastfeed your baby?
9. Do you have any problems with your breasts? If yes, (probe how she is treating the problem).

Specific Questions For Mothers Using Modified Cow's Milk

10. Can you explain to me how often you prepare the cow's milk for your baby and where you store the cow's milk during the day and at night? (PROBE if necessary to clarify if she prepares the cow's milk for use for a whole day and where she stores it.
11. How long do you intend to feed your baby only cow's milk?
12. Can you please show me how you prepare cow's milk for your baby? (PROBE if mother does not want to actually prepare the cow's milk at that time: Can you show me the steps you would take and the ingredients you use to prepare cow's milk for your baby?)
(Demonstration: Note each step that the mother takes or describes).

Specific Questions For Mothers Using Commercial Infant Formula

13. Can you explain to me how often you prepare the infant formula for your baby?(PROBE if necessary to clarify if the mother makes the formula up for each feed. If she indicates that she makes a larger quantity for all or part of each day or night, ask if she stores it in a thermos or where?)
14. Can you tell me how much infant formula you prepare at a time for your baby and how much he/she will drink everyday?
15. How long do you intend to feed your baby formula only?

16. Can you please show me how you prepare infant formula for your baby? (PROBE if mother does not want to actually prepare the infant formula at that time: Can you show me the steps you would take and the ingredients you use to prepare the infant formula for your baby?)
- Demonstration: Note each step that the mother takes or describes.

Specific Demonstration Questions For Breastfeeding Mothers

(Note each step that the mother takes or describes)

17. Can you please show me how you put the baby to the breast? (DESCRIBE in detail how the mother positions the baby, initiates breastfeeding, interacts with the baby, stops breastfeeding.)

General Questions About Counselling Job Aids (brochures)

18. Do you still using the brochure(s)? (Probe to clarify when & why is she using the brochures).
19. Have you shared the brochure with anyone else? If yes, (probe to clarify who, and what were the reactions of this person(s) towards the material.
20. Do you need or would like to request an additional material to help you with a transition to another feeding method? (Probe to clarify her specific request, e.g. formula to cow's milk (why), breastfeeding to cow's milk (why)?).

Questions that the mother has about infant feeding (answer only at the end of the survey)

21. Do you have any questions about feeding your baby? (NOTE EACH QUESTION. If the answer is in one of the infant feeding brochures, answer the question and give her that brochure if she does not seem to have a copy. If the mother has a difficult question or problem, encourage the mother to return to the clinic to talk to the counsellor.)
22. What are your major problem(s)/ concern(s) for the time being? & what are your future plans?
23. Would you like someone to continue visiting you? (Probe to know why? & write in details).

24. Observations

Please note (during the home visit or as soon as possible following the home visit) any relevant observations that you make during the actual interview, during the demonstration or while you are visiting in the mother's home. Things of interest include whether or not the mother: has a copy of the brochure or brochures given to her by the counsellor; the mother refers to the brochure for guidance without be prompted by the interviewer; has the utensils needed and the ingredients needed to

prepare replacement feed; says that she is using replacement feeding but breastfeeds child during the interview; says she is exclusively breastfeeding, but you see evidence of bottles or feeding cups used for that baby; seems confused or worried about the instructions that she has been given by the nurse, etc. Please be as complete and specific as possible in your notes.

ETHICAL PERMISSIONS

From MUCHS

KCMC-1st Proposal

KCMC-2nd additional for intervention

Norway

Appendix 13a

Oral informed consent to join the study for HIV-positive mothers (For contact-counsellor to discuss with an HIV-positive woman in Swahili)

Rights as a study participant

This research is being conducted by Sebalda Leshabari as part of her PhD study programme. She is working at Muhimbili University College of Health Sciences. Before I can decide whether or not to volunteer to participate in this research, I must understand all the information about the study including its purpose, benefits, risks, etc. I understand that my participation in this research is completely my choice and is entirely voluntary. I have the right to withdraw at any time during the research process without any repercussions, and I will remain anonymous throughout the study. If I choose to participate in the study, or if I decide to stop participating in the study, I will continue to receive all the services that I normally get from the hospital. If I perceive emotional upset or increased anxiety during interviews, the researcher will take extreme precaution, e.g. immediately discontinuing the interview, and I will also be free to withdraw from the study.

