# Counselling, child growth and feeding of children in Uganda in the era of HIV

Contexts and consequences

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# There is enough for everybody's need, but not for everybody's greed.

- Mahatma Gandhi

# **Abstract in English**

### Background

Despite gradual improvements in child survival, around 8 million children die globally every year before the age of 5 years. Infant feeding practices including breastfeeding vary considerably between settings, and health counselling both in the public health services and community based interventions has been suggested to be important to improve the feeding practices. Breastfeeding promotion in particular, is regarded as one of the most effective interventions to improve child health, and has been proposed to reduce under-5-mortality by 8%. Few studies have assessed the health outcomes after infancy of promotion of exclusive breastfeeding.

### Methods

This thesis utilises both quantitative and qualitative data, and also combine them in a mixed methods approach. The quantitative data includes two cross-sectional surveys and a follow-up assessment of a trial. The cross-sectional surveys collected information on infant feeding practices among children below 1 and 2 years of age. One of the surveys focused primarily on HIV-positive mothers while the other was a community-based survey conducted in the general population. A 2-years follow-up of the community-based cluster-randomised PROMISE-EBF intervention trial, promoting exclusive breastfeeding for 6 months with peer counsellors, was used to assess growth outcomes (ClinicalTrials.gov no. NCT00397150). Anthropometric analyses are presented from five interview visits that were conducted in the age range from birth up to 2 years of age.

To get a deeper understanding of the feeding practices and perceived challenges both in the general population and among people living with HIV, 15 focus group discussions were conducted. To assess health counselling within the health facilities, 18 key informant interviews were conducted with health workers from both the public health facilities and non-governmental organisations working with HIV. All the studies were conducted in Mbale District in Eastern Uganda between 2003 and 2008 and involved around 1850 participants.

### Results

From the surveys, it was shown that HIV-positive mothers breastfed their children for a shorter duration than the general population. Among the HIV-positive mothers, the breastfeeding duration was particularly short among those with higher education, with a median of 3 months (95% confidence interval [CI] 0–10.2), compared to a median of 18 months among mothers with no education (95% CI 15.0–21.0). Similarly, the poorest HIV-positive mothers also breastfeed for a longer duration than the less poor. The main reasons to stop breastfeeding among HIV-positive mothers were advice from health workers, general illness and the HIV-diagnosis.

The qualitative studies made it clear that infant feeding counselling in health facilities was often improvised, and many health workers had not been re-trained on infant

feeding since their professional training. Poverty among the mothers was seen as one of the main challenges for many of the health workers, and many mothers struggled with the feasibility of infant feeding recommendations. Several health workers tended to give one-sided and simplistic messages, which seemed to cause confusion in a number of cases. Other challenges that were reported were inadequate facilities and lack of sufficient health workers. Concerns related to disclosure of HIV-status among health clients also served as a barrier to good infant feeding practices.

In the intervention trial promoting exclusive breastfeeding for six months, the children of mothers having received peer counselling tended to have lower weight-for-length, length-for-age and weight-for-age z-scores compared to the control arm. This was seen in nearly all the time points. The situation was most severe for length-for-age (LAZ), which had a considerable left-shifted distribution. Stunting (LAZ<-2) was more common in the intervention arm than in the control arm. At the 2 year visit, 139 (45%) of the children were stunted in the intervention arm compared to 109 (37%) in the control arm, with an odds ratio of 1.7 (95% CI 1.1–2.4).

### Conclusion

Both mothers and health workers experienced numerous challenges related to infant feeding. This was often related to poverty and insufficient health resources. There were also several challenges related to infant feeding among HIV-positive mothers. The breastfeeding duration was shorter among HIV-positive mothers than in the general population, particularly among the most educated and least poor.

In the intervention trial promoting exclusive breastfeeding for 6 months with peercounsellors, there were no growth advantages in the intervention during the first 2 years of follow-up. For several aspects, the children in the intervention arm performed worse than children in the control arm.

It is time to reconsider how infant feeding support and health counselling best can be delivered.

# Table of content

Abstract in English	4
Background Methods Results Conclusion	4 4 5 6
Siandikho mu Lumasaaha (Abstract in Lumasaaha)	0
Sammendrag på norsk (abstract in Norwegian)	10
Articles in the thesis	10
Collaboration and funding	12
	13
Important definitions	17
Important admittions	17
	18
Importance of good infant feeding practices for child health Contextual and social considerations Infant feeding for HIV-positive mothers Strategies to improve breastfeeding practices Rationale for the studies	19 21 21 24 27
Aim and objectives	28
Specific objectives Methods	28 29
Mixed methods <i>Quantitative studies</i> <i>Qualitative studies</i> Study settings and geographical description Quantitative studies <i>Subjects in the quantitative surveys</i> <i>Subjects in the intervention trial</i> <i>Quantitative interviews</i> <i>Questionnaires</i> <i>Sample size calculation</i> <i>Data cleaning</i> <i>Data management</i> <i>Reliability</i> <i>Statistical analysis</i> Qualitative studies <i>Key informant interviews</i> <i>Focus groups discussions</i>	29 29 29 32 33 33 33 34 35 35 35 35 35 37 37 37 38 39 39
Qualitative analysis	41

Summary of topics, methods and type of analyses in the four papers	41
Ethics	42
Competing interests	42
Results	43
Article 1 and 2:	43
Article 3:	45
Article 4:	48
Discussion	49
Design	49
Truth value – internal validity and credibility	49
Information assessment	49
Selection assessment	53
Sample size	54
Confounding and interactions	55
Consistency – reliability and dependability	56
Causation	56
Applicability – external validity and transferability	57
Neutrality – objectivity and conformability	58
Infant feeding patterns	59
Infant feeding counselling	59
Culture and context	61
Child growth during a breastfeeding support intervention	62
Conclusions and the way forward	64
References	65
Article 1	
Article 2	

Article 3

Article 4

Appendices

Corrections and notes

# Siandikho mu Lumasaaba (Abstract in Lumasaaba)

(translated by Robert Byamugisha and Miriam Faith Mbasalaki) Khureberesa khwakholebwa ni sisitsililirwa, sye khukhwilamo bireebo bikhulu mu khureeberesa Isambo ye khu khwongeramo bulayi mu khukhula khwe babana. Nga niyo isambo ibonekhaane nga sifungo sinyala syayeta khu khendeesa babana babaffa nga abe balondelele isambo ye khununisa babana kimyesi kisesaba. Ya belewo khureberesa nga khuenza khungoonamo sye khununisa kimyesi kisesaba ni khuwooyawoya bamai, bawooye woye basye isambo ye tsi rika khu wooyana bongere khu bongere nga niyo isamboisi bakali babone nga niyo isambo indayi. Kila ari inzambaasa eyo ni tsinzambasa tsisindi tsiambana khu khuliisa babana nisaambo ifuurisa bulayi khu enzelesebwa nga sisikendelelwa mu khungoonamo isambo ye khununisa.

Khukhwilamu bireebo bino, ambi tsingo1800 nga tsilimo bamayi nibabana, bareebebwe bireebo bihamba khusambo kyebalisamo babana. Basawo balala barebebwa khubihangafa isi babiramo nga baramba ni basawo bawoyawoya. Iliwo lundi isi bamayi babamenya mu byalo bye njawulo isi bayiribwa kumusomo kwe tsinakhu musanvu nga sikendelelwa syaba khuyeta khwekela atwela mu khuwoya bamai musambo ye khununisa babana kimyesi kinyowa kisesaba. Kumusomo kuno kwaba mu disitrikiti ye Mbale ibwama enyanga ya Uganda nga barambira atwela ni sitongole sye likangilo lye babana batsywenge (Paediatrics & Child Health) mu University ye Makerere ni Centre ye International Health mu University ye Bergen.

Kumusomo kwokesa kuri basawo bawoyawoya babandu musambo ye khuliisa babana sibasomesa bulayi ttaawe balala nga sibamanya syesibakola tta.Atenga basawobo babandi sibainana khukhwirayo basome kumusomo kwe khuliisa babana mu myesi kisesaba nga nisikanibwa tta khukhwama nga nibemalira kumusomo kwabwe kumukyibole kwebusahu. Syenyola nga basawobo babandi balekeratsaka bibindi busa nga sibifanana ni byebasyewe tta. Bakali behambilisa bari basaali batambi bafuna buhangafu mu khuliisa babana babwe bari nga nibasali babandi bapana ni sisyambaso sye khunyalikhana khwe khuliisa babana babwe nga nisikanibwa. Basawo babandi balekelatsyaka syesi bambasa nganibo sinyala syayeta nga balekele musambo inyangu lukana khuambibwa atenga sili indufu mubikendelelwa atenga lukana ikosasa balekelwa mungeri tsitsindi. Sihangafu tsitsindi basawo baloma ate syenyola siri basawo babandiyetile khumulimo kuno syenyola nga bafiti lukali atenga ni lipeesa lyandibawebile nalyo litini lukali. Nga welile khusambo ye bulwale bwe khaukha kha muniafu, buhangafu bubwanyolebwa bwaba bukali nga bufura khubakhakana bamanyibwe bari balwala bulwaale bwe khaukha atenga niyo iminzani isi unyala wamilakho khulekela byendisa ye babana mu tsinyanga tsikhali ndwela tta. Ate lundi syenyola siri indiisa ye babana babalikho bamayi balwale be khaukha yaba nga lye njawulo nabi nibabandu babandi mungeri tsitsindi. Nga mulimo ni khulisiira babana mwi banga litiini nabi khufuura busyele. Ate wenyola nga nadala bamai baba somakho nga balisiira babana babwe. Sisera sitiini nabi nga balala balisira kimyesi kitaru kyongene nga wa lekhaasire ni kimyeesi likhumi na sinane. Kyesi bamai bakhasomako kyesi batera khulisira babana baabwe. Watsa wenyola nga silondelelwa mu misomo

kyino syareera buhangafu isi bamai atwela ni basawu wenyola nga sikendelelwe sya karangarane umundu khusimanya.

Nendi isi syanyalikhanila bulayi khukhwiyongela nikhununisa babana mu myesi kisesaba, ndi babana sibatsyowa bulayi nabi khu khwongela bamai kamani khutsya munonitta. Wenyola nga bisela bibindi bulayi bwaba butini nga nibabana sibatsyowa bulayi nga balala batsyowa bafiti lukali khu myakha kyabwe nga babandi ba boomba nabi sinyala syabamilamo khulwala namwe khuffa namwe bakatsowe khutakhuba babandu bakhulu balayi mu bulamu tta.

Akhaba nga khureberesa sikhwamamo sitsilililwa sye babana khutsowa bulayi tta, sisimanyisa siri khununisa umwana bulayi khumala kimyesi kinyowa kisesaba sisili sibitta nendi syokesa sili syandibele sirayi khurambisa bamai babene basomee bamayi basyebwe khu sye bulayi bwe khununisa babana kimyesi kisesaba nga wa bayilile mu musomo ikwe tsinakhu musanvu ne sye khununisa babana sibemo kamani.

# Sammendrag på norsk (abstract in Norwegian)

Til tross for en gradvis reduksjon i dødsfall blant barn, dør hver år 8 millioner barn før de fyller 5 år. Ernæring og amming regnes som en av de viktigste faktorene for god barnehelse. Samtidig er det stor variasjon i hvordan amming og ernæring av barn foregår i ulike deler av verden. Helseundervisning er viktig for barnehelse, men det er i liten grad kjent hvordan dette har fungert i Uganda. Det har også blitt foreslått at tiltak som fremmer fullamming fram til 6 måneders alder kan bedre ammemønstre og redusere barnedødelighet med 8 prosent. Det har ikke blitt bekreftet at dette stemmer, og at barn vokser tilstrekkelig godt når fullamming fremmes fram til 6 måneder. Denne avhandlingen vil evaluere ernæringspraksis blant småbarn i Uganda, helseundervisning i helsevesenet, og effekten på barnevekst av en studie som har fremmet fullamming.

Denne avhandlingen benytter både kvalitative og kvantitative forskningsmetoder. Dette inkluderer to tverrsnittsstudier som har sett nærmere på amme- og ernæringspraksis hos små barn i både den generelle befolkning og blant barna til mødre med HIV. Det har også det blitt gjennomført fokusgruppeintervjuer blant tilsvarende grupper, samt nøkkelinformantintervjuer blant helsepersonell. I tillegg er det gjort en toårsoppfølging av barn som har deltatt i en studie hvor fullamming har blitt fremmet fram til 6 måneders alder. Barnas høyde og lengdevekst har blitt brukt til å evaluere effekten av forsøket. Alle studiene ble gjennomført i Mbale i den østlige delen av Uganda mellom 2003 og 2008, og involverte rundt 1850 studiedeltakere.

De kvalitative studiene viste at helseundervisning i helsevesenet ofte var improvisert og at helsearbeiderne hadde tallrike utfordringer. Dette inkluderte mangel på helsearbeidere, tilstrekkelig utstyr og lokaler, samt sjeldne oppfriskningskurs, og store utfordringer med å støtte og gi råd til en befolkning med høy grad av fattigdom. Den utstrakte fattigdommen gjorde det i mange tilfeller vanskelig å få et godt og variert kosthold. Noe som gjorde dette spesielt vanskelig var at retningslinjene som var aktuelle da studiene ble gjennomført i for liten grad tok hensyn til den stedsspesifikke sitasjonen, de økonomiske faktorene og kulturen. En del helsearbeidere hadde også vanskeligheter med å balansere det å forenkle viktige budskap og samtidig gi et budskap som var tilstrekkelig nyansert til ikke å skape forvirring.

Resultatene viste også at mødre med HIV ammet kortere enn befolkningen for øvrig – særlig blant de minst fattige med høyest utdanning. Hovedårsakene til at mødre med HIV sluttet å amme var råd fra helsearbeidere, sykdom og HIV-diagnosen. En bekymring blant flere mødre med HIV var det at enkelte av de tidligere anbefalingene, og da særlig det å gi morsmelkserstatning fra tidlig alder, var forbundet med å bli ansett som HIV-positiv i lokalsamfunnet. Dette kunne by på store utfordringer for enkelte.

Det viste seg også at forsøket med å benytte mor-til-mor rådgivere for å fremme fullamming fram til 6 måneders alder ikke hadde positiv effekt på barnas vekst – verken i løpet av de første 6 månedene eller ved 2 års alder. Nærmere halvparten av barna til mødrene som fikk mor-til-mor rådgivning hadde svært lav høyde for alderen. Blant barna til mødrene som ikke fikk helserådgivning var over en tredel av barna svært lav høyde for alderen.

Avhandlingen viser at det er helt sentralt at retningslinjer tar den stedsspesifikke situasjonen og kulturen i betraktning. Samtidig er det på tide å revurdere hvordan man kan fremme ernæring blant barn på en best mulig måte.

# Articles in the thesis

Fadnes LT, Engebretsen IM, Wamani H, Wangisi J, Tumwine JK, Tylleskar T: Need to optimise infant feeding counselling: A cross-sectional survey among HIVpositive mothers in Eastern Uganda. *BMC Pediatr* 2009, **9**(1):2. <u>http://www.biomedcentral.com/1471-2431/9/2</u>

Fadnes LT, Engebretsen IM, Wamani H, Semiyaga NB, Tylleskar T, Tumwine JK: Infant feeding among HIV-positive mothers and the general population mothers: comparison of two cross-sectional surveys in Eastern Uganda. *BMC Public Health* 2009, **9**:124.

http://www.biomedcentral.com/1471-2458/9/124

Fadnes LT, Engebretsen IM, Moland KM, Nankunda J, Tumwine JK, Tylleskar T: Infant feeding counselling in Uganda in a changing environment with focus on the general population and HIV-positive mothers - a mixed method approach. *BMC Health Serv Res* 2010, **10**(1):260.

http://www.biomedcentral.com/1472-6963/10/260

Lars T Fadnes, Victoria Nankabirwa, Ingunn MS Engebretsen, Halvor Sommerfelt, Carl Lombard, Sonja Swanevelder, Jan Van den Broeck, Thorkild Tylleskär, James K Tumwine, for the PROMISE-EBF Study Group:

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This thesis is based on studies which have been done in collaboration between Centre for International Health at University of Bergen in Norway and Department of Paediatrics and Child Health at Makerere University in Uganda.

The studies which made the basis for the three first papers were conducted in collaboration with health facilities in Mbale region and with *The Aids Support Organisation (TASO)*, <u>http://www.tasouganda.org/</u>. TASO was the largest national-based non-governmental organisation working with HIV-positive people in Africa. It is a grassroots movement providing counselling, information, support and medical treatment.

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Centre Muraz, (Muraz) Burkina Faso http://membres.lycos.fr/centremuraz/

University of Montpellier, France http://www.chu-montpellier.fr/

Centre for International Health (CIH), University of Bergen, Norway www.cih.uib.no

School of Public Health, University of Western Cape (UWC), Cape Town, South Africa

http://www.uwc.ac.za/

International Maternal and Child Health (IMCH), Univ. of Uppsala, Sweden <a href="http://www.imch.kbh.uu.se/">http://www.imch.kbh.uu.se/</a>

Dept of Paediatrics and Child Health, Makerere Univ. (MAK), Uganda <u>http://www.makerere.ac.ug/</u>

Dept of Paediatrics and Child Health, School of Med, Univ. of Zambia <u>http://www.unza.zm/</u>

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Lars T Fadnes

# Important definitions

Feeding information was based on WHO definitions and recommendations as follows [1]:

**Exclusive breastfeeding** is when only breast milk is given to the child, except for medicines, vitamins or mineral supplements.

**Predominant breastfeeding** is when breast milk is nutritionally dominant while given in addition to water-based fluids including fruit juices, tea without milk or oral rehydration salts.

# Complementary feeding including breast milk (partial breastfeeding or mixed feeding):

These terms are used to describe when non-human milk, semi-solids or other solids are given to the child in addition to breast milk. The term mixed feeding does normally refer to the feeding practice specified above during the first half of infancy (under 6 months old).

**Replacement feeding** is defined as the feeding strategy when breastfeeding has been stopped, or if the child never has been given any breast milk. Exclusive replacement feeding was defined as when never having given any breast milk.

**Prelacteal feeding** is here defined as when any liquid or food item other than breast milk is given to the infants during the first 3 days after delivery, commonly associated with delayed initiation of breastfeeding.

# Important abbreviations

confidence interval
human immunodeficiency virus
inter-quartile range
length-for-age z-score
Prevention of Mother-to-Child Transmission
The Aids Support Organisation
weight-for-age z-score
World Health Organisation
weight-for-length z-score

# Introduction

Despite gradual improvements in child survival, around 8 million children die globally every year [2-5]. This is comparable to 60 jumbo jets crashing every day and hardly reaching the news. Around half of these deaths are in Africa [2], and many are within the first month of life as illustrated in figure 1 [6]. The millennium development goals were set in 2001 [7], and goal number 4 aimed to reduce the child mortality by two thirds from the level in 1990 within 2015. The progress has been evaluated several times [3-5, 8-10], and the development is not yet on track to reach this goal. Between 1990 and 2008, the number of child deaths was reduced from 90 to 65 per 1000 liveborn children globally, aiming towards a target of less than 30 child deaths per 1000 in 2015 [5, 8]. The deaths are unevenly distributed, with more than 95% of the deaths in 68 countries.



