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

SC Leshabari, A Blystad, KM Moland

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.

Sebalda Charles Leshabari is a lecturer at the School of Nursing, Muhimbili University College of Health Sciences, Tanzania. She has long standing interest in Maternal and Child Health. Her PhD study is focused on the dilemmas facing HIV-positive women in northern Tanzania, especially concerning infant feeding decisions and choices in the era of HIV/AIDS. She used formative research findings in the development of culturally sensitive counselling job aids aimed at improving infant feeding practices based on the international recommendations.

Astrid Blystad is associate professor at the Department of Public Health and Primary Health Care, University of Bergen. She is a social anthropologist and senior researcher at the Centre for International Health, University of Bergen, Norway. Her interest is in reproductive health and fertility issues. She has done extensive ethnographic fieldwork among the Datoga pastoralists of northern Tanzania. She is involved in a number of collaborative research projects with Universities in Africa.

Karen Marie Moland is a social scientist at the Faculty of Health and Social Sciences, Bergen University College. She is currently a post doctoral researcher at the Centre for International Health, University of Bergen, Norway. She has interest in reproductive health and health system research and has done extensive ethnographic fieldwork in Kilimanjaro region, northern Tanzania. She is involved in a number of collaborative research projects on prevention of mother-to-child transmission of HIV in Tanzania and Ethiopia.

Correspondence to: Sebalda C. Leshabari, University of Bergen, Centre for International Health, Armauer Hansen Building Haukeland Hospital, N–5021 Bergen, Norway. E-mail: seclebo@yahoo.com.
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 spelled 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 acceptability 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 Negit 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 Mashi 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
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; Coutsoudis, 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.
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; Coutousdis, 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; Kiario 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 (Klep 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 KCNC (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 KCNC 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 KCNC 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
Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania

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

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

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. Alerted 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 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.

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 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 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.

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.

Maua knew would become upset to find her daughter not breastfeeding her three-month-old grandchild.

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

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 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.

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”.

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.

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
the breastfed infants were given supplements in the form of porridge and cow’s milk from the third or the forth 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)
Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania

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; Coutsoudis, 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...
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 breastfeeding, 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.

Acknowledgement
This research was conducted as part of a PhD study at the University of Bergen in collaboration with Muhimbili University College of Health Sciences (MUCHS). It was supported by the GEGCA–NUFU project, University of Bergen, Norway. We wish to convey our gratitude to the mothers who participated in this study, who trusted and shared their experiences and feelings with the researchers and allowed them to see things from their perspective. Without them this research would not have been possible.

References
Bokoko, P. M. (2002). Lessons and experiences with early cessation of breast feeding among HIV infected women in Kampala, Uganda. In B. B. P. Konze-Booth, A. de Wagt, P. Hill, & J. Willumsen (Eds.), HIV and Infant Feeding: A Compilation of Programmatic Evidence, 2004 (pp. 66-68). USAID, UNICEF & QAP-URC. (full text: www.hiv.gov.gy/docs/companion_hivinfantfeeding.pdf).

Bucor, R., Carstens, B., Viho, I., Elulovski, D. K., Bucor, L., Elova, B., & et al. (2005a). Infant feeding practices before implementing alternatives to prolonged breastfeeding to reduce HIV transmission through breast milk in Abidjan. Cote d’Ivoire. Journal of Tropical Pediatrics. 51(3), 351-355.

Bucor, R., Elulovski, D. K., Viho, I., Sakamoto, C., Tsou, H., Carstens, K., & et al. (2005b). Acceptability of exclusive breast-feeding with early cessation to prevent HIV transmission through breast milk. ANRS 1201/1202 DRmatre Plus, Abidjan, Cote d’Ivoire. Journal of Acquired Immune Deficiency Syndrome. 40(3), 630-636.

Bredt, A., Gudaitis, B., Jishech, A., Mungin, Y., & Kumbu, S. (2005). Njap study: Clinical Trial. Nefroprote (NVP) use in parent–mother-to-child transmission of HIV in the breastfeeding infant. Addis Ababa: National Institute of Allergy and Infectious Diseases (NIAID).

Bhandari, N., Bahl, R., Mazumdar, S., Martines, J., Black, R. E., & Bhan, M. K. (2003). Effect of Nevirapine (NVP) use on parent–mother-to-child transmission of HIV in the breastfeeding infant. Addis Ababa: National Institute of Allergy and Infectious Diseases (NIAID).

Bland, Rollins, N. C., Coombas, A., & Coscolla, H. M. (2002). Breastfeeding practices in an area of high HIV prevalence in rural South Africa. Acta Paediatrica. 91(8), 704-711.