Purpose of the study

The study is based on the fact that pMTCT projects involve voluntary testing and counselling (VCT) of pregnant women attending antenatal clinics and the administration of antiretroviral drugs during pregnancy and childbirth to HIV-positive mothers. It has also been proved that the drug treatment does not totally prevent HIV transmission through breastfeeding. These mothers may be facing infant-feeding dilemmas and are therefore being counselled on two infant feeding options that are considered safe in terms of HIV transmission: breastfeeding exclusively for six months or replacement feeding from birth. The purpose of this study is therefore to generate culturally-sensitive knowledge about breastfeeding that can be used to inform the design and implementation of infant feeding strategies in relation to pMTCT. It is hoped that a study of this nature will explore responses to the problem of breastfeeding and HIV infection among childbearing women, nurse-counsellors and the community at large. This may contribute to grasping how women

perceive and act upon the new challenges that are confronting them, hence increasing people's understanding of the issues and discourses that may accompany changes in breastfeeding practices and in the ideologies and values that underpin them.

What does the study involve?

I understand that if I agree to participate in this study, the researcher will be asking me some questions and will monitor me throughout the antenatal period, during labour and even after delivery at home in order to extend her understanding of my experiences and views about feeding my baby. The researcher will also visit other women who are breastfeeding in my village as a necessary precaution to protect my HIV-status and to gain an understanding of the community practices for infant feeding.

Risks

I understand that there is no anticipated risk in my joining this study. The researcher is highly aware of the fact that the study focuses on the sensitive issue of HIV infection that touches upon sensitive personal emotional issues. But being a nurse-midwife and counsellor herself implies that she has some experiences and will approach me with great sensitivity. She will take great care to ensure that all the information collected will remain anonymous and confidential.

Potential benefits

I understand that there are no immediate benefits from this study. However, the results of the study will be used to improve future policy and programme interventions which will be of benefit to the mothers and children in this country.

Economic considerations

There is no direct economic gain from participating in this study. However, I understand that if the event arises when I have to spend money for any reason for this research or related activities, I will be reimbursed for all costs incurred.

Confidentiality

I understand that the information that I give shall remain confidential, and I will not be personally identified in any publication or presentation made from this study.

Whom to contact

I understand that if I have any questions about this study, I am free at any time to contact:

Mrs. Sebalda Leshabari at the School of Nursing, Muhimbili University College of Health Sciences, P.O. Box 65004, Dar es Salaam. Telephone no. 22 2137565, and also Dr. Gideon Kwesigabo at the Institute of Public Health, Muhimbili University College of Health Sciences, P.O. Box 65015, Dar es Salaam. Telephone no. 22 2153371. If I ever have questions about my rights as a research volunteer I may also contact Prof. F. Mhalu (Chairman of the College and Research and Publications Committee, Muhimbili University College of Health Sciences, Dar es Salaam).

Participation consent (to be re-checked by the researcher during recruitment talks)

..... has discussed and described to me all I need to know about this study and what is going to be done, the risks and benefits involved. I understand that my decision to participate or not in this study will not affect my usual health care. I am also free to withdraw from this study at any time and my identity will remain anonymous throughout and even after completion of this study. I understand that signing this consent form does not waive my legal rights, nor does it relieve the researcher of liability, but merely indicates that I have been informed about the research study in which I am voluntarily agreeing to participate.

Questions asked by the recruiting nurse-counsellor (to be filled in and signed by the counsellor)

Do you agree to the researcher monitoring and interviewing you during the antenatal period for her to understand your experiences during this period and also to learn how you are assisted in the choice of infant feeding method?

The participant agrees

The participant does not agree

Do you agree to the researcher monitoring and assisting you during delivery in order to become familiar with you and your baby and to understand your views and experiences during this critical time before discharge?

The participant agrees

The participant does not agree

Do you agree to the researcher visiting you at home after discharge when visiting other breastfeeding mothers in your village for her to explore infant feeding practices and views about the cultural significance of breastfeeding?

The participant agrees

The participant does not agree

.....

.....

.....