Figure 1: Regional causes of child deaths by Black et al [2].

Deaths are categorised into neonatal (between 0–27 days after birth) and later (children aged 1–59 months).

# Importance of good infant feeding practices for child health

During the last years, several feasible interventions reducing child mortality have been identified [3, 11, 12]. These include immediate and exclusive breastfeeding for six months, improved complementary feeding, improved sanitation and drinking water,

maternal health assessment and micronutrient supplementation with particularly vitamin A and zinc [13-15]. Good nutrition among children is not only important for child health in the short term [11, 16-19], it is also important for the health of today's children in their future life as adults, and even for the coming generations [20].

Breastfeeding is a cornerstone for feeding of children with several associated benefits compared to not breastfeeding, including a reduced incidence of diarrhoea and respiratory infections, as well as a reduction in child mortality [16, 21]. Breastfeeding also has several other benefits including a reduced risk of obesity [22, 23], lower risk of allergy and eczema [19]. It has also been suggested to be associated with better cognitive and motor function development, although there is still some ongoing discussion related to the latter points [24-26]. The composition of breast milk is very different from most types of non-human milk, which might explain several of the advantages [27].

It has been estimated from a modelling by Jones *et al* that as much as 13% of the under-5-mortality could be avoided with ideal practices of exclusive breastfeeding [12], which would reduce the loss of 37 million disability adjusted life years annually [13]. Based on these estimates, Bhutta *et al* calculated that widespread promotion of exclusive breastfeeding would prevent 8% of the child deaths [11, 21].

The optimal duration of exclusive breastfeeding has been discussed, with a study indicating lower risk of gastrointestinal infections among children being exclusively breastfed for 6 months compared to 3 months [28, 29]. A small association between prolonged amenorrhea and more exclusive breastfeeding has also been suggested [30]. It was also no clear evidence on growth deficits associated with 6 months of exclusive breastfeeding compared to 3 months [29]. Based on these findings, 6 months of exclusive breastfeeding was recommended [31]. Some have questioned the evidence for this recommendation [32].

There are a number of studies indicating that continued breastfeeding and good complementary feeding practices up to 2 years of life have beneficial effects on child growth [18, 33-35]. On the other hand, inadequate complementary feeding during the weaning period is a risk factor for poor growth outcomes including stunting [36]. Appropriate child growth is essential and is a protective factor for morbidity and mortality [13, 37]. The situation concerning child growth in Uganda has previously been reported to be sub-optimal [17, 38, 39], with a high prevalence of stunted and underweight children.

The time of initiation of breastfeeding has been found to be essential for child survival [14], with an increased risk of infant death even with a one hour delay between birth and breastfeeding initiation. Breastfeeding initiation is also closely connected to prelacteal feeding. Prelacteal feeding can be defined as when infants are given other liquids than breast milk during the first 3 days – before breastfeeding is well established. This is a challenge as it often causes delayed initiation of breastfeeding and in many cases might be associated with discarding the first milk, which is

particularly important for the child [14, 40]. The first milk, colostrum, is traditionally seen as unfortunate for the baby in many settings including Eastern Uganda [41-43].

### **Contextual and social considerations**

Breastfeeding is deeply culturally grounded in many settings [44, 45]. Although exclusive breastfeeding has several well proven benefits, it can be culturally challenging in some settings as it is perceived as important to also give other liquids and food items to the children [41, 44, 46]. The strong cultural and social expectations on breastfeeding also have psychological implications. Many mothers perceive themselves as failed mothers if they do not manage to provide the desired infant feeding options [44]. Family perspectives are also important as decisions on infant feeding in several settings might be influenced by the family [41, 47]. In other settings infant feeding has been considered to be the domain of women alone [45], while the men are expected to support financially [41].

Not only social and cultural factors are challenging good infant feeding practices. Formula feeding represents a considerable threat to proper infant feeding practices in various settings [48, 49]. It also puts a heavy financial burden on poor families. The producers of formula milk use a considerable amount of money on marketing of their products [49]. In the United States, the formula milk producers spent \$30 on marketing per baby per year, outweighing the information campaigns from the US Department of Health Promotion, which spent \$0.21. To limit the negative influence from formula feeding marketing on child health, the International Code of Marketing of Breast milk Substitutes has been made [50]. 'The Code' endorses countries to implement regulations on marketing of formula milk. Uganda is among the countries that have implemented the International Code of Marketing of Breast milk Substitutes [5, 50, 51].

### Infant feeding for HIV-positive mothers

In 1985, a probable transmission of HIV from mother to child through breastfeeding was described by Ziegler [52]. This finding was confirmed some years later by van de Perre *et al* in Rwanda and Nduati *et al* in Kenya [53-56]. With this knowledge, infant feeding counselling got more complicated in several settings with a high prevalence of HIV. It was soon clear that the risk of HIV-transmission from mother-to-child increases with increasing duration of breastfeeding [57].

The infants who are infected with HIV carry a heavy burden of diseases, in addition to a high risk of early death [58-60]. However, the children who acquire HIV have a better prognosis if they are breastfed for a longer duration than if they are weaned early [61].

Paradoxically, abrupt weaning have also been reported to be associated with increased risk of HIV or death, and infants born to HIV-positive mothers in many settings seems to be better off with continued breastfeeding rather than a short duration of breastfeeding [61-63]. One reason for the increased HIV-transmission with abrupt weaning may be related to increased viral loads in the breast milk after weaning [63].

This might be a particular hazard for those who try to stop breastfeeding, but re-initiate it due to difficulties sticking to their initial choice. Breast health problems such as mastitis and sub-clinical mastitis are also associated with increased risk of HIV-transmission [55, 64]. Other important factors increasing the risk of HIV-transmission include a low CD4 count in the mother, a high maternal viral load [57, 65] and early introduction of solid- or semi-solid food while breastfeeding [66].

During the 1990s and early 2000s, the WHO guidelines on infant feeding for HIVpositive mothers focused on limiting breastfeeding as much as possible [67, 68]. Unfortunately, the knowledge on HIV-transmission through breast milk also seemed to have caused confusion among HIV-positive mothers as well as a spill-over effect where recommendations aimed at HIV-positive mothers were adopted into the general population [69-72]. Studies also showed that many counsellors were uncertain on how to advise on infant feeding, especially as formula feeding and exclusive breastfeeding have not been regarded as feasible or culturally acceptable [70, 73]. Several of those who intended to exclusively formula feed struggled to stick to that choice and ended up with mixed feeding [74].

The question whether infants born to HIV-positive mothers should be breastfed is a balance between the risks of HIV-transmission on one hand and health benefits related to breastfeeding on the other hand [66, 75-79]. In 1999, a landmark study from Durban in South Africa was published by Coutsoudis *et al* [80]. The study revealed that exclusive breastfeeding was associated with lower HIV-transmission than mixed feeding. The positive effect of exclusive breastfeeding on HIV-free survival was later confirmed in larger studies both in South Africa, Zambia and Zimbabwe [61, 62, 66, 75, 81].

A possible explanation for the lower HIV-transmission risk when breastfeeding exclusively compared to practicing mixed feeding is lower rates of breast health problems such as engorgement and mastitis among exclusively breastfeeding mothers, as breast health problems are associated with increased risk of HIV-transmission [55, 64, 82]. Other explanations include that mixed feeding can cause inflammation in the intestinal tract of the children which increases transmission, and that breast milk might improve the immune system [65].

Studies on whether replacement feeding would increase HIV-free survival in African settings have also been undertaken [56, 83]. A Ugandan study by Kagaayi from 2008 showed that replacement feeding among HIV-positive mothers was associated with 18% child mortality up to one year of age, compared to 3% among breastfeeding HIV-positive mothers [83]. HIV-free survival tended to be higher among breastfeeding children than children receiving formula feeding (92% vs. 86%). One of the challenges for the formula feeding mothers was difficulties in following the recommendations on sterile preparation of the feeds. Another negative effect reported from formula feeding programs has been a contamination or spill-over effect, where recommendations were adopted into the general population [71, 72].

The studies from South Africa, Zambia and Zimbabwe, caused a shift in the recommendations on infant feeding to HIV-positive mothers [67, 68, 84-86], with a stronger focus on breastfeeding also in the context of HIV. As it was known that antiretroviral drugs reduce viral load of HIV, several studies started to investigate to which degree different regimen of antiretroviral prophylaxis could reduce transmission of HIV from mother-to-child. The Petra study that was published in 2002 made it clear that antiretroviral prophylaxis was effective in reducing vertical transmission of HIV, although HIV was transmitted during periods without antiretroviral protection [87].

This study was followed by several studies confirming the effectiveness of antiretroviral therapy to reduce the HIV-transmission from mother to child. This included the Mashi study from Botswana [88], the PEPI trial in Malawi [89], the Mitra and Mitra Plus studies from Tanzania [90, 91], the Mma Bana Study from Botswana [92], BAN study from Malawi [93], the multicentre SWEN study that took place in Ethiopia, Uganda and India [94], and the multicentre Kesho Bora study in Burkina Faso, Kenya and South Africa [95].

The conclusion from these studies which was also summarised in Cochrane reviews by Volmink *et al* in 2007 Horvath *et al* in 2009 [96, 97], was that both prophylaxis to the children and antiretroviral therapy to the mothers were highly effective when given for the duration of breastfeeding – and could reduce HIV-transmissions down to around 1%. This strengthened the arguments for a longer duration of breastfeeding. With this knowledge [98], the World Health Organization changed the guidelines on infant feeding in the context of HIV in 2009 and then again in the end of 2010 [99-102].

The view on counselling has changed over the last guidelines on infant feeding in the context of HIV from WHO, with a current approach focusing more on disclosure of a single option as standard [102]. Figure 2 below illustrates the current rationale for the counselling approach from the last guidelines.

# Characteristics of intervention

- Balance of risks and benefits of different options not clear (equipoise)
- Effective interventions supported by high quality evidence and cost benefit analysis
- Danger to others if intervention not adhered to

#### 'Counselling' approach

- Non-directive counselling (e.g., genetic testing; medical research)
- Disclosure of all options combined with professional recommendation (e.g., most major medical treatment)
- Disclosure of single option as standard, with notification of right to refuse (e.g., HIV testing)
- Disclosure of single option as standard; right to refuse may be recognized, but patients are not notified of this right (e.g., tuberculosis treatment)
- Non-consensual interventions (e.g., psychotropic medications to stabilize dangerous patients)

**Figure 2:** The current rationale for counselling approach (from the WHO guidelines on HIV and infant feeding in 2010 [102])

### Strategies to improve breastfeeding practices

Breastfeeding has been on the agenda of World Health Organisation (WHO) and UNICEF for many years with initiatives such as the Baby-Friendly Hospital/Health Initiative (BFHI) launched in 1991, and the Integrated Management of Childhood Illness (IMCI) launched in 1995 [103, 104]. These initiatives have focused primarily on infant feeding within the public health services. Despite these initiatives, good promotion of exclusive breastfeeding is still far from universal as illustrated in the figure below indicating the coverage rate of several interventions [8].



**Figure 3**: Coverage estimates for various maternal and child health interventions in 68 priority countries by Bhutta *et al* [8]. Exclusive breastfeeding is labelled with yellow.

In addition to supra-governmental initiatives, there are several studies which have tested interventions to promote exclusive breastfeeding [19, 26, 28, 105-107]. These include both health-facility based interventions and community-based interventions.

An important contribution to the research on interventions to improve breastfeeding practices came from the PROBIT study led by Kramer [19, 26, 28, 107]. In this

cluster-randomised intervention trial, 17,000 infants were included and followed-up for 1 year [19]. Using an intervention inspired by the baby-friendly hospital initiative, exclusive breastfeeding rates at 3 months increased from 6% in the control arm to 43% in the intervention arm. Parallel with the increased practice of exclusive breastfeeding, a reduction in gastrointestinal infections were observed – from 13% in the control arm to 9% in the intervention arm. Atopic eczema was also less common among the children included in the intervention with promotion of breastfeeding. This study evaluated long-term effects of differences in durations of exclusive breastfeeding, and it did not find any difference in outcomes at 6.5 years between 3 or 6 months of exclusively breastfeeding [26, 28].

There are several studies on breastfeeding promotion that have been conducted in other settings. A randomised controlled study in Ghana involving intensive infant feeding counselling showed an increase in the prevalence of exclusive breastfeeding from 20% to 40%. A study from India involved various types of health workers in the counselling and showed a substantial increase in the practice of exclusive breastfeeding breastfeeding as well as a reduction in the rates of diarrhoea [106].

An extensive Cochrane review from 2007 on the effect of breastfeeding support was done by Britton *et al* [108]. A total of 34 trials with nearly 30,000 mother-infant pairs were included in the review with the conclusion that support of breastfeeding prolonged the duration of breastfeeding. A combination of lay support and professional support was most effective, and this combination also increased the duration of exclusive breastfeeding.

Another review reported by Guigliani and Victoria in 2008 concluded that few studies had assessed growth outcomes of breastfeeding support, and none had reported growth outcomes from Africa [109]. Breastfeeding support was associated with an insignificant trend to better growth outcomes at 4 months. There were also no studies that had assessed growth outcomes after 1 year of age with intention-to-treat analysis.

A South African study investigated the cost effectiveness of promoting exclusive breastfeeding, and concluded that the cost to extend exclusive breastfeeding by one month is between \$29 and \$88 depending on the intensity of the counselling intervention [110]. There are also successful reports on broad scale-up of interventions to improve infant feeding counselling summarised in a review by Bhandari et al [111]. One of these studies evaluated a program in Madagascar, Ghana and Bolivia where early breastfeeding initiation and exclusive breastfeeding had been promoted [112]. This was done through a range of strategies including media campaigns, community counselling and counselling within the health service, with increased practice of exclusive breastfeeding and early initiation of breastfeeding as outcomes.

The effect of scientifically sound programs does not always give the results that are expected. A study from Guinea Bissau published in 2008 did not find beneficial effects on morbidity or mortality from an intervention that promoted exclusive breastfeeding by peer-counselling [113]. Similarly, an evaluation from the implementation of the

Accelerated Child Survival and Development programme (ACSD) in West Africa showed that child mortality was reduced, but not more than the national trends [114]. This program focused on vaccination coverage, nutritional advice, antenatal care, treatment of malaria and diarrhoea diseases and other infections. Despite promoting exclusive breastfeeding, comparison areas had better rates of exclusive breastfeeding than the intervention clusters. This underlines the importance of evaluating programs and interventions.

# Rationale for the studies

As shown in the introduction, good infant feeding practices are fundamental for child health. The infant feeding practices vary substantially across the world, with different proportions practicing breastfeeding, differences in the duration of breastfeeding and different degrees of mixing between breast milk and other food-items in the early age [115]. Thus, regional and setting specific knowledge about infant feeding is essential. Before the surveys were conducted, there was limited knowledge on infant feeding practices in Eastern Uganda, both among HIV-positive mothers and in the general population. A lack of knowledge was also seen in the cross-section between infant feeding in the context of HIV, while few had assessed how this was working on the ground in Uganda. These were the main knowledge gaps that the two first papers aimed to fill.

At the time of the studies and study planning, there was a lack of knowledge concerning several factors including how health counselling in the public and non-public facilities worked, and which obstacles that were perceived as most challenging among mothers and health workers. The third paper used both qualitative and quantitative studies to fill this shortcoming in knowledge.

Promotion of exclusive breastfeeding has been targeted out as one of the most promising interventions to reduce the number of child deaths. With this in mind, a community-based cluster-randomised intervention trial was conducted to promote exclusive breastfeeding for 6 months. Even if interventions to support exclusive breastfeeding have been assumed to be beneficial, there is limited knowledge on the health outcomes from such interventions, particularly related to child growth. Anthropometric assessment is a good way to evaluate child growth [37, 116]. This was the rationale for the fourth article which will assess growth outcomes up to 2 years of age.

## Aim and objectives

The first aim of this thesis was to assess how infant feeding practices and health counselling worked in Eastern Uganda, and identify barriers to improved infant feeding practices.

The second aim was to assess child growth outcomes from an intervention with the aim to increase exclusive breastfeeding in Eastern Uganda.

### **Specific objectives**

- 1. Identify feeding patterns among infants and young children of HIV-positive mothers. This objective was the focus for paper 1.
- 2. Compare feeding patterns between the infants born to HIV-positive mothers and infants of mothers in the general population. The second paper concentrated on this point.
- 3. To assess infant feeding counselling to pregnant women in health facilities including health clinics, hospital, and non-governmental organisations working with people living with HIV. The third paper assessed this objective.
- 4. To assess anthropometric growth outcomes from an intervention promoting exclusive breastfeeding for 6 months through peer-counsellors. This objective was targeted in the fourth paper.

# Methods

To answer the questions stated in the objectives, this thesis has utilised both quantitative and qualitative methods, and has also combined them in a mixed methods framework [117, 118]. This means that both qualitative and quantitative aspects have been integrated in different stages of the process.

## **Mixed methods**

Different scientific questions can be answered with different methods [117]. Qualitative methods are often better suited to answer questions on *why* and *what*, while quantitative methods in general are superior in answering questions about *how much* and *how often*. Qualitative and quantitative questions can thus go hand in hand to give broadened perspectives.

The third paper used triangulation with a '*concurrent nested*' design combining both qualitative and quantitative data which were carried out in parallel and integrated in the design, implementation and analysis phase [119]. A multilevel design framework was used as described by Tashakkori and Teddlie [120]. This meant that different types of interviews were used for different information sources; key informant interviews were conducted with health workers and focus-group discussions were conduced with mothers.

A total of seven studies have built the groundwork for this thesis (see figure 4):

### Quantitative studies

- A cross-sectional survey where 235 HIV-1 positive mothers were analysed with respect to infant feeding practices and feeding predictors [121, 122]
- A community-based cross-sectional survey with 727 mothers from the general population was used in comparison to the survey among the HIV-positive mothers. This survey was analysed with regards to infant feeding practices and socio-economic factors [122]
- Two years follow-up of a community-based cluster-randomised controlled trial promoting exclusive breastfeeding for six months (ClinicalTrials.gov no. NCT00397150) [123]

### Qualitative studies

- Focus-group discussions among HIV-positive people; including 5 groups involving mothers below 35 years of age, one group with HIV-positive men and one with HIV-positive women above 35 years [124]
- Community based focus-group discussions highlighting the view of parents on infant feeding practises [41]
- Key informant interviews among health personnel working with HIV-positive people both in the public hospital and in non-governmental organisations [124]
- Key informant interviews with health workers from the public sector working particularly with maternity education, infant feeding guidance and child health [124]



Figure 4 (above): Chart with participant profile for the different studies forming the fundament for the thesis. A timeline illustrates when each study was conducted and the colour coding illustrates in which articles the studies have been presented.