Bland, Rollins, N. C., Solanki, G. C., & Tumakai, A. (2001). A longitudinal study of infant feeding practices. Constraints to exclusive breastfeeding. Thirtenth International Conference on AIDS, 9-14 July, 2000. Durban, South Africa. Abstract#WeC407.

Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. In New Educator. Vol. 11, pp. 461-466.

Cano, L. N., Choua, L., Jin, R., & Luana, M. (2002). Quantifying the benefits of breastfeeding: A summary of the evidence: Pan American Health Organization (PAHO) and the LINKAGES project. full text www.linkagesproject.org/mesh/publications/technica1s/9289.pdf/ERI (2003). The Community Promoter Program: A successful strategy. Addis Ababa: National Institute of Allergy and Infectious Diseases (NIAID).

Chopra, M., Shik, N., Sanders, D., Songwe, J., Psomas, T., & Pirozzi, E. (2000). Summary of the findings and recommendations from a formative research study from the Muyumbia MTCT Programme, South Africa. In B. B. P. Konze-Booth, A. de Wagt, P. Hill, & J. Willumsen (Eds.), HIV and Infant Feeding: A Compilation of Programmatic Evidence, 2004 (pp. 50-52). USAID, UNICEF & QAP-URC. (full text: www.hiv.gov.gy/docs/companion_hIVinfantfeeding.pdf).

Cava, L. N., Chessa, L., Jay, R., & Luann, M. (2002). Acceptability of exclusive breast-feeding with early cessation to prevent HIV transmission through breast milk. ANRS 1201/1202 Drmatre Plus, Abidjan, Cote d’Ivoire. Journal of Acquired Immune Deficiency Syndrome. 40(3), 630-636.

Dhaliwal, N., Bilbo, R., Marandla, S., Martens, J., Blich, R. E., & Bhan, M. K. (2003). Effect of community-based promotion of exclusive breastfeeding on diarrheal illness and growth a cluster randomised controlled trial. Lancet. 364(9437), 1418-1423.
Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania

Chung, M. H., Kariuki, J. N., Richardson, B. A., Leliana, D. A., Overbaugh, J. & John-Stewart, G. C. (2005). Breast milk HIV-1 suppression and decreased transmission: a randomized trial comparing HIVNET 012 nevirapine versus short-course zidovudine. AIDS, 19(3), 1415-1422.

Clydes, D. (2005). Made to Order - Breaks on buying. HIV Timeshare Bulletin, 6(4), 9-10.

Coumoua, A. (2005). Infant feeding dilemmas created by HIV South Africa experience. Journal of Nutrition, 135(4), 956-959.

Coumoua, A., Courode, H. M. & Noveli, M. L. (2005). Reply to “Mode of infant feeding and HIV infection in children in a program of prevention of mother-to-child transmission by Uganda” by Maguina et al. AIDS, 19(15), 1718-1719; author reply 1720-1721.

Coumoua, A., Piko, K., Kula, S. L., Spoor, E., Tsui, W. W. & Courode, H. M. (2005). Method of feeding and transmission of HIV-1 from mothers to children by 15 months of age: prospective cohort study from Durban, South Africa. AIDS, 19(5), 379-387.

Coumoua, A., Section, P., Spoor, E., Kula, S. L. & Courode, H. M. (1999). Influence of infant-feeding practices on early mother-to-child-HIV transmission in Durban, South Africa: a prospective cohort study. South African Medical Journal, 89(13), 1764-1768.

De Cock, K. M., Foulk, M. G., Mercere, E., De Vincenzi, I., Sieu, J. & Heff Et al. (2000). Prevention of mother-to-child HIV transmission in resource poor countries. Journal of the American Medical Association, 283, 1175-1180.

De Cock, K. M., Foulk, M. G., Mercere, E., De Vincenzi, I., Sieu, J. & Heff Et al. (2000). Prevention of mother-to-child HIV transmission in resource poor countries. Journal of the American Medical Association, 283, 1175-1180.

De Cock, K. M., Foulk, M. G., Mercere, E., De Vincenzi, I., Sieu, J. & Heff Et al. (2000). Prevention of mother-to-child HIV transmission in resource poor countries. Journal of the American Medical Association, 283, 1175-1180.

De Cock, K. M., Foulk, M. G., Mercere, E., De Vincenzi, I., Sieu, J. & Heff Et al. (2000). Prevention of mother-to-child HIV transmission in resource poor countries. Journal of the American Medical Association, 283, 1175-1180.