Counsellor's name

Counsellor's signature

Date

Appendix – 13b

Informed consent to join the study for nurse-counsellors

My rights as a study participant

This research is being conducted by Sebalda Leshabari as part of her PhD study programme. She is working at Muhimbili University College of Health Sciences. Before I can decide whether or not to volunteer to participate in this research, I must understand all the information about the study including its purpose, benefits, risks etc. I understand that my participation in this research is completely my choice and is entirely voluntary. I have the right to withdraw at any time during the research process without any repercussions, and I will remain anonymous throughout the study. If I choose to participate in the study, or if I decide to stop participating in the study, I will continue to receive all the services that I normally get from the hospital. If I perceive emotional upset or increased anxiety during

interviews, the researcher will take extreme precaution, e.g. immediately discontinuing the interview, and I will also be free to withdraw from the study.

Purpose of the study

The study is based on the fact that pMTCT projects involve voluntary testing and counselling (VCT) of pregnant women attending antenatal clinic and the administration of anti-retroviral drugs during pregnancy and childbirth to HIV-positive mothers. It has also been proved that the drug treatment does not prevent HIV transmission through breastfeeding. These mothers may be facing infant-feeding dilemmas and are therefore being counselled on two infant feeding options that are considered safe in terms of HIV transmission: breastfeeding exclusively for six months or replacement feeding from birth. The purpose of this study is therefore to generate knowledge about infant feeding counselling that can be used to inform the design and implementation of infant feeding counselling in relation to pMTCT. It is hoped that a study of this nature will explore responses to the experiences and challenges that nurse-counsellors face when counselling mothers on infant feeding options. This may contribute to grasping how nurse-counsellors perceive and act upon the new challenges that are confronting them, hence improving future counselling services.

What does the study involve?

I understand that if I agree to participate in this study, the researcher will be asking me questions about my experiences and the challenges I face during counselling HIV-positive mothers on infant feeding options, either individually and/or as a group of counsellors. The researcher will take great care to ensure that all the information collected will remain anonymous and confidential.

Risks

I understand that there is no anticipated risk in my joining this study. The researcher is highly aware of the fact that the study focuses on the sensitive issue of HIV infection that touches upon sensitive personal emotional issues. But being a nurse-midwife and counsellor herself implies that she has some experiences and will approach me with great sensitivity.

She will take great care to ensure that all the information collected will remain anonymous and confidential.

Potential benefits

I understand that there are no immediate benefits from this study. However, the results of the study will be used to improve future policy and programme interventions which will be of benefit to both counsellors and mothers in future.

Economic considerations

There is no direct economic gain from participating in this study. However, I understand that if the event arises when I have to spend money for any reason for this research or related activities, I will be reimbursed for all costs incurred.

Confidentiality

I understand that the information that I give shall remain confidential, and I will not be personally identified in any publication or presentation made from this study.

Whom to contact

I understand that if I have any questions about this study, I am free at any time to contact:

Mrs. Sebalda Leshabari at the School of Nursing, Muhimbili University College of Health Sciences, P.O. Box 65004, Dar es Salaam. Telephone no. 22 2137565, and also Dr. Gideon Kwesigabo at the Institute of Public Health, Muhimbili University College of Health Sciences, P.O. Box 65015, Dar es Salaam. Telephone no. 22 2153371. If I ever have questions about my rights as a research volunteer I may also contact Prof. F. Mhalu (Chairman of the College and Research and Publications Committee, Muhimbili University College of Health Sciences, Dar es Salaam).

Participation consent (signature page)

..... has discussed and described to me all I need to know about this study and what is going to be done, the risks and benefits involved. I understand that my decision to participate or not in this study will not affect my usual health care. I am also free to

withdraw from this study at any time and my identity will remain anonymous throughout and even after completion of this study. I understand that signing this consent form does not waive my legal rights, nor does it relieve the researcher of liability, but merely indicates that I have been informed about this research study in which I am voluntarily agreeing to participate.

.....

Counsellor's name

Counsellor's signature

Date



MUHIMBILI UNIVERSITY COLLEGE

OF HEALTH SCIENCES

A College of the University of Dar es Salaam

OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

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E-mail: dpgs@muchs.ac.tz

29th September, 2003

MU/PGS/AEC/IV

Mrs. S. C. Leshabari
School of Nursing,

Re: Ethical Clearance

We wish to inform you that your submission requesting for ethical clearance for research titled, "Breastfeeding in the Era of HIV/AIDS: Policy and Programme Implications for Maternal and Child Health Care Services in Tanzania" has been approved by the Chairman on behalf of the Academic Board.

You may wish to proceed with planned activities and please keep us informed of the progress.