Figure 5: Map of the site of the studies (Mbale District, Eastern Uganda, Eastern Africa).

The author of the thesis coordinated the fieldwork of the cross-sectional survey with HIV-positive mothers, the focus groups among HIV-positive people, conducted several of the key informant interviews, and was also involved in several phases of the other studies.

### Study settings and geographical description

The studies were conducted in Mbale District. Mbale is situated at the foot of mountain Elgon in Eastern Uganda just north of the equator (see map in figure 5). The climate in Mbale is tropical with an average temperature of around 22 °C, between 8 and 20 wet days monthly, and around 1200 mm of precipitation annually [125].

Mbale had a population of 403,100 in 2008 after being divided into a smaller district [126]. Before the division, the district had around 720,000 inhabitants [127]. The district is predominantly rural with subsistence farming as a main activity. Mbale municipality, which is the district centre, has a population of around 84,000. The literacy rate in Eastern Uganda was 56% among women and 71% among men in 2005–6. Around 84% of the population in Uganda are Christians and 12% are Muslims. In Mbale region, the numbers are probably more even between Christians and Muslims. There are several languages spoken in the vicinity of Mbale, including Lumasaaba, Lugwere, Ateso and Luganda.

Uganda has a rapid population growth, with an annual birth rate of 1.4 millions added to the population of just below 30 millions in 2006 [5, 126]. The life expectancy was 52 years for women and 49 years for men. The health expenditure per capita was about US \$135 (2006). This accounted for 10% of the Ugandan national budget. The density of health workers was just below 1 per thousand in 2004.

There were 59% home deliveries and an antenatal attendance of 95%. One in 25 mothers died in pregnancy related deaths. From 1990 to 2008, the under-5-mortality was reduced from 186 to 135 per 1000 [8]. Unfortunately, Uganda is unlikely to achieve the millennium development goal number 4 to reduce mortality among children below 5 years of age by two thirds of the 1990 level by 2015 [3-5, 7, 9, 126].

Even though the prevalence of HIV in Uganda has been declining during the second half of the 1990s [128], 7.5% among fertile women and 5.0% among men 15–49 years were infected in 2004–5 [126, 129, 130]. There is some evidence about changes in sexual behaviour, which might be part of the explanation for the reduction [131]. The regional HIV-prevalence in Mbale is slightly lower than the national prevalence, with 6.2% among fertile women in 2004–5 [126, 129]. A '*provider-initiated routine HIV counselling and testing algorithm*' was implemented in Uganda hospitals in 2006 and increased the testing rate substantially within the hospitals [132-135]. This strategy was also seen as highly accepted among health clients. The PMTCT program was introduced in Uganda first as a pilot in 1998, and then more widely in 2001 [136].

### **Quantitative studies**

#### Subjects in the quantitative surveys

Two cross-sectional surveys were conducted in the end of 2003 and the beginning of 2005 in the same area in Eastern Uganda using analogous questionnaires.

The first survey was a community-based study conducted from September to November 2003 and included 793 randomly-selected caretaker-infant pairs from urban (Mbale municipality) and rural areas (Bungokho) in Mbale district [43]. Information about the areas including sizes of villages was retrieved from the Uganda Bureau of Statistics in Entebbe (<u>http://www.ubos.org</u>). A cluster-design with probability of inclusion proportional-to-size was used to recruit mother-infant pairs [43, 137]. Villages in each parish were randomly selected according to parish size and seven households were randomly selected in each village. With this design, 793 mothers with infants below 1 year of age were recruited. Due to non-responses (n=30) and incomplete data (n=36), 727 mother-infant pairs were left for in the analysis. Information about the mothers' HIV status was not collected. These participants are referred to as '*general-population mothers*.'

The second survey was conducted in 2005 and included 240 mother-child pairs. This survey was the basis for paper 1, 2 and partly also 3. This study was coordinated by the author of the thesis and performed in collaboration with The Aids Support Organisation (TASO) [138]. TASO is a non-governmental organisation working for HIV-positive people in Uganda and provides counselling, information, support and medical treatment for HIV-positive people. The mothers were approached through TASO-Mbale, including their outreach clinics in Mbale district and adjacent areas. Consecutive sampling was used to recruit these participants. All approached mothers agreed to participate in the study. The children were below 2 years of age. Five mother-infant pairs were excluded from analysis due to extensive missing information, or to the child being 2 years of age or more. All women recruited through TASO were known to have HIV-positive status, and are in this thesis described as HIV-positive mothers.

For the second paper, data from both these surveys were merged, and a pooled analysis was done. Both the surveys had unified definitions, and could be analysed as a metaanalysis with individual data which is one of the better strategies for data pooling [139]. This gave a total of 962 mothers-infants pairs for analysis. There were no case overlaps between the two cross-sectional studies. Comparisons of infants in paper 2 were made with corresponding age-groups in the two surveys.

### Subjects in the intervention trial

The fourth paper evaluated growth outcomes from a 2 year follow-up of a communitybased cluster-randomised controlled trial promoting exclusive breastfeeding for six months (ClinicalTrials.gov no. NCT00397150) [123]. The study was a multicentre trial taking place in Burkina Faso, South Africa, Uganda and Zambia, while the 2 year follow-up was additional and unique for Uganda. A total of 24 clusters in Mbale District were chosen, from which 886 mother-infant pairs were approached, and 863 recruited. The inclusion criteria were that women lived in the selected cluster areas, were 7 months or visibly pregnant, intended to breastfeed, and planned stay in the cluster area throughout the forthcoming year. Among these, 98 were excluded due to death of the infant or the mother before 3 weeks after delivery, mother having moved away or being lost-to-follow-up, twin delivery, or conditions as severe malformations. Thus, 765 remained in the analysis.

The mother-infant pairs were scheduled to be interviewed at 3, 6, 12 and 24 weeks after birth, in addition to a follow-up interview at around 2 years of age. The following time ranges were regarded as timely interview visits: 3: 1.5–4.5; 6: 4.5–9; 12: 9–18; 24: 18–28 weeks and 2 years: 1–3 years. Anthropometric measurements collected outside these ranges are not presented in the tables and figures. The median follow-up time was 18 months, and the mean age at the 2 years follow-up visit was 22 months. The data were collected between 2006 and 2008.

The control clusters received standard health care from the public health services, and no additional care compared to the intervention arm. Mothers in the intervention clusters received breastfeeding support by peer-counsellors. These counsellors were trained in a one-week course by a research team using a curriculum based on the WHO courses: '*Breastfeeding Counselling: a Training Course*' and '*HIV & Infant Feeding Counselling: a Training Course*' and '*HIV & Infant Feeding Counselling: a Training Course*' [140, 141]. Each mother was offered at least five visits with the first before giving birth, and then scheduled at week 1, 4, 7 and 10 after delivery.

The peer counsellors provided information and supported EBF for six months. The information focused on good attachment and positioning, frequent breastfeeding, benefits of emptying one breast before changing to another breast, how to deal with a crying baby, expressing and storing breast milk, and to assess baby stools and urination. The mothers who had any breastfeeding problems that could not be dealt with by the peer-counsellor were referred to a health worker with training in lactation management.

To assess infant growth, the WHO growth standards were used as a reference [37]. Anthropometric measurements were carried out in line with the guidelines from WHO with the use of '*Baby/infant/adult Length-height measuring system SET 2*' and '*Infant scale spring type, 25kg, 100g*' from the UNICEF supplies [142]. Length was measured to the nearest 0.1 cm and infant weight was recorded to the nearest 0.1 kg. Validity and reproducibility exercises were conducted at least twice annually during the data collection period.

### Quantitative interviews

The recall periods that were used for dietary assessment in the survey among the HIVpositive mothers and the intervention trial were 24-hour recall, 7-day recall and since birth recall. For the survey in the general population, 24-hour recall and since birth recall were used.

#### Questionnaires

All the quantitative studies used structured questionnaires focusing on socio-economic factors, mother's and father's education, infant feeding knowledge, infant feeding practices, child growth and child health. The questionnaires also included a dietary list of liquids, semi-solids and solid foods. The structured interviews used in the two cross-sectional surveys were based on analogous questionnaires with generally similar or identical questions. The study questionnaires were pre-tested to ensure that the questions were understood well. The interviews were conducted by data collectors who were fluent in the local language Lumasaaba.

The questionnaire for the HIV-positive mothers also contained some additional questions regarding the time when mothers were diagnosed with HIV and whether they had participated in the PMTCT-program. The questionnaires that were used are available with links to the questionnaires given in the appendix of the thesis.

#### Sample size calculation

The sample size calculation for the survey among the general population from 2003 used a calculation for cluster surveys and has been described elsewhere [143]. A total of 645 participants were needed for this survey.

The sample size was not calculated prior to the survey among the HIV-positive mothers as it was a concern that it could be difficult to recruit a sufficient number of participants. However, it was considered that the information would still be important even with a low number of informants. A post-hoc power calculation was done with the use of OpenEpi to find differences in replacement feeding [144]. This calculation used a two-sided confidence interval of 95% with 235 in the 'exposed' group and 727 in the 'unexposed' group. The prevalence in each group was set to the point estimates of replacement feeding from the results, which were 8% among the HIV-positive mothers and 0.1% in the general population. This gave a power of nearly 100%.

For the intervention trial, the sample size calculation was targeted to detect an increase in exclusive breastfeeding from 20% to 40% in each country and used cluster randomisation as described by Donner [145]. To detect such a difference with 80% power ( $\beta$ =0.20,  $\alpha$ =0.05) and 95% confidence, 12 clusters were needed per arm if the clusters had a size which provided 35 deliveries per year.

### Data cleaning

Data cleaning was done in line with the description of Van den Broeck *et al* [146]. This included that data were checked for errors such as impossible values, which were recoded as missing if the correct value could not be found. Data that was lost in some categories was attempted retrieved from interviews done earlier or later, or in other corresponding variables, and matching of categorised and non-categorised variables was checked carefully. Graphical plots including scatter plots and histograms were printed for many combinations of variables to assess the distribution of the data. This was done after the plan for analysis was completed to avoid a multiple comparison

bias. Figure 6 below illustrates the cleaning process, and figure 7 illustrates how values are assessed.



Figure 6: The data cleaning process from Van den Broeck et al [146].

For the data from the intervention trial, data cleaning of the anthropometric measurements was done in two stages. First, the absolute differences between measurements in length and weight were checked for outliers. The second step was based on the attained z-scores from the WHO Child Growth Standards (with weightfor-age z-scores [WAZ], length-for-age z-scores [LAZ] and weight-for-length z-scores [WLZ]). Measurements were regarded as implausible and unlikely to be correct if one of the following criteria were true:

1) WAZ < -6 or > 5 2) LAZ < -6 or > 6 3) WLZ < -5 or > 5 or 4) LAZ < -3 and WLZ > 3

Extreme changes were also regarded as implausible. This included when there were gross differences in LAZ- and WHZ-scores between two subsequent interview measurements. Changes of more than 2.5 or 3 z-scores between subsequent interviews during the first 4 visits were regarded as unlikely. Unless no justification for the criteria above were found (e.g. a note indicating marasmus), the corresponding measurements were set to missing.


**Figure 7:** Assessment of data in the cleaning process from Van den Broeck *et al* [146].

#### Data management

The data from the two surveys were entered in EpiData 3.1, and SPSS 14 was used for data analysis. Stata (version SE11.1, Stata Corporation, <u>www.stata.com</u>) was used to re-analyse several of the analyses from the two first papers and for the quantitative analyses in paper 3.

The intervention trial used an electronic data collection strategy. Data was collected through interviews, and entered directly into handheld computers with the program EpiHandy using an electronic questionnaire [147]. EpiHandy has been further developed into the program openXdata [148]. Stata SE11.1 was used for data analysis for paper 4.

### Reliability

To check the reliability, 15 mothers from the survey among HIV-positive mothers were re-interviewed by another pair of data collectors some weeks after the initial interview. The answers in the initial and reliability interviews were compared and showed only minor discrepancies and a high degree of consistency. Breastfeeding duration and whether the mother was still breastfeeding were reported similarly in both interviews by all respondents (Kappa 1.0). Whether cow's milk or milk formula were given during the earliest postnatal days was similarly reported among 13 (87%) of the mothers: Kappa 0.71, p<0.01. Digit preference was seen in the reported age of the mothers, peaking especially at 20, 25 and 30 years. The age of the youngest child was quite consistently reported.

The reliability of survey among the general population has been assessed with a detailed description given elsewhere [149]. In summary, the reliability was quite good also for this study.

The reliability of intervention trial was checked with assessment across different interviews among the same cases. In general, the reliability was good.

#### Statistical analysis

The analyses of the quantitative material have been done by the author of the thesis in collaboration with co-authors. Plans for most of the analyses were made within the research group prior to the analyses.

Baseline characteristics were examined utilising frequency tables and cross-tabulations with Pearson  $\chi^2$ . Breastfeeding duration was analysed by Kaplan–Meier time-to-event statistics to get a good estimate of breastfeeding duration as the participants had children in a range of ages. The time that the mothers reported to have stopped breastfeeding was used as event time.

All the mothers in the pooled data from the two surveys were grouped into socioeconomic quintiles based on wealth assessment using a principal component factor analysis [38, 150-152]. Housing characteristics and assets including toilet facilities, number of rooms and beds, roof material, lantern, radio, television, bicycle and motor vehicles were included in the model. Quintiles were inferred from the first principal component. This method is recognised as a good proxy for household wealth [153]. The fourth paper used a multiple correspondence analysis which is analogous to using principal component analysis, and is better opted for categorical data [154]. The correlation between these indexes was very high. The Mann–Whitney–Wilcoxon test for independent samples was used to compare socio-economic ranks.

In order to do Cox regression analysis, several assumptions need to be satisfied [155]. The assumption of proportional hazards was checked with Schoenfeld residuals, both graphically and with a significance test. Tied cases were handled with the exact partial-likelihood method. Log linearity was checked by plotting of Martingale residuals for the complete model vs. a model with one omitted variable. Correlation between the variables was checked. With the exception of mothers' and fathers' education in the first papers, no variables were too strongly correlated to be included in models together (>0.7). Both a crude/unadjusted model and an adjusted model using stepwise selection with removal set at 0.1 are presented. A log-rank test was performed on significant associations (p<0.05).

For the Cox regression analyses, interactions were evaluated on a multiplicative model. Meaningful interactions were evaluated, and no interactions in paper 4 were significant with magnitude comparable to the individual factors in the model. For the first paper that used a Cox regression model to assess factors associated with breastfeeding cessation, a later re-analysis indicated an interaction between mother's education and socio-economic rank.

To reduce multiple comparison bias with multiple tests, which each has a small chance of being significantly associated with an outcome by chance, a plan for the analyses was made before carrying out most of the analyses [156]. A concept with a 'gate

*mechanism*' was used for some analyses. This implies that if there were not found relevant associations with analyses planned *a priori*, further analysis was not done.

For paper 4, categorical outcomes were analysed with a binomial generalised linear model while continuous outcomes were analysed with linear regression. All analyses were adjusted for cluster and site (urban or rural) [157].

There was some missing data due to missed interview visits, the data cleaning process, and as some mothers did not consent for their children to be measured. At 3, 6, 12, 24 weeks and at 2 years, the proportion of missing valid anthropometric measurements were 25%, 16%, 11%, 12% and 21% respectively. Baseline characteristics were compared between participants having valid and missing information to assess whether missing information might have caused a selection bias. At the 2 years interview, there were more missing anthropometric measurements in urban than in rural areas.

A complete-subject analysis is only recommended when measurements are missing randomly. As the measurements were not distributed completely at random, an inverse-probability weighted method was carried out [158]. A probit regression was used to calculate population weights based on the following factors: intervention or control arm allocation, likelihood of non-participation in the study based on missing measurements at other time points, site, socio-economic status, mother's education and age, parity, gender of the infant, marital status, whether the child was weighted at birth, place of delivery, intended feeding strategy before delivery, and feeding practices at 12 and 24 weeks. The models gave more weight to cases with valid data that had the highest probability of having missing data based on the listed factors. The means for the population weights in the different interviews were between 1.1 and 1.2. The factor that influenced the weights most was whether the informant had a valid preceding interview.

A longitudinal analysis was done for time-dependent change in WLZ, LAZ and WAZ to compare each arm using a mixed model adjusting for both cluster and site. Linear prediction lines for each arm were also made. Change in the prevalence of stunting was checked with a multilevel mixed-effects logistic regression.

# **Qualitative studies**

To assess infant feeding counselling in health facilities, which was the third objective, the thesis also used qualitative methods including key informant interviews, observation and focus group discussions.

# Key informant interviews

Key informant interviews were conducted with 18 health workers. The interviews aimed at an open and non-judgemental approach, and used open questions to assess experiences and perceived challenges for the health workers [159]. The selection criterion was that the health workers participated in health education in the health facilities in Mbale. The participants including nurses, midwives, clinical officers and doctors were recruited from health facilities within Mbale Municipality and the

surroundings which could be reached within a one hour minibus drive. Most health facilities within this distance were reached.

The interviews were done with interview guides which are available through links in the appendix. The duration of the interviews was around one hour. The interviews were conducted in English, tape-recorded and transcribed by the two first authors of the third article.

In all the public health facilities that were included, health education sessions were conducted. The counselling was organised with large groups typically involving 20–50 mothers in each session. Health workers that were involved in the PMTCT program had been given a 2-weeks course on PMTCT counselling and a 1-week course on infant feeding counselling [135].

#### Focus groups discussions

To go into issues such as perceived challenges related to breastfeeding among mothers from both the general population and people living with HIV, 15 focus group discussions were conducted. All the discussions focused on infant feeding practises, perceived challenges and cultural and contextual issues related to infant feeding. Seven of the focus groups were conducted among HIV-positive people and 8 groups in the general population.

The HIV-positive people were recruited consecutively from the TASO clinic in Mbale. A total of 5 focus group discussions were conducted with mothers below 35 years of age having children below 5 years of age, one group was conducted with HIV-positive men, and one group was carried out with HIV-positive women above 35 years of age. The focus groups with the general population were community-based and situated in their villages. A total of 4 groups with women and 4 groups with men were conducted. The number of focus groups for the groups in the general population was decided mainly based on a geographical criterion – with one female and one male group from each sub-district. The number of groups among the HIV-positive people was partly based on the literature of what was commonly used in similar studies, and partly on the information from the focus group discussions.

The focus groups discussions lasted for one to two hours. The discussions were moderated by trained research assistants with university diplomas in social sciences under the supervision of the principal investigators (two first authors of the third paper). All discussions were conducted in the local language Lumasaaba or the more regional language Luganda, tape recorded, translated and transcribed. After the discussions were finished, they were discussed within the team consisting of the moderator, the note taker and the principal investigator. The transcripts of the interviews were also read immediately after transcription and uncertainties were clarified.

#### Qualitative analysis

To increase the validity, the qualitative data were analysed by two of the researchers independently using inductive thematic content analysis in line with Graneheim *et al* and Pope *et al* [160-162]. The analytical process consisted of systematic reading of the transcripts, condensation of the text fragments, coding and re-categorisation, and identification of themes.

#### Summary of topics, methods and type of analyses in the four papers

Table 1: Overview over topics, methods and type of analyses used in the four papers.

Article	Торіс	Method	Type of analyses
1	Infant feeding patterns among HIV-positive mothers	Cross-sectional survey using a structured interview	<ul> <li>Kaplan–Meier time- to-event analysis</li> <li>Cox regression</li> <li>Principal component analysis to assess socio- economic indicators</li> </ul>
2	Comparison of infant feeding among HIV-positive mothers and in the general population	Comparison of cross-sectional surveys using structured interviews	<ul> <li>Frequency tables and χ<sup>2</sup> statistics</li> <li>Kaplan–Meier time- to-event analysis</li> <li>Principal component analysis to assess socio- economic indicators</li> </ul>
3	Assessment of counselling on infant feeding in both public health facilities and non-governmental organisations working with people living with HIV	Mixed method (qualitative and quantitative) using a concurrent nested design	<ul> <li>Inductive thematic content analysis of key informant interviews and focus group discussions (triangulation)</li> <li>Systematic reading, coding a re- categorisation</li> <li>Frequencies and distribution</li> </ul>
4	Anthropometric outcomes at 2 years from a trial promoting exclusive breastfeeding for six months	Community-based cluster-randomised controlled trial	<ul> <li>Comparison of means</li> <li>Mixed model regression</li> <li>Longitudinal analysis</li> </ul>

### Ethics

Ethical approvals for all the studies were granted from Makerere University, Faculty of Medicine Ethics and Research Committee, the Uganda National Council for Science and Technology. For the all the studies conducted in 2003 and between 2006 and 2008, ethical approvals were also granted from the Regional Committee for Medical Research Ethics, Western Norway. Due to changed guidelines this was not relevant for the survey and qualitative interviews conducted in 2005. Signed or thumb-printed informed consent was obtained from each mother prior to study participation. The consent procedure was approved by the ethical committees.

Disclosure of HIV is one ethical aspect which is particularly relevant when working with HIV-positive people. If HIV-positive people are recruited openly, people may be forced to disclose their HIV-status to their communities. By recruiting from inside an HIV-clinic, the risk of unwanted disclosure was minimised. To check the reliability of the quantitative survey among the HIV-positive mothers, we needed to approach some of them in their homes. In this situation, we used discretion to avoid the interview being associated with HIV.

Keeping the informants anonymous in qualitative research can be challenging [161]. This is especially relevant when there is a limited number of possible informants, and when quotes give sufficiently detailed descriptions to be able to identify an individual. In the studies involving key informant interviews from health workers, there were a limited number of possible informants. We have tried to keep the anonymity as good as possible by not labelling the exact affiliation of the informants when reporting our data, but rather group them into public health workers and health workers in non-governmental organisations.

The studies have taken some time from numerous participants. The participants themselves are not likely to have benefitted much on this, but the knowledge from this research could benefit the societies around them.

### **Competing interests**

The author of the thesis and the co-authors of the articles on which the thesis is based have no competing interests.

# Results

# Article 1 and 2:

The two first articles described the infant feeding situation in Eastern Uganda and showed how infant feeding patterns varied between the general population and among the children of mothers living with HIV. There was also variation in the feeding patterns between groups with different background related to education and socioeconomic factors.

The median maternal age was 30 years (inter-quartile range [IQR] 28–35) for the HIVpositive mothers and 24 years (IQR 20 - 30) for mothers in the general population. The mothers in the general population were more educated with a median of 7 years of education (IQR 4–9) than the HIV-positive mothers with a median of 5 years of schooling (IQR 3–7). There were no differences in the fathers' education between the two groups (table 1 from paper 2). More among the general population had farming as the main activity than among the HIV-positive mothers. Half the HIV-positive mothers were widowed, while nearly all mothers in the general population were either married or cohabiting.

The socio-economic rank of the HIV-positive mothers was slightly lower than among the generally population. Children from the least poor quintile were given more food items (5.8 [95% confidence interval 5.0–6.6]) than children from poorest quintile (3.9 [95%CI 3.3–4.5]), see table 3 from paper 2.

There were differences in breastfeeding duration among HIV-positive mothers and in the general population, figure 4 from paper 2. Among the HIV-positive mothers, there were strong associations between various factors and duration of breastfeeding, table 3 from paper 1. The most educated among the HIV-positive mothers breastfed for a median of 3 months (95%CI 0–10), while the least educated breastfed for 18 months (95% CI 15–21), log-rank test p < 0.001. Among the poorest HIV-positive mothers, the median duration of breastfeeding was 17 months (95% CI 15.2–18.8) compared to 8 months (95% CI 5.9–10.1) among the least poor, log-rank test p<0.01.

Those who reported to have talked with anyone about breastfeeding, breastfed shorter than those who had not, with median duration of 12 months (95% CI 11.5–12.5) compared to 18 months (95% CI 15.7–20.3), log-rank test p<0.001. Similarly, participation in the PMTCT-program was also associated with a shorter duration of breastfeeding, with a median of 9 months (95%CI 7.2–11) compared to 14 months (95%CI 11–17) among those not having participated, log-rank test p<0.001.

A re-analysis of the Cox regression was done to complement the published results. This analysis included interactions between the factors associated with breastfeeding duration indicated an interaction between mother's education and socio-economic rank, table 2 (below). High education and high socio-economic status were more strongly associated with shorter breastfeeding together than these factors were associated individually.

The most important reasons for stopping breastfeeding were advice from health workers, general illness and the HIV-diagnosis, table 4 from paper 1.

Prelacteal feeding was given to the 150 (64%) of the infants of HIV-positive mothers as well as 414 (57%) of the infants of mothers in the general population, figure 3 from paper 2. Non-water based pre-lacteals were given significantly more often to children of HIV-positive mothers than mothers in the general-population. Mixed feeding was the most common feeding pattern among the infants below 6 months of age in both groups, figure 5 from paper 2.

Exclusive replacement feeding was significantly different between HIV-positive mothers who knew their HIV diagnosis prior to birth and general-population mothers (p<0.001). Except for mothers not initiating breastfeeding, the time when breastfeeding was initiated was similar across the groups, figure 3 from paper 2.

During the first half of infancy, exclusive breastfeeding was practised more frequently among mothers in the general population than among HIV-positive mothers (p<0.05). The opposite was seen with replacement feeding (p<0.001). The feeding practices were also different among infants during the second half of infancy, p<0.001.

**Table 2**: Hazard ratios (HR) for breastfeeding cessation with 95% confidence intervals (CI) presented with an adjusted Cox regression model. Only significantly associated factors are included in the table.

	n (%)	HR for breastfeeding cessation with 95%CI
	235	Adjusted model
Mother's education and socio-economy (interaction)		
Among poorest 60% <b>and</b> less than 7 years of education	102 (43)	1
Among the least poor 40% or 7 years of education or more	88 (37)	1.04 (0.65–1.67)
Among the least poor 40% <b>and</b> 7 years of education or more	45 (19)	1.92 (1.09–3.39)
Anyone talked about breastfeeding?		
No	44 (19)	1
Yes	191 (81)	2.52 (1.43–4.45)
Belief about 6 months of exclusive breastfeeding		
Sure it would be good	29 (12)	1
Think it would be good	42 (18)	0.33 (0.15–0.75)
Think it would hurt	104 (44)	0.39 (0.20–0.75)
Sure it would hurt	59 (25)	0.18 (0.08–0.39)

The following variables were included in the initial model, but were not kept in the adjusted model through the stepwise selection procedure: Father's education, mother's age, marital status, mother's work, living area, HIV-diagnosis, participation in the PMTCT program, mother's self-rated health and mother's-rated health of the child.

## Article 3:

The following main themes emerged from the analysis: 1) The context influencing infant feeding teaching; 2) Feeding of severely ill children; 3) Challenges related to breastfeeding; 4) The counselling process; 5) Simplifying messages; 6) HIV-infected mothers' disclosure and choice; 7) Feasibility and capacity challenges.

Several topics were touched upon during the counselling sessions that usually lasted for 30–60 minutes, including infants feeding, care during pregnancy, nutrition of pregnant women, postnatal care, sexually transmitted diseases including HIV, family planning, prevention of malaria, use of medicines, hygiene, first aid of conditions like diarrhoea with oral rehydration, and immunization of babies.

The study found extensive variation in the counselling and the messages that were given. There were also several challenges for the health workers including lack of resources, minimal staffing, frequent changes in programs and guidelines, and inadequate training and follow-up. These challenges came in addition to the challenge of meeting the complex situations of the health clients who often struggled with deep poverty, stigma and acceptability issues. Many health workers tried to meet this with pragmatic solutions. The findings from the themes listed above are summarized in table 3 below.

	Key informant health w	interviews with ⁄orkers in	Focus group dis	scussion among	Cross-sectic	nal surveys
	public health	HIV-clinics and	HIV-positive	General	General	HIV-positive
	hospitals	with HIV	HIV-clinic	population (community- based)	community- based)	HIV-clinic
Context influencing infant feeding teaching	<ul> <li>improvised</li> <li>teaching</li> <li>training varied</li> <li>pragmatic</li> <li>approaches</li> </ul>	<ul> <li>often have</li> <li>extended</li> <li>counselling training</li> <li>pragmatic</li> <li>approaches</li> </ul>	- poverty was a challenge	- poverty was a challenge	- minority had discussed infant feeding with health worker	- majority had discussed infant feeding with health worker
Feeding of severely ill children	<ul> <li>some extra teaching capacities to targeted individuals</li> <li>poverty and knowledge reported as challenging</li> </ul>	- poverty was a challenge	- poverty was a challenge	<ul> <li>poverty, social structure within the families and psychological difficulties were challenging</li> </ul>	<ul> <li>poverty was a challenge</li> <li>clear association with infant feeding practices and socio-economic status</li> </ul>	<ul> <li>poverty was a challenge</li> <li>clear association with infant feeding practices and socio-economic status</li> </ul>
Challenges related to breastfeeding	<ul> <li>health workers had to work against traditional beliefs</li> <li>pragmatic options suggested for mothers not breastfeeding</li> <li>For HIV-positives, breast-feeding seen as 2. option</li> </ul>	<ul> <li>health workers had to work against traditional beliefs</li> <li>busy mothers often avoided breastfeeding</li> <li>For HIV-positives, breast-feeding seen as 2. option</li> </ul>	<ul> <li>HIV transmission during pregnancy often underlined</li> <li>busy mothers often avoided breastfeeding</li> <li>Mothers not breastfeeding were often suspected to be HIV-positive or accused of being irresponsible</li> </ul>	<ul> <li>a pregnancy was a common reason to stop breastfeeding</li> <li>busy mothers often avoided breastfeeding - Mothers not breastfeeding were often suspected to be HIV-positive or accused of being irresponsible</li> </ul>	<ul> <li>exclusive</li> <li>breastfeeding often</li> <li>regarded as</li> <li>insufficient and</li> <li>practiced at a low</li> <li>rate</li> <li>mixed feeding</li> <li>common</li> </ul>	<ul> <li>exclusive</li> <li>breastfeeding often</li> <li>regarded as</li> <li>insufficient and</li> <li>practiced at a low</li> <li>rate</li> <li>mixed feeding</li> <li>common</li> </ul>

Table 3: The following tables give an overview over the main findings from the different studies sorted under themes.

The counselling process	<ul> <li>variation in messages</li> <li>some used interactive counselling strategy</li> </ul>	<ul> <li>Many health workers put much effort into communication and a good, caring and empathic attitude</li> <li>variation in messages</li> </ul>	<ul> <li>positive feedback</li> <li>on health workers'</li> <li>counselling</li> </ul>	<ul> <li>positive feedback</li> <li>on health workers'</li> <li>counselling</li> </ul>	
Simplification of messages	<ul> <li>simplistic</li> <li>messages</li> <li>exaggerated</li> <li>some perspectives</li> </ul>	<ul> <li>simplistic</li> <li>messages</li> <li>exaggerated</li> <li>some perspectives</li> </ul>			
HIV-infected mothers' disclosure and choice	- HIV disclosure was a challenge	<ul> <li>HIV disclosure was a challenge</li> <li>less stigma</li> <li>mixed feeding</li> <li>seen as</li> <li>consequence of</li> <li>non-disclosure</li> </ul>	<ul> <li>HIV disclosure was a challenge</li> <li>many pay high price for HIV disclosure</li> <li>many felt</li> <li>supported when disclosing HIV-</li> <li>status</li> </ul>		<ul> <li>no differences in infant feeding practices seen between mothers having disclosed or not</li> <li>many pay high price for HIV disclosure</li> </ul>
Feasibility and capacity challenges	<ul> <li>inadequate facilities, staffing &amp; equipment</li> <li>need for training and follow-up, e.g. refreshing courses</li> <li>meeting their clients' complicated situations</li> </ul>	<ul> <li>programs</li> <li>stopping abruptly</li> <li>meeting their</li> <li>clients' complicated</li> <li>situations</li> </ul>	- difficult choices - poverty - stigma	- poverty - difficult choices	- poverty - stigma

# Article 4:

This article compared the growth outcomes LAZ, WLZ and WAZ at the 2 years follow-up from the intervention trial that promoted breastfeeding for 6 months.

The median age of the mothers was 25 years (IQR 20–30), with a median of 6 years of schooling (IQR4–6). Most lived in rural areas (566 [74%]) and were married or cohabiting (701 [92%]). It was an even gender distribution among the infants with 387 (51%) males and 375 (49%) females. A total 232 (31%) had one or two siblings while 347 (46%) had three or more.

WLZ tended to be lower in the intervention arm compared to the control, table 1 in paper 4. The LAZ and WAZ values were higher in the control arm than in the intervention arm in all interviews, and WAZ was significantly different at 24 weeks, table 2 and table S1 in paper 4. The distribution of the LAZ indicated a clear left-shift away from the WHO growth standards.

Stunting was more common in the intervention arm than in the control arm, table 3 in paper 4. At the 2 year visit, 139 (45%) were stunted in the intervention compared to 109 (37%) in the control arm, with an odds ratio of 1.7 (95%CI 1.1–2.4). Wasting was also more common in the intervention arm at the 12 and 24 week visits, but no clear differences were seen in the other interviews. There was also a clear tendency to more underweight in the intervention arm.

Adjusting prevalence ratios of wasting, stunting and underweight for socio-economic status, in addition to cluster and the site, did not change the association, and hardly changed the confidence intervals. A longitudinal assessment confirmed that WLZ, LAZ and WAZ were associated with arm allocation. When the weight or length measurements at the 3 week visit were included in the model for WLZ, LAZ and WAZ, the  $\beta$  coefficient of the arm was reduced and insignificant.

The multilevel mixed-effect logistic regression model confirmed that arm allocation was associated with stunting. The association was still significant when adjusting for height at 3 weeks. To check whether the negative influence from the intervention on stunting at the 2 year follow-up was mediated through the feeding pattern, feeding patterns (exclusive breastfeeding or not) at 12 and 24 weeks of age were included in the model. Inclusion of these did not change the association.

# Discussion

The thesis has described several challenges related to both the infant feeding practices and the health counselling situation in Eastern Uganda. It has also assessed the effect on growth of an intervention with the aim to increase exclusive breastfeeding, with far from optimal growth outcomes at the follow-up around 2 years of age. This discussion will look closely into several methodological aspects of this thesis while discussing the findings on the basis of research literature.

# Design

A strength of the thesis was the combined use of qualitative and quantitative data to shed light on different aspects related to infant feeding in Eastern Uganda. Concerning design, the first two articles and partly also the third are based on cross-sectional data. A cross-sectional design has some disadvantages compared to a prospective design, including challenges related to recall, and often a short record period that is evaluated, which can cause a lack of representativeness of the data. In principle, cross-sectional studies provide a 'snapshot' of the reality, which makes it challenging to draw causal conclusions. As there were limited resources available, a cross-sectional design was still regarded as sufficient to answer the main questions in the two first objectives. The fourth paper is based on a prospective follow-up from a randomised trial. This design is stronger but also has some limitations. These issues will be discussed thoroughly in this section.

# Truth value - internal validity and credibility

A fundamental research question is whether studies measure what they intend to measure. In this respect, information bias, selection bias and confounding are some of the main threats to research [163-165]. Bias has been defined by Last as "any trend in the collection, analysis, interpretation, publication, or review of data that can lead to conclusions that are systematically different from the truth" [166].

### Information assessment

Information assessment is essential for the validity of the thesis as all the studies in the thesis rely on self-reported information. Two key aspects when having self-reported information, is recall and social desirability [167-169]. The longer the recall period, the more difficulties respondents will have to remember events and daily behaviour [170, 171]. Difficulties in remembering do not necessarily cause bias unless it is differently distributed among groups, but is nevertheless likely to reduce the precision. Recall periods of many years have also been reported to increase the tendency to report desired behaviour [172]. On the other hand, a short recall period has the disadvantage of often being less representative than a longer period. Asking frequent questions can itself be enough to influence behaviour [164]. To have a favourable frequency of the follow-up is important, as too frequent and extensive questions are risks for response fatigue among the research participants, which can hamper the quality [173].

The quantitative studies of the thesis have used a combination of 24-hour, 7-day and ever recall. In nutritional studies, one-day recall has been reported not to be sufficiently representative of the feeding patterns [168]. Ever recall, recalling from the time of birth up to the time of the interview, can be particularly challenging [170]. Bland *et al* have suggested the use of 1 week repeated dietary recalls to have a high sensitivity and specificity for e.g. exclusive breastfeeding to a given age [167]. The cross-sectional studies used single interviews, which are not optimal with respect to this issue. Still, the validation interviews that were carried out in the studies presented in the thesis to check the consistency indicated that the information was quite reliable [149]. For the intervention trial that had repeated visits, the recall strategy that was used was closer to the strategy recommended by Bland *et al* [167].

Recall is often different for various aspects of life [169, 171, 174, 175], and some aspects simply seem to stick better to memory than other aspects. Which specific food items that children have received one or several weeks ago might be challenging to remember for many. However, there might be several routines which will make it easier to remember what is part of the routines, and also when behaviour differs from these. When reporting on ages and numbers, there was some degree of reporting of digit preference values, i.e. that a slightly higher proportion reported their breastfeeding duration to a rounded number as e.g. one year of age than the distribution curve would have suggested.

The method that was used to analyse breastfeeding duration (Kaplan-Meier time-toevent) is usually utilized for follow-up studies, and less commonly for cross-sectional studies. The breastfeeding duration for each child was based on retrospective recall. As children had different ages at the interview, which corresponds to follow-up time in cohort studies, it would have given wrong estimates if time-to-event analysis was not used. In many cross-sectional studies with different follow-up time, a mean breastfeeding duration is reported only among cases who have stopped breastfeeding. This reduces the likelihood of including mothers who are breastfeeding for a longer duration and increase the likelihood of including those who are breastfeeding shorter. If this strategy had been chosen, the duration estimates would have been biased to a shorter duration. This can be illustrated with an example with a group of 30 mothers, where 10 mothers breastfeed their infant for 6 months, 10 mothers breastfeed for 12 months, and ten mothers breastfeed their children for 18 months. If all these mothers were interviewed when their children were 15 months of age (e.g. nested to a vaccination program), an analysis excluding mothers not having stopped breastfeeding would estimate a median and mean breastfeeding duration of 9 months (95%CI 7.6-10). The true median and mean duration is 12 months. Kaplan-Meier analysis will give an estimate of 11 months for mean breastfeeding duration (95%CI 9.7–12.) and 12 months for median breastfeeding duration, which is the true value.