A. Y. Maselle

Director, Research and Publications.

C.c. Principal
MUCHS

C.c. Dean
School of Nursing



**TUMAINI UNIVERSITY
KILIMANJARO CHRISTIAN MEDICAL COLLEGE**

All correspondences should be
Addressed to the Provost

P. O. Box 2240, **MOSHI**, Tanzania
Tel: Gen. line 255-027-2754377/83 Ext 443
Direct Line 255-27-2753616
Fax: 255-027-2754381
Email: ddtsec@kcmc.ac.tz
Web page: <http://www.kcmc.ac.tz>

Ref. No. TU/KCMC/T.4/11

Date: 04 August 2003

Mrs. S. C. Leshabari
Centre for International Health
Haukeland Hospital
Armeuer Hansens Building University of Bergen
N-5021, Bergen – Norway.

Dear Mrs. Leshabari,

RE: PERMISSION TO CARRY OUT A PHD DISSERTATION RESEARCH ON PMTCT AT KCMC

With reference to your letter of June 2003, I am pleased to inform you that permission has been granted for you to carry out the study at KCMC. Your proposal received on 16 July 2003 and given registration number 065 has been sent to reviewers. As agreed during our discussions on 18 July 2003, KCMC will assign to you collaborators with whom you will always be liaising with. These will include:-

- Prof. R. Olomi - Head of Paediatrics Department and Deputy Director of Hospital Services, also a Co-PI of KCMC based PMTCT project.
- Dr. M. Swai - Director Hospital Services and also a Consultant Paediatrician

Since your PhD registration is with the University of Bergen, there will be no need to call for a Memorandum of Understanding since there is already an existing one.

You are advised to thoroughly discuss your proposal with the KCMC collaborators before starting your studies.

Yours sincerely

Dr. F. W. Mosha
For **EXECUTIVE DIRECTOR, KCMC**



TUMAINI UNIVERSITY
KILIMANJARO CHRISTIAN MEDICAL COLLEGE
P. O. Box 2240, MOSHI, Tanzania

ETHICAL CLEARANCE CERTIFICATE

No. 038

For Research Proposal No. 065

Title: Breastfeeding in the Era of HIV/AIDS: Policy and
Programme Implications for Maternal and Child Health
Care Services in Tanzania.

PhD Student (P.I.) Sebalda C. Leshabari

KCMC Supervisors Dr. M. Swai and Prof. R. Olomi

Sponsor GEGCA - NUFU Project

Extension September 2003 - August 2004

Proposal Extension Approved by
KCMC Ethics Committee on 16 September 2003

Dr. F. W. Masha
SECRETARY

Mrs. J. P. Chugulu
CHAIRPERSON

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*Regional komité for
medisinsk forskningsetikk
Vest-Norge (REK Vest)*

Bergen, 30.06.03

To whom it may concern

Confirmation (REK Vest no. 098.03)

We hereby confirm that the research protocol, *Breastfeeding in the Era of HIV/AIDS: Policy and Programme Implications for Maternal and Child Health Care Services in Tanzania* by, Sebalda C. Leshabari, has been evaluated by The Regional Committee for Medical Research Ethics in Western Norway (REK Vest).

The protocol is now cleared.

Sincerely,

Arne Salbu

Secretary

UNIVERSITETET I BERGEN

Det medisinske fakultet

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*Regional komité for
medisinsk forskningsetikk
Vest-Norge (REK Vest)*

www.etikkom.no/REK

Bergen, 30.06.03

Jnr.: 098.03

Førsteamanuensis Astrid Blystad
Institutt for samfunnsmedisinske fag
Ulriksdal 8c
5009 BERGEN

Ad. Prosjekt: Amming og HIV/AIDS: Implikasjoner for planlegging av sykepleietjenester til mor og barn i Tanzania (REK Vest nr. 98.03)

Det vises til ditt brev datert 03.06.03 med svar på komiteens merknader.

REK Vest v/leder har vurdert saken og en har ikke ytterligere merknader. Studien er da endelig klarert fra denne komité sin side.

Vi ønsker dere lykke til med gjennomføringen og minner om at komiteen setter pris på en sluttrapport, eventuelt en kopi av trykt publikasjon når studien er fullført.

Vennlig hilsen

Grethe Seppola Tell
leder

Arne Salbu
sekretær