Social desirability was another challenge that has been emphasised for both research on nutrition and related to sensitive topics such as HIV [176-179]. In nutritional studies among adults, it has been reported that food items that were regarded as unhealthy were underreported to a larger extent than other food items [180]. When

adults report on behalf of children, less underreporting has been reported [181]. Still, it could be possible that behaviour that was regarded as unhealthy was also reported to a lesser extent than beneficial behaviour in these studies. In the intervention trial, mothers were visited around 5 times by peer counsellors who emphasised the importance of exclusive breastfeeding which could have influenced what the mothers regarded as socially desirable. When the mothers were visited by data collectors, the answers of the mothers could have been made more socially desirable. The use of data collectors who were independent from the peer counsellors is likely to have reduced this threat. The data collectors were in principle also blinded with respect to arm allocation, but it is not unlikely that the peer counselling could have been mentioned spontaneously in some cases by the mothers or other people in the cluster. That sub-optimal blinding should have influenced anthropometric measurements is less likely.

It is not unlikely that all the questions about infant feeding in both the control and the intervention arm could have influenced the behaviour, but it is less likely that this was markedly different between the control and intervention clusters. The emphasis of anonymity was another measure that was taken to reduce the tendency towards social desirable reporting. Other strategies could also have been implemented to reduce socially desirable reporting, including audio computer-assisted self-interviewing, or the randomised response interview technique [182-184]. These strategies were not used mainly for logistical reasons.

The importance of the interview situation and the use of proper interview tools have been underlined in several studies [185-187]. The interview visits in the studies of the thesis attempted to ensure that the interview situation was both comfortable and private, and the individual interviews were done in the homes of the families, in offices of the health workers, and some outside the HIV-clinic in a quiet area.

The wording of questionnaires and answer options are also important to ensure that the questions are both well-understood, not seen as threatening or prejudiced, and that the answer alternatives provide a sufficient range to reflect the experiences of the interviewees [188]. The questionnaires were translated to the local language Lumasaaba and pre-tested to ensure proper understanding of the questions. Still, there were some few questions which were not optimal including a question on how many times the mothers had breastfed their children during the last 24 hours. In general, it seemed difficult for many to quantify behaviour in open ended questions. Consequently, caution was taken when analysing such variables.

One way to validate self-reported behaviour is to compare with e.g. biological parameters [180, 189]. In the studies that have been presented, it could have been possible to use doubly-labelled water in a subset to validate breastfeeding patterns. This would have been expensive and would also have been associated with logistical challenges.

For the qualitative studies, the use of triangulation was a strengthening factor that increased both the consistency and credibility of the studies [190]. Several of the

themes that came up were seen from different informants and different views. This allowed a deeper discussion while comparing similarities and differences in views. Most of the messages were similar between health workers and health clients, but there were also some aspects where different groups gave diverging reports. One such example was related to hygiene. Several health clients perceived it important to clean the breasts before breastfeeding, and reported that this was encouraged by health workers. The health worker on the other hand reported that they discouraged this practice.

One limitation of the qualitative studies was the use of a concurrent nested design, where data collection of the focus group discussions and key informant interviews were done more in parallel than sequential. This gave less room to follow-up on findings from analysis than a clear sequential design. On the other hand, a concurrent data collection increased the amount of data that could be gathered within a specific time, which was an advantage and increased the consistency. The collection was carried out over two periods, which also gave the qualitative studies some extent of a sequential approach, which increased the contextual understanding. On the other hand, more information from health workers working with HIV was collected in 2005, while more information from the public health services was collected in 2003. This was taken into consideration when analysing and there were also no major changes in guidelines during this period.

One shortcoming of the focus groups in this thesis is that they were analysed mainly by two researchers who did not speak the local language and based the analysis on translated transcripts. When translating transcripts, it is a risk that some of the details are lost in the process. In addition, much of the communication is not given with words, but through body language, pauses in the flow of speaking and the social atmosphere. A good interpretation is thus dependent on taking all important communicative input into account. The note takers and moderators were encouraged to note such details, which were considered when interpreting. The debriefing after the focus group discussions were conducted, as well as clarification discussions between the transcriber and the principal investigator, which may have reduced the loss of important information. Nevertheless, it is unlikely that all important non-verbal messages have been captured. With these limitations in mind, it is reassuring to see that the findings are in line with other studies done in similar settings. Another shortcoming was that the two researchers analysing the focus group discussions could not be moderators due to the language barrier. Thus, the choice on which of the themes to probe further into, was left to the supervised moderators.

For the qualitative analysis, inductive thematic content analysis was used [159-161]. Content analysis is well suited when investigating opinions and interpretations, and has been used extensively for similar research. Another alternative would have been to use grounded theory which has many similarities.

#### Selection assessment

A proper selection of informants is essential for epidemiological research as selection bias can distort the results [158]. In the comparison study between the general population and the HIV-positive mothers, information was collected from two different samples. While the general population was approached in their homes, the HIV-positive mothers were recruited from an HIV-clinic. Presenting to an HIV-clinic in Uganda is a barrier to many, which might introduce some challenges related to selection. There might also be some degree of selection into which of the HIV-clinics that different families approach, and TASO which gives their services practically for free might have a slightly poorer sample of the population than clinics such as Joint Clinical Research Centre (JCRC), which requires a larger fee. JCRC is outside the hospital area, and it might be easier to visit the clinic without being associated with an HIV-clinic than for example TASO. The recruited population from TASO are also likely to be different from HIV-positive mothers who have not tested themselves. Thus, the finding of a difference in socio-economy between the mothers in the general population and the HIV-positive mothers might not necessarily imply that HIVpositive mothers are poorer in general even if the sample was poorer. A consecutive selection of all mothers that fulfilled the selection criteria was used in the survey among the HIV-positive mothers. Nearly all of those who fulfilled the criteria were reached as all who came to the HIV-clinic were registered at the entrance. This probably reduced selection bias within the HIV-clinic.

The qualitative informants were also recruited from the same settings as the surveys, and are likely to have a similar representation. With respect to the interviews among the health workers, the interviewed health workers had infant feeding counselling as one of their tasks, but not all had it as their main role. There were also groups that were not interviewed which could have given counselling to some mothers including traditional birth attendants.

Lost-to-follow-up is not directly a concern for cross-sectional surveys. However, there are probably some children who would have been included in the surveys if they had not died at an earlier time. Thus, these surveys are likely to have some fewer among the sickest children than would be expected in a cohort study following up the children from birth as done in the intervention trial.

For the intervention trial, between 10 to 25% of the children did not have valid measurements for each interview visit. There were some differences between those with valid and missing measurements in where they lived, with a better follow-up among the rural than among the urban participants. These differences were adjusted for using an inverse-probability weighted method [158]. The weights were in general small, and inclusion of the weights did not change the estimates much, which indicates that the estimates probably would not have been biased by missing even without the weights.

Assessment of growth was initially planned as one of the key variables in the survey among the HIV-positive mothers. As around half of the mothers did not bring their youngest child to the HIV-clinic and thus could not be measured, this assessment was not analysed and presented as the selection of infants could be severely biased.

To avoid 'contamination' of the peer counselling effect of the intervention in the trial, a cluster-randomised design was chosen instead of an individual randomised design. In a cluster, research participants within the same cluster are likely to be more similar than research participants from other clusters, as people from similar socio-economic backgrounds tend to cluster together in the same neighbourhoods. Thus, the variance between cases within a cluster is less than if the cases were completely independent from each other (e.g. from another geographic area). This effect was adjusted for using cluster-weighted analyses. It could also be argued that cluster adjustment could have been used for the first papers too. A counter argument is that nearly all studies have recruitment with some degree of clustering and that taking this to the extreme, nearly all studies should be cluster adjusted. The participants from the two first surveys were also originating from a wide range of villages far higher than the number of clusters in the trials. The need to adjust for potential cluster effects is thus reduced, and adjusting is unlikely to have changed the estimates much.

An issue which is related to selection bias is multiple comparison bias. When multiple comparisons and tests are made, which each involve an error margin that is added up, this can cause spurious findings to appear when in reality they are associated by chance. To reduce this threat, planning of the statistical analyses and intended presentation was done prior to the analysis process. The analyses of the first paper were to lesser extent predefined, and multiple analyses were performed, which gave it a more explorative approach. As the main findings presented in the article were highly significant (p<0.001 and p<0.01), it is less likely that these associations were due to chance. The findings were also coherent with the literature, which strengthened their validity.

Many statistical analyses depend on various assumptions, which were checked carefully before interpreting findings. The findings that were presented in the thesis were in many cases also confirmed with robust methods with less rigorous assumptions. An example of measures taken to reassure proper robustness was the use of log rank tests to confirm findings from Cox regression models.

#### Sample size

Sufficient power is essential in order to answer the research questions and ensure that true associations are found (avoiding type II errors) [191]. For the survey among HIV-positive mothers, power was not calculated in advance as it was a concern that it could be difficult to recruit a sufficient number of participants and that the information would still be important even with a low number of informants. Nevertheless, post-hoc assessment confirmed that the power was sufficient to find differences in e.g. replacement feeding. The ranges of the confidence intervals are good indicators of power, with higher power when ranges are smaller, and when the difference between the point estimates is larger. This can indicate that the power was also appropriate to give a reasonable precision for the estimates of breastfeeding duration.

For the intervention trial, anthropometry was a secondary outcome and the power was calculated for the primary outcomes change in breastfeeding practices and diarrhoea. Still, relatively narrow confidence intervals particularly for the continuous analyses indicated that the power was rather good for anthropometric assessment.

Regarding the size of qualitative studies, some argue that data should be collected until '*saturation*' [162]. Saturation is often defined as the point when new insight is not gained. Morgan, Krueger and King have suggested a practical approach to this where 3 to 4 focus groups are conducted before assessing whether more data is needed. As it is difficult to assume that new insight will not come when adding more participants, we also based the choice on the number of discussion groups from the literature on what has been used in similar research. After having analysed the material, it is evident that many of the themes were quite saturated with few new topics coming up.

#### Confounding and interactions

When investigating associations, it is important to keep both interactions (effect modification) and confounding in mind. According to Rothman, confounders have three key characteristics; they are (direct) extraneous risk factors for the outcome, associated with the exposure, and not an intermediate factor in a causal chain [158].

Randomised trials, such as the intervention trial, are less prone to confounding as the randomisation in theory should assign exposure randomly. Practically, the fewer randomisation units a trial has, the more prone it is to have slightly imbalanced randomisation by chance. This is particularly true for cluster randomised trials; as the number of clusters normally is lower than the number of participants in individual randomised trials. For the intervention trial that was assessed in this thesis, there were slight differences between the control and intervention clusters in socio-economic status. The fact that adjusting for these hardly changed the estimates is reassuring and indicates that none of the measured factors confounded the study noticeably. There were some few variables that were not measured that could have been useful to include such as birth weight. Birth weight was *a priori* considered too costly to collect and was dropped for this reason.

For the associations presented in the surveys such as between breastfeeding duration and mothers' education, it is not unlikely that there are confounders causing the shortened breastfeeding duration that were not measured. Even if mothers' education is not a causal factor for shortened breastfeeding duration, it can still be useful as a predictor, for example when targeting interventions to specific risk groups.

A strategy to reduce confounding in general is to include all the factors that are likely to could influence the dependant variable in the model. When having a limited number of study participants, it might not be desirable to include all factors in the model at the same time, as this will reduce the statistical power substantially. An important question when needing to limit the number of variables in the model is how to select the factors. In the analyses in this thesis, factors regarded as likely to be associated and where data was available were included in a model with a stepwise selection. The stepwise selection procedure removed insignificant factors starting with the least associated and continuing until all factors remaining in the model were associated (with a p>0.1). Even if the procedure is partly automated, a critical assessment is essential, for example to avoid including highly correlated variables in the same models at the same time (as mothers' and fathers' education).

Interaction is when different factors influence the dependent variable of the model differently when appearing together than separately. According to Rothman there will always be interactions when two factors are associated with a dependent variable, either on an additive scale or a multiplicative scale [163]. How interactions are assessed in practice, is often depending on the models that are used. A Cox regression model was used in this thesis, and thus interactions were assessed on a multiplicative scale. In the studies presented in this thesis, different interactions between two factors that gave meaning were assessed. Re-analysis of the first paper showed an interaction between mothers' education and socio-economic status that was more important than the factors separately. In other words, it was the combination of both high education and high socio-economic status that was most strongly associated with shortened breastfeeding duration, not each of the factors separately. This interaction could still be confounded by other factors, such as work situation. Nevertheless, the presence of such associations can be helpful as predictors both to understand situations and settings, and to could direct interventions to where they are needed. In this case, if the aim is to promote longer breastfeeding duration, it would be important to emphasise how to manage this among mothers with higher education and less poor socioeconomic status.

# Consistency – reliability and dependability

To ensure good consistency of the data, several efforts were made. For the anthropometric measurements, this included repeated follow-up of the data collectors and checking of intra-observer reliability. Inter-observer reliability was also checked by repeating some interviews with a group of other data collectors. The data on intra-observer reliability and inter-observer reliability indicated good consistency in both the interviews and anthropometric measurements.

In the qualitative studies, dependability can be assessed with some similarities to reliability in quantitative contexts [190]. A strategy that was used in this respect was the combination of note taking and verbatim recording of the qualitative interviews with subsequent transcription as elaborated on above.

### Causation

Bradford Hill suggested criteria to assess whether associations were causal [192]. These criteria involve assessment of the strength of an association, consistency between methods and sources, specificity of the association, temporality – i.e. that the causal factor is preceding the outcome (the opposite is often referred to as reverse-causality), biological gradient (e.g. dose-response relationship), plausibility, coherence with existing knowledge, experiment and analogous examples.

For the intervention trial, most of these criteria are met. The strengths of the associations are not sufficiently strong to categorically conclude that the intervention had negative impacts on growth, but are strong enough to conclude that there were no positive impacts on growth. The consistency criterion is also well met with nearly all differences going in the same direction – i.e. lower values in the intervention. Temporality was also met, as both the randomisation, case inclusion and peer counselling intervention, all started before birth. There seemed to be a biological gradient with increasing differences in stunting between the groups with increasing age.

The question on plausibility can be seen from two angles – on the one hand it can be regarded as plausible that children could have quicker growth when receiving some additional food items as they are approaching six months. On the other hand, exclusive breastfeeding has been reported to decrease the risk of e.g. gastrointestinal infections [21, 28, 106], which are associated with growth deficits. This leads into the discussion of the next criterion on how the findings are consistent with existing literature. There is an extensive literature on effects on breastfeeding. There is limited literature on long-term outcomes of exclusive breastfeeding, and the existing literature on this aspect has not concluded with beneficial effects on growth [26]. The design of the cluster-randomised intervention trial is also among the strongest of the studies that have reported growth outcomes from breastfeeding interventions.

On the aspect of analogous examples, a large programme to improve child health was implemented in Benin, Mali and Ghana [114]. The Accelerated Child Survival and Development programme focused on nutritional counselling, vaccinations and antenatal care. Surprisingly, despite including well-documented interventions, the programme did not show improved health outcomes in the intervention areas when compared to the control areas.

The finding of a shorter duration of breastfeeding among the most educated and least poor of the HIV-positive mothers was also strong and had a clear biological gradient, with a stronger association with higher values. There are also several potential plausible explanations for why this could be the case. Highly educated mothers are more likely to be formally employed, which might compromise infant feeding, something which both the qualitative and quantitative findings in the thesis confirms. There is also a correlation between education and socio-economic factors, and more educated mothers often have more resources and can provide more alternative options – i.e. more money to buy other food items. HIV-positive mothers often knew about the potential risks of HIV-transmission from mother-to-child through breastfeeding, and this knowledge might have reached the most educated to a larger extent.

### Applicability – external validity and transferability

The findings in this thesis are based on studies done in Mbale District, Eastern Uganda. Still, many of the findings will have importance for a broader area. To assess

the external validity and transferability, it is necessary to relate the individual findings to the settings.

The counselling situation described in the thesis has also been described to be similar in studies from Botswana, Kenya, Malawi, South Africa and Uganda [69, 73]. This suggests that the findings were likely to have been valid for a broader area of Sub-Saharan Africa. However, it is important to acknowledge that there have been substantial changes in for example infant feeding guidelines since the time of the study. For this reason, even if the situation was similar in several other settings, it may now have changed. Nevertheless, some of the findings are to a larger degree independent of time. This includes the psychological aspects around infant feeding. If mothers experience social and psychological pressure related to infant feeding choices, this might compromise and influence the behaviour. A further discussion on these issues will be included under the specific topics.

### Neutrality - objectivity and conformability

Concerning neutrality, the studies presented in this thesis have several strengths. All studies were funded by supra-institutional and governmental funding (including the European Union and Norwegian Programme for Development, Research and Education). None of the studies or researchers involved were funded from sources that have financial interests, such as formula milk industry, organisations with specific interests or pharmaceutical industry. The funding was also independent of national interests. There were also no restrictions from the funders on the involved researchers on publishing or analysis.

Predisposition is a threat for all researchers, and although trying to be as objective as possible, it is hard to argue that research can be completely neutral [161]. When having read literature from various sources about feeding practices, both hypotheses and understanding are building up consciously and unconsciously. This may pose a challenge when collecting data, as the mind tends to look for information in line with current understanding. When findings appear which are conflicting to the current paradigm and understanding, the important details might not be noticed. By trying to be conscious about this challenge and put extra attention to contrasting information, it is possible to reduce this tendency.

Proper reporting is also essential. In the two first articles, the reporting of the studies have been conformed according to the guidelines from '*Strengthening the Reporting of Observational Studies in Epidemiology*' (STROBE) [193], the third article has been reported in line with the RATS guidelines [194], while the fourth paper is reported in line with the '*Consolidated Standards of Reporting Trials*' (CONSORT) [195].

Another strength of the thesis is that several of the researchers who were involved in the studies have experience from various settings. When comparing systems this might be an advantage as it will broaden the standard of reference. At the same time, even though all the researchers have been in Uganda for some time, some of the researchers including the author of the thesis could still have benefitted from having more complete cultural insight. However, all the studies in this thesis have involved several researchers from Uganda with extensive knowledge of different aspects of the culture, traditions and history.

In addition to the issues discussed together with the methodological aspects above, there are some additional important matters that will be discussed.

#### Infant feeding patterns

A study from Zambia that was published by Kuhn *et al* partly changed how the findings presented in the first article about breastfeeding duration should be interpreted [61]. Prior to that study, a short duration of breastfeeding with subsequent abrupt weaning was regarded as beneficial for the children according to the guidelines and literature. Seen in view of the Zambian study, the difference in breastfeeding duration between the HIV-positive mothers and the general population is not necessarily beneficial. Breastfeeding cessation is only recommended when appropriate feeding options are available [31, 102]. The question is thus whether the children of the HIV-positive mothers had sufficient complementary feeding diets. There seemed to be a slightly better food diversity among children born to HIV-mothers as compared to the general population, which might have been a compensation for the earlier breastfeeding cessation.

There were also other reasons for early weaning of breastfeeding. A new pregnancy was another reported reason for stopping breastfeeding – both in the qualitative and quantitative studies. This has also been reported from a study in the South-Western Uganda, which indicated that this might be due to a belief that continued breastfeeding after getting pregnant can cause kwashiorkor in the breastfeeding child [196]. The studies in the thesis indicated that delayed initiation of breastfeeding and prelacteal feeding were commonly practiced both among HIV-positive mothers and in the general population. These practices are associated with increased mortality [14, 40].

Several health indicators are closely interlinked with socio-economic factors, as seen clearly in the web tool Gapminder and in several studies [17, 38, 197-199]. The studies in this thesis showed several associations between socio-economic rank and health indicators such as food diversity and duration of breastfeeding. Concerning growth outcomes, which were generally poor at the 2 years follow-up, socio-economy did not have much influence. This can indicate that the diets among many of the children were far from optimal, also among the less poor.

The findings on feeding patterns reported from the two first papers are well in line with other studies having assessed feeding patterns in the vicinity, including studies from Western Uganda and Tanzania [199, 200].

#### Infant feeding counselling

The third article described several challenges in health counselling. This included lack of sufficient resources and staff, infrequent updating of knowledge and appropriate facilities, and also concerns on how to meet the difficult situations of the health clients.

The counselling process itself also has importance. Counselling was challenging as counsellors on one hand tried to simplify messages to make them easily understandable, while on the other hand they tried to give sufficient information for mothers to take informed choices. Insufficient information could have caused that health clients received contradicting messages when different sides of the same issue were presented simplistically from different health workers. The thesis has indicated that the pendulum seemed to have swung too far in the direction of simplification, with the consequence of inadequately balanced information. The guidelines on infant feeding in the context of HIV from the WHO have recently put more attention to this aspect, and currently recommend disclosing a single standard option, and putting less emphasis on other alternatives.

Another issue with respect to counselling is how to keep counsellors sufficiently up to date. The findings suggested that this was a problem in this area, with many of the counsellors not having got refresher courses to boost their knowledge on infant feeding since the time of their studies. The same issue has also been reported in other Sub-Saharan countries. Assessments of health workers from Botswana, Kenya, Malawi, Niger, South Africa and Uganda similarly concluded that health counselling was often sub-optimal [69, 73, 201]. Health workers often overestimated the risk of HIV-transmission from mother to child, and conveyed their messages in an authoritarian way without giving balanced information. There is a need to change this situation, and there are studies that have shown good effects on health workers behaviour when providing regular refresher seminars and workshops [202-204].

Priority setting is another topic that arises from these studies. One example is the differences in resources seen when comparing health counselling in public health facilities and non-governmental organisations working with people living with HIV – with respect to the number of available staff and facilities. The non-governmental organisations had more resources, which translated into the ability to give individualised counselling that seemed to be beneficial. Whether the solution is to make room for more non-governmental organisations to counsel, or to rather use the resources to upgrade the public health system is a question that has been debated. A study by Lu et al indicated that funding through non-governmental organisations seemed to increase countries own health spending, while funding through governments seemed to reduce the countries own share of the health expenditures [205]. On the other hand, governments have several good reasons to reduce their own contribution to a sector and smoothen the budget when they get earmarked aid, as aid often is unreliable [206]. There are also several challenges when giving funding through nongovernmental organisations and not through governments, including difficulties to coordinate the efforts [207]. Since the time of the studies, it has been carried out some improvements of some of the health facilities including the regional hospital.

Another aspect is time conflict. Many mothers are pressed for time as they also are responsible for several other tasks. As found in the studies from this thesis, mothers' education and work were strongly associated with breastfeeding duration. The

qualitative interviews also indicated that the time was an important factor influencing infant feeding practices.

There were also poverty-related issues which were emphasised in many of the interviews. The surveys also indicated that socio-economic factors were also associated with breastfeeding duration. Many families had neither enough money to buy a variety of food, nor soil to grow it. Lack of utensils and assets were also barriers to safe preparation of formula milk, which was recommended to several of the mothers. This was a challenge for counsellors as the guidelines at that time did not acknowledge these limitations sufficiently.

Another challenge for the health workers related to infant feeding was HIV disclosure. Several mothers ended up with mixed feeding already early in infancy as they intended to formula feed their children, but also breastfed their children when seen by other people to not be suspected to be HIV-positive. Not disclosing HIV has also been reported to increase the rates of mixed feeding in South Africa [208]. Disclosing HIV can have both positive and negative consequences. Among the women who disclosed their HIV status, many got support. Important barriers to disclosure were fear of abandonment, accusations of infidelity, discrimination and violence, and several of the mothers in the studies in this thesis had such experiences. Stigma and negative consequences of disclosing HIV are setting specific [208-211], and it was also indicated in the interviews among health workers that this problem was gradually reducing over time.

#### **Culture and context**

It is important to acknowledge that people have prior knowledge and beliefs which are setting specific [212, 213]. Some of the issues were more culturally grounded or had their roots in traditional beliefs. This included the belief that continued breastfeeding after getting pregnant could cause kwashiorkor in the breastfeeding child. Even if this belief also has been reported in some other settings [196], it is probably less transferable than some of the other findings. The potential conflict between health workers' counselling and cultural beliefs and perceptions is more general, and has been reported also by several other studies [42, 44, 70, 214, 215].

It is hard to make guidelines that build on values that are independent of culture and history. Thus, guidelines need to be adapted to their settings to work well. The consequences of not acknowledging these aspects have been numerous, including severe difficulties with feasibility of the recommendations, confusion among both mothers and health workers, stigmatisation of families, fear, guilt and harmful feeding practices with diets that have been inadequate to meet the nutritional needs of the children [212]. This thesis also underlines the importance of taking culture and context into consideration when making and adapting guidelines.

The guidelines on infant feeding in the context of HIV have within a decade first moved far away from the traditional infant feeding practices before recently coming much closer to the customary practices, with the addition of antiretroviral therapy or prophylaxis to reduce HIV transmission [212, 216]. The guidelines from 2001 and 2010 stand in stark contrast to each other [67, 102, 216], and are examples on how the scientific knowledge on implementation, culture and contexts, biology and medicines, are all essential. This change has probably reduced the burden on many families both socially and financially [48, 49]. The choice of infant feeding strategy has also moved towards recommending a single option as standard for a setting, rather than putting the burden of the choice only on the mothers [102], which might reduce the confusion that has been seen. The frequent changes in guidelines might have been a challenge in itself, as it is necessary to circulate the changes to the involved health workers.

The history of infant feeding guidelines in the contexts of HIV is many ways parallel to the history of political health reforms in Uganda. Okuonzi evaluated twenty Ugandan health reforms over two decades and concluded that most of them were pushed from other countries and supra-governmental institutions, and the majority of them had negative health consequences [217-219]. The importance of taking the setting into account can in other words hardly be emphasised enough.

#### Child growth during a breastfeeding support intervention

The fourth paper did not show any improvements in child growth among the children that took part in the intervention where exclusive breastfeeding was promoted by peercounsellors. In general, the growth situation was poor both in the intervention and the control arm, with increasing rates of stunting with increasing age, with nearly half of the children being stunted at 2 years of age. A poor growth outcome is a serious threat to the health of children [13, 37]. This is true not only in the short term – undernourished children are also more likely to be short adults, have lower educational achievement, be socio-economically less fortunate, and give birth to smaller children [20]. Undernutrition in infancy is also strongly correlated with obesity in adult age. Undernutrition can thus cause a spiral of unfortunate consequences.

Having the negative growth outcomes in mind, the follow-up question is how the intervention worked. The intervention with peer-counsellors to promote breastfeeding was highly accepted in Uganda [123, 220, 221], with nearly all the mothers expressing satisfaction with the intervention. It also increased the prevalence rates practicing breastfeeding exclusively both at 12 weeks of age and 24 weeks of age [222]. At 12 weeks age in Uganda, 82% practiced exclusive breastfeeding in the intervention arm compared to 44% in the control arm. At 24 weeks, the absolute numbers were lower, but the relative differences were higher.

A study from Guinea Bissau similarly found negative growth outcomes when promoting exclusive breastfeeding [113]. In addition, they did not find any other health benefits from their intervention. The implementation of the Accelerated Child Survival and Development Programme from UNICEF in West Africa is a reminder that interventions must be put into their contexts [114]. In some cases, intervention areas show improvements, but this may still be exceeded by the general trend using other intervention approaches. There has been some discussion on whether exclusive breastfeeding and predominant breastfeeding have significant differences in survival or HIV-transmission [35, 57, 75]. Studies by Iliff *et al* and Piwoz *et al* have suggested that exclusive breastfeeding tended to be superior in terms of a slightly reduced risk of HIV transmission and a better weight gain, but many studies have shown no difference in these outcomes.

It is important to acknowledge that even if the study presented in the fourth paper did not find beneficial growth outcomes, this does not necessarily imply that exclusive breastfeeding is negative. One aspect indicating that exclusive breastfeeding did not influence the outcome much, is that including breastfeeding pattern into the model with stunting at two years of age did not change the estimates markedly.

What caused the negative findings then? A theory is that the emphasis on the importance of giving only breast milk during the first 6 months might have reduced the recognition of the importance of providing a sufficiently balanced diet during the second half of infancy. Another hypothesis is that the emphasis on the beneficial effects of exclusive breastfeeding may have given the families a false security that reduced their health seeking behaviour. Proper health seeking behaviour is essential in settings with a high burden of infectious diseases such as measles and malaria. An argument against this hypothesis is that there were not found any differences in timely vaccination across the intervention and control arms from a study in the same group [223].

That some of the differences were partly explained by differences in height and weight at the 3 weeks visit, can either suggest that randomisation was not optimal, or that there was a difference in weight and height gain taking place between birth and the age of 3 weeks. Another possibility could be that the children in the intervention to a lesser extent were given additional liquids during severe or moderate diarrhoea infections.

A question is whether a one-week course to train peer-counsellors is enough to give beneficial support. Community-based breastfeeding support requires resources – both financially and in terms of personnel resources [110, 221]. When striving for improved child health through improved infant feeding, it is also important to acknowledge other major killer diseases including malaria and vaccine preventable diseases [2, 224], as well as the importance of good complementary feeding after the first half of infancy.

# Conclusions

This thesis has shown that both mothers and health workers have experienced numerous challenges related to infant feeding. This was often related to poverty and insufficient health resources, which provided several challenges. HIV-positive mothers struggled much in terms of infant feeding. One of the concerns was related to the fact that several of the recommended feeding options at the time of the studies made it necessary to disclose the HIV-status. The breastfeeding duration among HIV-positive mothers was shorter among HIV-positive mothers than in the general population, particularly among the most educated HIV-positive mothers. The feasibility and acceptability of the former guidelines were also considered as challenging both among mothers and health workers, and the guidelines did not seem to sufficiently take the context into consideration. Frequent changes in programs and guidelines were other challenges.

In the community-based intervention trial promoting exclusive breastfeeding for 6 months with peer-counsellors that were trained in a one-week course, there were no growth advantages during the first 6 months or at the 2 years follow-up. It was a high number of stunted children at the two years follow-up, both in the intervention and the control arms. For several measurements, the growth outcomes of the children in the intervention arm were worse than for children in the control arm. The infant feeding practices at 12 weeks were not associated with the outcome.

Thus, it is time to reconsider how infant feeding support can be delivered most successfully.

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# Article 1

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# Research article

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# **Need to optimise infant feeding counselling: A cross-sectional survey among HIV-positive mothers in Eastern Uganda** Lars T Fadnes<sup>\*1</sup>, Ingunn MS Engebretsen<sup>1</sup>, Henry Wamani<sup>2,3</sup>, Jonathan Wangisi<sup>4</sup>, James K Tumwine<sup>2</sup> and Thorkild Tylleskär<sup>1</sup>

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### Abstract

**Background:** The choice of infant feeding method is important for HIV-positive mothers in order to optimise the chance of survival of their infants and to minimise the risk of HIV transmission. The aim of this study was to investigate feeding practices, including breastfeeding, in the context of PMTCT for infants and children under two years of age born to HIV-positive mothers in Uganda.

**Methods:** In collaboration with The Aids Support Organisation Mbale, we conducted a cross-sectional survey involving 235 HIV-positive mothers in Uganda. Infant feeding practices, reasons for stopping breastfeeding, and breast health problems were studied. Breastfeeding duration was analysed using the Kaplan-Meier method based on retrospective recall.

**Results:** Breastfeeding was initiated by most of the mothers, but 20 of them (8.5%) opted exclusively for replacement feeding. Pre-lacteal feeding was given to 150 (64%) infants and 65 (28%) practised exclusive breastfeeding during the first three days. One-fifth of the infants less than 6 months old were exclusively breastfed, the majority being complementary fed including breast milk. The median duration of breastfeeding was 12 months (95% confidence interval [CI] 11.5 to 12.5). Adjusted Cox regression analysis indicated that a mother's education, socio-economic status, participation in the PMTCT-program and her positive attitude to breastfeeding exclusively, were all associated with a reduction in breastfeeding duration. Median duration was 3 months (95% CI 0–10.2) among the most educated mothers, and 18 months (95% CI 15.0–21.0) among uneducated mothers. Participation in the PMTCT program and being socio-economically better-off were also associated with earlier cessation of breastfeeding (9 months [95% CI 10.8–17.2] and 8 months [95% CI 5.9–10.1] vs. 17 months [95% CI 15.2–18.8], respectively). The main reasons for stopping breastfeeding were reported as: advice from health workers, maternal illness, and the HIV-positive status of the mother.

**Conclusion:** Exclusive breastfeeding was uncommon. Exclusive replacement feeding was practised by few HIV-positive mothers. Well-educated mothers, mothers who were socio-economically better-off and PMTCT-attendees had the shortest durations of breastfeeding. Further efforts are needed to optimise infant feeding counselling and to increase the feasibility of the recommendations.

# Background

Widespread promotion of exclusive breastfeeding could prevent child mortality by 8% [1]. However, transmission of HIV through breast milk has made breastfeeding counselling more complicated in low-income countries where HIV is prevalent.

Every year, more than half a million infants become infected with HIV. These infection rates are disproportionately distributed geographically; mother-to-child-transmission, in the context of antiretroviral prophylaxis is below 1% in Europe and the USA, but exceeds 30% in many poorly resourced countries, with Sub-Saharan Africa carrying the highest burden [2,3]. The incidence of HIV infection among children has fallen in many areas, but this seems to be more related to a reduction of the HIV prevalence among mothers than gains in the PMTCT program [4].

In many countries where HIV is prevalent, the infant mortality rate is high. Considering the risks of both infant mortality and HIV transmission, breastfeeding is strongly correlated with a higher HIV-free child survival rate compared to formula feeding where the infant mortality rate is above 4% [5,6]. Exclusive breastfeeding can be associated with higher HIV-free survival at 6 months than mixed feeding [6,7]. Post-natal vertical HIV transmissions increase with a longer breastfeeding duration [8]. Cessation of breastfeeding at the age of 6 months has consequently been recommended wherever replacement feeding at that age is acceptable, feasible, affordable, sustainable and safe [8,9]. Failure to sustain replacement feeding and re-introduction of breastfeeding after initial cessation is particularly risky in terms of mother-to-child transmission of HIV [10]. Infant feeding recommendations for HIV-positive mothers are confusing and have resulted in disadvantageous feeding patterns and mixed feeding in particular [11]. Mixed feeding is associated with a higher morbidity and mortality risk than exclusive breastfeeding for infants of both HIV-positive and HIVnegative mothers, and with increased HIV transmission from HIV-positive mothers [6,7,12-16]. Exclusive breastfeeding is also associated with a reduced risk of breast health problems [17].

The frequencies with which exclusive breastfeeding, mixed feeding, prelacteal feeding and replacement feeding are practised differ widely throughout Africa [18]. Region-specific measurements are essential to develop regional-specific recommendations.

We have investigated infant feeding practices, including breastfeeding, for infants and children under 2 years of age born to HIV-positive mothers in Mbale, Eastern Uganda.

### Methods Study area

The study was conducted during 2005 in Eastern Uganda in collaboration with The Aids Support Organisation (TASO). TASO is the largest national-based non-governmental organisation working with HIV-positive people in Africa. It is a grassroots movement providing counselling, information, support and medical treatment.

The study area included Mbale district, together with areas accessed through TASO Outreach Clinics in adjacent regions in the districts of Sironko, Pallisa and Kumi. Mbale district has a population of 720,000 of predominantly Bagisu people, with 90% living as subsistence farmers in rural environments. The overall literacy rate is 64% for men and 49% for women [19]. Uganda has an HIV prevalence of 7.5% in women aged 15–49 years (2005) [20]. In the period of the study, introduction of routine HIV counselling and testing was starting in Ugandan hospitals [21]. The acceptance of testing had increased substantially. The national PMTCT program was introduced in Uganda first as a pilot in 1998 and more widely in 2001 [22].

This cross-sectional study collected information from 240 HIV-positive mothers with children aged 0–23 months. All mothers were recruited from TASO by consecutive sampling, and they participated voluntarily with informed consent. No mother contacted as a potential interviewee refused to participate. Five mother-infant pairs were excluded from the study because of missing information or the child was over 23 months old. Accordingly, 235 HIV-positive mothers were included in the study. Three pairs of data collectors who were fluent in Lumasaba (the local language), Luganda (the language of the central region) and English conducted the interviews with the mothers.

To check the reliability, 15 mothers were re-interviewed by another pair of data collectors 2–4 weeks after the initial interview. The answers showed only minor discrepancies and a high degree of consistency.

# Questionnaire

The structured interview contained topics concerning breastfeeding and feeding habits, feeding knowledge, mother's and father's education, occupation, household assets, time of HIV diagnosis, self-rated health [23], mother-rated health of infant and PMTCT program participation. A list of 30 liquid, semi-solid and solid foods was utilized with 24-hour recall, 1-week recall and recall since birth. Using a symptom-based semi-quantitative approach, we examined breastfeeding problems and reasons for stopping breastfeeding. The questionnaire was pre-tested to ensure correct understanding of the questions.

## Data handling

Double entry was done in EpiData 3.1, and SPSS 14 was used for data analysis.

# Definitions

Feeding information was based on World Health Organisation (WHO) definitions and recommendations [24], as follows. Exclusive breastfeeding: giving breast milk only, except for medicines and vitamin or mineral supplements; predominant breastfeeding: breast milk is nutritionally dominant, but with the possible addition of water-based fluids, fruit juices, tea without milk or oral rehydration salts; complementary feeding including breast milk (often referred to as mixed feeding): nonhuman milk, semi-solids or other solids given in addition to breast milk; replacement feeding: breastfeeding stopped or never being given any breast milk. Exclusive replacement feeding was defined as never having given any breast milk. Pre-lacteal feeding was defined as any food item or liquid other than breast milk given to the infant during the first 3 days after delivery.

## Ethics

Ethical approval was obtained from Makerere University, Faculty of Medicine Ethics and Research Committee, and the Uganda National Council for Science and Technology. Informed consent was obtained from each participant.

# Statistics

Baseline characteristics were examined with frequency tables. Feeding patterns were compared using  $\chi^2$  statistics. Consistency was checked by Cohen's Kappa statistic.

The participants were grouped socio-economically into quintiles based on wealth assessment using principal component factor analysis [25]. Housing characteristics and assets including toilet facilities, number of rooms and beds, roof material, lantern, radio, television, bicycle and vehicles were included in the model. The quintiles were based on the first principal component, a recognised method as a good proxy for household wealth [26]. Breastfeeding duration in this cross-sectional study was estimated using Kaplan-Meier survival analysis with a Mantel-Cox log rank test to compare the estimates. Selfreported breastfeeding duration is used in the model. Cox regression analysis was used to estimate the independent impact of each factor on breastfeeding duration. Co-linearity, hazard plots and residual plots were checked. A backward "conditional" regression model was used in the multivariate analysis with removal set at a 0.1 level of significance.

# Results

The median maternal age was 30 years (inter-quartile range [IQR] 28–35) (Table 1). The age distribution of the infants and children was: 0–5 months: 37 infants; 6–11 months: 53 infants; 12–17 months: 65 children; 18–23 months: 80 children [see Additional file 1]. Median maternal education was 5 years of schooling (IQR 3–7). Fathers were more educated than mothers with a median of 7 years of education (IQR 5–10). Half the mothers were widowed.

## Feeding practices

Of 235 HIV-positive mothers, 215 (91.5%) initiated breastfeeding while 20 (8.5%) never breastfed their infants. Among 128 mothers who attended the PMTCT program, 18 (14%) avoided breastfeeding completely, while 2 of those not participating did not breastfeed (p < 0.001). Among the attendees and non-attendees in the PMTCT program, the proportions opting for exclusive breastfeeding during the first three days were not significantly different, 28.1% versus 27.1%, respectively. Ten among the 46 mothers in the better-off quintile did not initiate breastfeeding within the first three days. Nine of these 10 (90%) mothers continued with exclusive replacement feeding. Among the poorer 189 mothers, 11 (42%) out of 26 mothers who did not initiate breastfeeding within the first three days continued with exclusive replacement feeding, whereas 15 mothers introduced breastfeeding later on (p < 0.05).

Within the first two hours after delivery, 131 (56%) had initiated breastfeeding, with 178 (76%) having done so within the first day. Pre-lacteal feeding was given by 150 (64%) while 65 (28%) practised exclusive breastfeeding during the first three days. Replacement feeding was practised by only one of the 85 mothers diagnosed with HIV after delivery.

One-week recall and 24-hour recall gave similar results for the infant feeding patterns, giving a Spearman correlation coefficient of 0.96 among infants below 6 months of age and 1.0 above 6 months of age (Table 2). Among the infants less than 6 months old, one-fifth were exclusively breastfed and most were fed complementary including breast milk. Two-thirds of the infants older than 6 months were fed complementary including breast milk and the remaining third were replacement fed. The rate of replacement feeding increased with age. Among children aged 12–17 months, 37 (58%) were replacement fed, while 75 (93%) of children aged 18–23 months were replacement fed.

# Breastfeeding duration

The median duration of breastfeeding was 12 months (95% confidence interval 11.5–12.5). Education was

Table 1: Median breastfeeding duration with Kaplan-Meier analysis including all the infants (n = 235) and a Mantel-Cox log rank test to compare ranking of the estimates

	n (%)	Median in months	95% CI	Log Rank test (Mantel-Cox)
Mother's education				$^{2}$ = 240 (4 df <sup>a</sup> )
None	27 (11)	18	15.0 - 21.0	b < 0.001
Stopped in primary	125 (53)	14	12.1 - 15.9	P
Completed primary (7 years)	39 (17)	12	8.0 - 16.0	
Secondary education	37 (16)	8	6.8 - 9.2	
Higher education ( $\geq$ 12 years)	7 (3)	3	0-10.2	
Father's education				$^{2}$ = 11.4 (4 df)
None	14 (6)	b	b	p < 0.05
Stopped in primary	72 (32)	13	.6 –  4.4	
Completed primary (7 years)	62 (27)	15	11.8 – 18.2	
Secondary education	50 (22)	9	7.3 – 10.7	
Higher education ( $\geq$ 12 years)	30 (13)	8	3.8 - 12.2	
Mother's age				$^{2} = 1.7 (1  df^{ac})$
≤ 24	22 (10)	18	16.3 – 19.7	p = 0.20
25 – 29	61 (26)	12	10.9 - 13.1	1
30 – 34	85 (36)	12	11.3 – 12.7	
≥ 35	67 (29)	12	11.3 – 12.7	
Marital status				$^{2}$ = 2.5 (2 df)
Married/cohabiting	91 (39)	12	94-146	b = 0.29
Widowed	112 (48)	12	114 - 126	p 0.27
Divorced/separated or single	32 (14)	13	4.5 – 21.5	
Socio-economic status				2 = 93 (1 df)
Bottom quintile poorest	47 (20)	17	152-188	- 7.5 (7 0)
and quintile, poorest	47 (20)	17	13.2 - 18.8	p = 0.01
	47 (20)	12	11.3 - 12.7	
Ath quintile	46 (20)	7	6.0 - 12.0	
Ath quintile	48 (20) 46 (20)	10	F 0 101	
rop quintile, least poor	46 (20)	o	5.7 - 10.1	
Mother's work				$^{2}$ = 7.5 (1 df)
Farming	201 (86)	12	10.9 – 13.1	p < 0.01
Do not farm	34 (14)	8	6.9 – 9.1	
Living area				$^{2}$ = 3.3 (1 df)
Rural	205 (87)	12	11.0 – 13.0	p = 0.07
Urban	30 (13)	8	4.7 – 11.3	
HIV-diagnosis				$^{2} = 10.1 (1 \text{ df})$
After delivery	85 (36)	15	10.5 – 19.5	þ < 0.01
Before delivery	150 (64)	12	10.4 - 13.6	
Participation in the PMTCT-program				<sup>2</sup> = 17.5 (1 df)
Did not attend	107 (46)	14	10.8 – 17.2	p < 0.001
Attended	128 (54)	9	7.2 – 10.8	,
Anyone talked about breastfeeding				$^{2}$ = 12.6 (1 df)
No	44 (19)	18	157 - 203	$h \le 0.001$
Yes	191 (81)	12	11.5 – 12.5	P 0.001
Mothers' self-rated health				$^{2} = 0   (1 dR)$
Very healthy	22 (14)	10	95_145	b = 0.73
Ouite bealthy	33 (17)  38 (59)	12	1 4 - 124	P 0.75
Not very healthy	64 (07)	12	97 - 183	
i tot very meaning	UT (27)	14	7.7 - 10.5	

Mothers'-rated health of child				$^{2} = 0.4 (1 \text{ df}^{c})$
Very healthy	37 (16)	9	5.1 – 12.9	p = 0.54
Quite healthy	(48)	12	10.1 – 13.9	
Not very healthy	83 (36)	12	10.8 - 13.2	
Belief about 6 months of exclusive breastfeeding				$^{2}$ = 9.2 (1 df <sup>c</sup> )
Sure it would be good	29 (12)	7	5.6 – 8.4	p < 0.01
Think it would be good	42 (18)	12	8.6 – 15.4	
Think it would hurt	104 (44)	12	11.0 – 13.0	
Sure it would hurt	59 (25)	15	12.0 - 18.0	

Table 1: Median breastfeeding duration with Kaplan-Meier analysis including all the infants (n = 235) and a Mantel-Cox log rank test to compare ranking of the estimates (*Continued*)

<sup>a</sup>df (degrees or freedom)

<sup>b</sup> could not be measured (only 3 stopped among 14 cases and 151 months of follow-up)

<sup>c</sup> linear trend assumed

associated with a marked reduction in duration of breastfeeding, with a median duration of 3 months (95% CI 0-10.2) among mothers with more than 12 years of schooling, and a median of 18 months (95% CI 15.0-21.0) among mothers lacking education (Figure 1). This effect was seen both with and without adjusting for other factors with Cox regression with a 4.5 and 6.4-fold increase in hazard ratio for breastfeeding cessation, respectively (Table 3). The level of the father's education, whether the mother was a farmer, and the timing of HIV-diagnosis in relation to birth had similar effects on the crude analysis, but not in the adjusted Cox regression analysis. Breastfeeding duration differed substantially among mothers in the poorest and least poor quintiles. The median duration was 8 months (95% CI 5.9-10.1) among the least poor and 17 months (95% CI 15.2-18.8) among the poorest (Figure 2). Mother's age, marital status, rural or urban life, self-rated health of the mother and mother-rated health of the infant were not significantly associated with breastfeeding duration. Mothers counselled in the PMTCT program stopped breastfeeding earlier than those who did not attend the program. Duration of breastfeeding was shorter among mothers who had discussed breastfeeding with someone compared to those who had not. Those who considered exclusive breastfeeding to be beneficial for the infant, stopped breastfeeding earlier compared to those who considered it harmful. In a restricted analysis including children above 18 months of age, the median duration of breastfeeding was 12 months (95% CI 11.4–12.6).

### Reasons for cessation of breastfeeding

Breastfeeding had been stopped by 116 mothers at the time of the interview. Advice from health workers, illness of the mother, and the fact that the mother was HIV-positive were reported as the main reasons for stopping breastfeeding (Table 4). Other reasons for stopping breastfeeding were: breastfeeding difficulties, perceived insufficient milk production, the notion that the child was "old enough" or "big enough", and that the child could eat without help. Family pressure, work and new pregnancies were reported by only a few mothers. Those stopping breastfeeding before the infant was six months old gave similar reasons to all the mothers stopping breastfeeding.

Fewer than half the breastfeeding mothers experienced problems relating to breastfeeding [see Additional file 2]. A fifth had problems with breastfeeding related to illnesses, such as generalised pain, frequent fever and a feeling of weakness. Breast pain, sore and cracked nipples,

Table 2: Recall comparison of different feeding patterns based on 24-hour, I-week and since birth recall. N (%) of infants in age range feeding in particular pattern based on specific recall period.

	24-hour recall	I-week recall	Since birth recall
0 – 5 months			
Exclusive breastfeeding	9 (24)	8 (22)	5 (14)
Predominant breastfeeding	3 (8)	3 (8)	5 (14)
Complementary feeding incl. breast milk	19 (51)	20 (54)	21 (57)
Replacement feeding	6 (16)	6 (16)	6 (16)
6 – II months			
Exclusive breastfeeding	0 (0)	0 (0)	0 (0)
Predominant breastfeeding	0 (0)	0 (0)	0 (0)
Complementary feeding incl. breast milk	36 (68)	36 (68)	36 (68)
Replacement feeding	17 (32)	17 (32)	17 (32)

0 - 5 months: n = 37; 6 - 11 months: n = 53.

Table 3: Cox regression of breastfeeding cessation, unadjusted and adjusted hazard ratio (HR). Only factors in the final adjusted model have HR estimates (right-hand columns).

	Breastfeedin	g cessation, unadjusted (crude)	Breastfeed	aling cessation, adjusted 95% CI	
Mother's education					
None	I		I		
Stopped in primary	1.3	0.7 – 2.4	1.3	0.7 – 2.5	
Completed primary (7 years)	1.9*	1.0 – 3.7	2.1*	1.0 - 4.2	
Secondary education	3.0*	1.5 – 6.0	2.4*	1.1 – 5.0	
Higher education ( $\geq$ 12 years)	6.4*	2.2 – 18	4.5*	1.4 – 15	
Father's education					
None	1				
Stopped in primary	1.7	0.6 - 4.8			
Completed primary (7 years)	1.7	0.6 - 4.9			
Secondary education	3.0*	11-84			
Higher education $(> 12 \text{ years})$	3.0	10-88			
righer education (= 12 years)	5.0	1.0 - 0.0			
Mother's age					
≤ 24	I				
25 – 29	1.8	0.8 - 3.7			
30 – 34	1.7	0.9 – 3.5			
≥ 35	1.8	0.9 – 3.7			
Marital status					
Married/cohabiting	I				
Widowed	1.2	0.9 – 1.8			
Divorced/separated or single	1.5	0.8 - 2.6			
Socio-economic status					
Bottom quintile, poorest	1		I.		
2nd quintile		10-32	2.4*	12-48	
3rd quintile	2.0*	1.0  3.2	2.1	1.2 1.0	
Ath quintile	13	1.2 - 1.0	2.0	1.5 - 3.1	
	1.5	17 55	7.1	0.5 - 2.5	
Top duittie, least pool	5.1	1.7 - 5.5	5.0	1.5 - 0.0	
Mother's work					
Farming	1				
Do not farm	1.8↑	1.1 – 2.7			
Living area					
Rural	I				
Urban	1.5	0.9 – 2.5			
HIV-diagnosis					
After delivery	I				
Before delivery	1.7*	1.2 – 2.4			
Participation in the PMTCT-program					
Did not attend	I.		I		
Attended	2.0*	1.4 – 2.8	2.0*	1.3 – 3.0	
Anyone talked about breastfeeding					
No	I		1		
Yes	2.2*	1.4 – 3.7	1.9*	1.1 – 3.3	
Mothers self-rated health					
Very healthy	11	0.6 - 1.9			
Ouite healthy		0.8 - 1.7			
Not very healthy	1	0.0 1.7			
	•				

Mothers-rated health of child				
Very healthy	1.3	0.7 – 2.1		
Quite healthy	1.0	0.7 – 1.4		
Not very healthy	I			
Belief about 6 months of exclusive breastfeeding				
Sure it would be good	2.8*	1.5 – 5.0	3.1*	1.6 – 5.8
Think it would be good	1.3	0.7 – 2.2	1.7	1.0 – 3.1
Think it would hurt	1.3	0.9 – 2.1	2.0*	1.2 – 3.2
Sure it would hurt	I		I	

Table 3: Cox regression of breastfeeding cessation, unadjusted and adjusted hazard ratio (HR). Only factors in the final adjusted model have HR estimates (right-hand columns). (Continued)

\*p < 0.05 (group is significantly different from reference group) HR (hazard ratio)

and swelling of the breast also burdened 40 (19%) mothers. Three mothers (1%) were diagnosed with mastitis or breast abscess.

### Discussion

This study shows that exclusive breastfeeding was uncommon among the HIV-positive women who opted to breastfeed. Thus, most infants received complementary feeding including breast milk from a very early age, which is an unfavourable situation. Our findings in Uganda agree with studies in other parts of Africa among both HIV-positive mothers and the general population [18,27]. A positive finding is that breastfeeding duration is shortened by many HIV-positive mothers, especially among the well educated, the socio-economically better-off, and those who have attended the PMTCT program or discussed infant feeding with someone. Well-educated mothers breastfed for ~1 year less than their uneducated peers. Whether the shortened breastfeeding duration had any negative effects on the children was not assessed in our study. A recently published randomised study from Zambia indicates that early abrupt weaning of breastfeed-



### Figure I

**Breastfeeding duration in months (x-axis) for different groups of mothers based on their education**. Proportion still breastfeeding (y-axis) visualised with a Kaplan-Meier-plot. ing does not significantly reduce HIV-free mortality rates [28]. In addition, prolonged breastfeeding gave a higher survival rate for HIV-positive children compared to those weaned early. HIV screening using a dried blood spot from infants was a feasible approach to the early identification of HIV-positive infants who may benefit from prolonged breastfeeding [29].

Exclusive breastfeeding of infants under 6 months old was less commonly practised among HIV-positive mothers than among the general population reported in the DHSstudy in Uganda – 24% of HIV-positive mothers and 63.2% of the general population mothers according to the 24-hour recall data [18]. Similarly, a study of the general population in the same area also reported higher rates of exclusive breastfeeding [30]. Is this an effect of information about the risk of HIV transmission through breastfeeding reaching the HIV-positive mothers? Counselling on infant feeding in many African countries, including Uganda, has been reported to be suboptimal and may be one of the important reasons for the widespread practice of complementary feeding including breast milk [31].



### Figure 2

**Breastfeeding duration in months (x-axis) for different socio-economic groups**. Proportion still breastfeeding (y-axis) visualised with a Kaplan-Meier-plot.

### Table 4: Reasons for stopping breastfeeding

	Main reason	Additional reasons <sup>a</sup>	Total ª
	n (%)	n (%)	n (%)
Health workers advice	32 (28)	22 (19)	54 (47)
Illness (weakness, body pain etc)	29 (25)	23 (20)	52 (45)
HIV-diagnosis	20 (17)	54 (47)	74 (64)
Not enough milk	10 (9)	16 (14)	26 (22)
Breastfeeding difficulties	10 (9)	5 (4)	15 (13)
Custom related (e.g. grown "big enough")	9 (8)	II (9)	20 (17)
Family pressure	2 (2)	0 (0)	2 (2)
New pregnancy	2 (2)	0 (0)	2 (2)
Work situation	I (I)	4 (3)	5 (4)
Other reasons	I (I)	4 (3)	5 (4)
Total	116 (100)		

<sup>a</sup> Reasons other than main reason reported to be important for the choice to stop breastfeeding. 16 (14%) reported main reason only, 66 (57%) reported one additional reason, 28 (24%) reported two additional reasons and 6 (5%) reported three additional reasons.

Health workers often overestimated the risk of HIV transmission through breastfeeding and many gave the impression that HIV transmission from mother-to-child is nearly universal [22,31]. Based on key informant interviews, our impression was that replacement feeding was promoted more strongly in the national PMTCT program, whereas exclusive breastfeeding seemed to be more counselled in the non-governmental organisations working with HIV (unpublished data). Although breastfeeding duration was shorter among participants in the national PMTCT program than those not participating, we did not see differences in the rates of exclusive breastfeeding. Another explanation for the dominance of complementary feeding including breast milk may be the fear of making the infant totally reliant on breast milk, which could be particularly true for HIV-positive mothers [32].

In rural and semi-urban HIV-positive mothers in Eastern Uganda, replacement feeding was uncommon. This agrees with a Tanzanian study where replacement feeding with infant formula or cow's milk was seen as unacceptable or infeasible [11]. Introduction of breastfeeding after initial replacement feeding was common except among the socio-economically better-off. Initiating breastfeeding after abrupt weaning is associated with increased viral loads of breast milk, and consequently could be hazard-ous [10].

Only 56% of the mothers initiated breastfeeding within the first two hours after delivery and 76% initiated it within the first day. A study in Ghana indicated a 2.4-fold increase in risk of neonatal death among infants for whom breastfeeding was not begun within the first day compared to those for whom it was [15]. The authors of that study calculated that 16.3% of neonatal deaths could have been prevented if all neonates had been breastfed within the first hour. Pre-lacteal feeding was given by 64% of the HIV-positive mothers in our study. Not breastfeeding exclusively during the first days has also been shown to increase neonatal mortality [15,33].

Although being HIV-positive was a major reason for stopping breastfeeding by 64% of the mothers, the median breastfeeding duration was 12 months. Breastfeeding duration among HIV-positive mothers was clearly shorter than among the general population, which in the DHSstudy in Uganda was 19.9 months [18]. It may seem counterintuitive that mothers perceiving exclusive breastfeeding to be beneficial were breastfeeding for a shorter time than mothers considering exclusive breastfeeding to be harmful. We interpret this as an indication that counselling had some impact, both in terms of increasing knowledge of infant feeding and of influencing behaviour.

Self-reported breastfeeding problems were similar to those given by mothers in the general population in the same area of Uganda, and were slightly more common than among HIV-positive and general population mothers in South Africa [17,34]. The low rate of exclusive breastfeeding probably contributed to the higher proportion of breastfeeding problems. Mothers with breast health problems have a greatly increased risk of infecting their children with HIV [17,35]. Data from South Africa indicate a greater than threefold risk of transmitting HIV from mother to infant when the mother had a serious breast health problem. Similarly, any breast health problems show an increased hazard ratio for HIV transmission compared to the absence of such problems [17].

The cross-sectional design of the study inherently left out diseased children. A similar cross-sectional study in 2003 provided a comparative group in the general population [30]. A limitation of this study is that Kaplan-Meier and Cox regression analyses were conducted in a population

where half the infants were censored at the last time-point due to ongoing breastfeeding, which may limit the precision of our estimates and could introduce bias. However, we observed similar associations in an analysis restricted to children with at least 18 month follow-up, and with much lower censoring rates. A third of the HIV-positive mothers acquired their HIV-status after delivery, which might influence the Cox regression analysis compared to the situation where all mothers were diagnosed HIV-positive before delivery. A restricted analysis excluding the mothers acquiring their HIV-diagnosis after delivery gave similar results in the Cox regression compared to when all mothers were included (not published). The use of antiretroviral medicines was not recorded, but was not common even if roll-out started approximately at the time as the study in Mbale. The recall setting in this study was not optimal, and there may also have been socially desirable answers. It has been suggested that dietary recall once a week has high sensitivity and specificity for exclusive breastfeeding and other feeding patterns to a given age [36]. In our study, recall periods of 24 hours and 1 week yielded similar results. Some studies have indicated that breastfeeding duration is overestimated to an escalating degree with increasing age [37,38], while others have stated that breastfeeding duration is accurately reported [39]. The fact that there was full agreement about breastfeeding duration between the initial and re-interviews reduces the likelihood that this measurement was significantly biased. The fact that all mothers were recruited through TASO may have caused a socio-economically skewed selection. We still feel confident that the data are representative of a large proportion of HIV-positive women in the region in Uganda.

There was a wide difference between the infant feeding practices in this group and WHO recommendations. Infant feeding recommendations for HIV-positive mothers have been confusing [11], which might explain the shortcomings of the practices. More beneficial practices among the well educated is a reason to increase the level of education, while also putting more efforts into counselling of less well-educated mothers.

### Conclusion

Well-educated mothers breastfed for a substantially shorter time than their less well-educated peers. Mothers who were socio-economically better-off or had participated in the PMTCT program also breastfed for shorter durations.

Except among a limited group in this population, replacement feeding was not considered a realistic option in this rural setting. Complementary feeding including breast milk was the dominant practice for infants under 6 months old among the HIV-positive mothers.

There still seems to be many obstacles to optimal infant feeding. Further efforts are needed to optimise counselling on infant feeding and increase the implementation of the recommendations.

# Abbreviations

CI: confidence interval; DHS: Demographic and Health Surveys; HIV: human immunodeficiency virus; IQR: interquartile range; PMTCT: Prevention of Mother-to-Child Transmission; SPSS: Statistical Package for the Social Sciences; TASO: The Aids Support Organisation; WHO: World Health Organisation.

## **Competing interests**

The authors declare that they have no competing interests.

## **Authors' contributions**

LTF: design, implementation, analysis and writing. IMSE: design, analysis and co-writing. HW: analysis and co-writing. JW: implementation of the study and co-writing. JKT: initiation of the study and co-writing. TT: initiation of the study, design, implementation, analysis and co-writing.

# Additional material

### Additional file 1

Infant age histogram; age in months. Age distribution of infants at the time of the interview represented with histogram. Click here for file [http://www.biomedcentral.com/content/supplementary/1471-2431-9-2-S1.pdf]

### Additional file 2

Reported breastfeeding problems among 215 breastfeeding mothers. Frequency of breastfeeding problems among 215 breastfeeding mothers. Click here for file [http://www.biomedcentral.com/content/supplementary/1471-2431-9-2-S2.pdf]

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# Article 2

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# Research article

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# Infant feeding among HIV-positive mothers and the general population mothers: comparison of two cross-sectional surveys in Eastern Uganda

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### Abstract

**Background:** Infant feeding recommendations for HIV-positive mothers differ from recommendations to mothers of unknown HIV-status. The aim of this study was to compare feeding practices, including breastfeeding, between infants and young children of HIV-positive mothers and infants of mothers in the general population of Uganda.

**Methods:** This study compares two cross-sectional surveys conducted in the end of 2003 and the beginning of 2005 in Eastern Uganda using analogous questionnaires. The first survey consisted of 727 randomly selected general-population mother-infant pairs with unknown HIV status. The second included 235 HIV-positive mothers affiliated to The Aids Support Organisation, TASO. In this article we compare early feeding practices, breastfeeding duration, feeding patterns with dietary information and socio-economic differences in the two groups of mothers.

**Results:** Pre-lacteal feeding was given to 150 (64%) infants of the HIV-positive mothers and 414 (57%) infants of general-population mothers. Exclusive breastfeeding of infants under the age of 6 months was more common in the general population than among the HIV-positive mothers (186 [45%] vs. 9 [24%] respectively according to 24-hour recall). Mixed feeding was the most common practice in both groups of mothers. Solid foods were introduced to more than half of the infants under 6 months old among the HIV-positive mothers and a quarter of the infants in the general population. Among the HIV-positive mothers with infants below 12 months of age, 24 of 90 (27%) had stopped breastfeeding, in contrast to 9 of 727 (1%) in the general population. The HIV-positive mothers were poorer and had less education than the general-population mothers.

**Conclusion:** In many respects, HIV-positive mothers fed their infants less favourably than mothers in the general population, with potentially detrimental effects on both the child's nutrition and the risk of HIV transmission. Mixed feeding and pre-lacteal feeding were widespread. Breastfeeding duration was shorter among HIV-positive mothers. Higher educational level and being socio-economically better off were associated with more beneficial infant feeding practices.

# Background

For mothers in Sub-Saharan Africa, an appropriate choice of infant feeding is fundamental to optimising infant survival and minimising infant morbidity. Promotion of exclusive breastfeeding has the potential to prevent 8% of child mortality, or save 37 million disability-adjusted life years every year [1,2]. It is well documented that exclusive breastfeeding can benefit infants of HIV-negative mothers [1,3-5]. How to optimise survival and avoid morbidity among the infants and children of HIV-positive mothers is an ongoing discussion [6-10]. Replacement feeding can reduce HIV-transmission, but is also associated with morbidity related to diarrhoea and respiratory infections [11,12]. For mothers without access to piped water and cooking fuel, or who have not disclosed their HIV-status, replacement feeding does not seem to increase HIV-free survival [13].

Practical implementation of the previous infant feeding recommendations for HIV-positive mothers from the World Health Organisation (WHO) has often created confusing messages resulting in disadvantageous feeding patterns, mixed feeding in particular [14-16]. Compared to exclusive breastfeeding, mixed feeding is associated with increased morbidity and mortality for infants of both HIV-positive and HIV-negative mothers, and with increased HIV transmission for HIV-positive mothers [2-5,8,9,17]. A concern is that promotion of replacement feeding to infants of HIV-positive mothers has created a spill-over effect among the infants of HIV-negative mothers, resulting in increased usage of maternal milk replacements including formula milk [16,18].

The aim of this study was to compare feeding practices, including breastfeeding, between infants and children under the age of two years born to HIV-positive mothers and infants born to general-population mothers in East-ern Uganda.

# Methods

### Study settings

This study compares two cross-sectional surveys conducted in the end of 2003 and the beginning of 2005 in



### Figure I Study enrolment overview.

the same area in Eastern Uganda using analogous questionnaires (Figure 1).

Mbale district has a population of 720,000, predominantly Bagisu people, with 90% living in rural areas and being subsistence farmers. The overall literacy rate is 64% for men and 49% for women [19]. Uganda has an estimated national HIV-prevalence of 7.5% in women aged 15 – 49 years (2005) [20].

The first survey was a community-based study conducted in 2003 and included 793 randomly-selected caretakerinfant pairs from urban and rural areas in Mbale district [21]. The infants were 0 - 11 months old. Owing to nonresponses (n = 30) and incomplete data (n = 36), 727 mother-infant pairs remained in the analysis. The recruitment and selection procedures have been reported previously [21]. We did not collect information about the mothers' HIV status. These participants are referred to as "general-population mothers."

The second survey was conducted in 2005 and included 240 mother-child pairs. This study was performed in collaboration with The Aids Support Organisation (TASO) [22]. TASO is a non-governmental organisation working for HIV-positive people in Uganda. It provides counselling, information, support and medical treatment for HIVpositive people. The mothers were approached through TASO-Mbale, including their outreach clinics in Mbale district and adjacent areas. The children were 0 - 23 months old. Comparisons of infants were made with corresponding age-groups in the general population. Consecutive sampling was used to recruit these participants. All the mothers approached agreed to participate in the study. Five mother-infant pairs were excluded from analysis owing to missing information or to the child being at least 24 months old. All women recruited through TASO were known to have HIV-positive status and are described as HIV-positive mothers in this study.

Data from both surveys were merged yielding a total of 962 mothers-infants pairs for analysis. There were no case overlaps between the two cross-sectional studies.

To increase reliability, a total of 20 mothers were re-interviewed by different data collectors some days or weeks after the initial interview. The agreement between the initial interviews and the reliability interviews was generally high.

### Data management

The structured interviews in both surveys were based on analogous questionnaires. It contained topics concerning infant feeding practices including breastfeeding, feeding knowledge, mother's and father's education, occupation and household assets. We examined a list of thirty liquid, semi-solid and solid foods using 24-hour dietary recall. The questionnaire for the HIV-positive mothers also contained questions regarding time of HIV diagnosis and participation in the PMTCT-program. Time of HIV-diagnosis was used to categorize mothers who got their HIV-diagnosis before birth and mothers who got their diagnosis after birth. We pre-tested the questionnaires and worked with data collectors who were fluent in the local language, Lumasaba, and English to conduct the interviews. Data were entered in EpiData 3.1 and SPSS 14 was used for data analysis.

### Definitions

Feeding information was based on WHO definitions and recommendations [23], as follows. Exclusive breastfeeding: giving breast milk only, except for medicines and vitamin or mineral supplements; predominant breastfeeding: breast milk is nutritionally dominant, but with the possible addition of water-based fluids, fruit juices, tea without milk or oral rehydration salts; mixed feeding: non-human milk, semi-solids or other solids given in addition to breast milk; replacement feeding: breastfeeding stopped or never being given any breast milk. Exclusive replacement feeding was defined as never having given any breast milk. Prelacteal feeding was defined as any food item or liquid other than breast milk given to the infant during the first 3 days after delivery.

### Statistics

Baseline characteristics were examined utilising frequency tables and cross-tabulations with Pearson  $\chi^2$ . One-way analysis of variance (ANOVA) was used to calculate factors influencing the nutritional items given to the children and a linear regression model was used to investigate associations between education, socio-economic status and HIV-status, controlling for living area. Breastfeeding duration was analysed by Kaplan-Meier survival statistics.

All the mothers in the merged data were grouped socioeconomically into quintiles on the basis of wealth assessment, using principal component factor analysis [24]. Housing characteristics and assets including toilet facilities, number of rooms and beds, roof material, lantern, radio, television, bicycle and motor vehicles were included in the model. Quintiles were inferred from the first principal component. This method is recognised as a good proxy for household wealth [25]. The Mann-Whitney-Wilcoxon test for independent samples was used to compare socio-economic ranks.

The results will be presented in the following order: First, we will present data from all mother-infant-pairs with prelacteal feeding and breastfeeding duration as the main topics. Second, we will include only mothers with infants under one year old, focusing on feeding patterns based on 24-hour recall. Third, we will examine breastfeeding initiation time, comparing general-population with HIV-positive mothers, the latter being stratified into those who were diagnosed pre-natally and those who were diagnosed post-natally. Lastly, we will present the differences in socio-economic status.

### Ethics

Ethical approvals were granted from Makerere University, Faculty of Medicine Ethics and Research Committee, the Uganda National Council for Science and Technology and the Regional Committee for Medical Research Ethics, Western Norway. Informed consent was obtained from each mother prior to study participation.

## Results

The HIV-positive mothers were older than the generalpopulation mothers, median age 30 years (inter-quartile range 28 - 35) versus 24 years (IQR 20 - 30) (Table 1). The general-population mothers were more educated than the HIV-positive mothers. There was no difference in the education levels of the fathers of the infants in the two groups. Farming was the dominant occupation among both groups of mothers, but the general-population crosssectional survey included more urban mothers than the TASO-affiliated survey among HIV-positive mothers. Marital status was dissimilar in the two groups. Most of the general-population mothers reported being married or cohabiting, with 19 (3%) being widowed, separated or divorced. In contrast, only 90 (39%) of the HIV-positive mothers were married, half were widowed and some were separated or divorced. HIV-positive mothers had more children and lived under more crowded conditions than their counterparts in the general population. Socio-economically, the HIV-positive mothers were more often among the poorest and less often among the least poor.

### Early feeding practices

More than half the mothers gave something in addition to breast milk during the first three days (Figure 2). Pre-lacteal feeding was more often non-water-based, including non-human milk, among the HIV-positive mothers than among the general-population mothers. Breastfeeding was initiated within the first few hours by approximately half the mothers and within the first day by three-quarters in both groups (Figure 3). Pre-lacteals were less commonly given by more educated mothers (Table 2). HIVpositive mothers with many children gave pre-lacteal feeding more often than mothers with few children. Mother's age, marital status and owning house or land were not significantly associated with the initial feeding patterns in either group. Among the general-population mothers, feeding breast milk only during the first three days was associated with the father having higher education and the mother not being farmer, whilst these variables were not significantly associated with initial exclusive breastfeeding among the HIV-positive mothers. The better-off among the general-population mothers were exclusively breastfeeding more often than the poorer mothers during the first three days, while the HIV-positive mothers who were better-off opted for exclusive replacement feeding more often than their poorer peers. Education of the mothers was also associated with a higher rate of exclusive replacement feeding among the HIV-positive mothers and a higher proportion of initial exclusive breastfeeding among the general-population mothers.

### **Breastfeeding duration**

The median breastfeeding duration among the HIV-positive mothers was 12 months (95% confidence interval 11.5 to 12.5) (Figure 4). In the group of general-population mothers with infants under one year old, only 9 out of 727 (1%) mothers had stopped breastfeeding. In contrast, 24 out of 90 (27%) HIV-positive mothers with infants under 12 months old had stopped breastfeeding. Breastfeeding duration was significantly shorter among the HIV-positive mothers than among the general-population mothers (Mantel-Cox log rank test p < 0.001). There was a shorter breastfeeding duration among HIVpositive mothers who were diagnosed before birth, with a median of 12 months (95% C.I. 10.4 – 13.6), in contrast to 15 months (95% C.I. 10.5 – 19.5) among those diagnosed post-partum (Log Rank test: p < 0.05).

### Breastfeeding patterns and dietary information

Exclusive replacement feeding was reported by 20 (8.5%) HIV-positive mothers and one (0.1%) mother from the general population. Among the 20 HIV-positive mothers practising exclusive replacement feeding, all except one were diagnosed HIV-positive prior to birth. Based on the 24-hour dietary recall, half the general-population mothers exclusively breastfed their infants under 6 months old, in contrast to a quarter of the HIV-positive mothers (Figure 5). Approximately half the mothers in both groups gave their infants mixed feeding. Half the infants below 6 months of age born to HIV-positive mothers received water, non-human milk and staple food including bananas, maize and beans (Table 3). Fewer mothers from the general population gave these food items to their infants under 6 months old. HIV-positive mothers gave more food items to their infants than the mothers in the general population.

Infants over 6 months old were mostly mixed fed with a third of the HIV-positive mothers practising replacement feeding. Some of the general-population mothers with infants over 6 months old still gave only breast milk and clear liquids. Staple foods were universally given by the HIV-positive mothers and by most of the mothers in the

Table I: Baseline characteristics for HIV-positive mothers and mothers from the general population

	<u>HIV-positive</u> n = 235 (%)	<u>General-population mothers</u> n = 727 (%)	$\frac{\text{Chi-square}}{\not p (\chi^2)}$
Gender of infant			
Girl	109 (46)	346 (48)	
Воу	126 (54)	381 (52)	
Age of infant			
< 6 months	37 (16)	415 (57)	
6 – 11 months	53 (23)	312 (43)	
12 – 17 months	64 (27)	()	
18 – 23 months	81 (34)		
Mother's education			
None	27 (11)	59 (8)	< 0.01
Stopped in primary	125 (53)	301 (41)	0.01
Completed primary (7 years)	39 (17)	139 (19)	
Secondary education	37 (16)	183 (25)	
Higher education (12 years and above)	7 (3)	45 (6)	
Forth a broad and			
Pather's education	14 (0)	40 (7)	
None Stars ad in animany	14 (6)	40 (6)	
Stopped in primary	72 (32) (2 (37)	161 (26)	
Completed primary (7 years)	62 (27) 50 (22)	154 (25)	
Secondary education	50 (22)	177 (29)	
Higher education (12 years and above)	30 (13)	83 (14)	
Mother is farming		()	
Yes	201 (86)	507 (70)	< 0.001
No	34 (14)	218 (30)	
Marital status			
Married or cohabiting	91 (39)	667 (92)	< 0.001
Widowed	112 (48)	6 (I)	
Separated or divorced	28 (12)	13 (2)	
Single	4 (2)	41 (6)	
Owning land and/or house			< 0.01
Yes	162 (69)	561 (78)	
No	73 (31)	154 (22)	
Pural	205 (87)	401 (55)	< 0.001
Urban	30 (13)	326 (45)	\$ 0.001
Orban	30 (13)	320 (43)	
Socio-economic wealth index	(5 (20)		
Poorest quintile	65 (28)	122 (17)	< 0.001
	49 (21)	141 (20)	
3 <sup>rd</sup> quintile	52 (22)	143 (20)	
4 <sup>m</sup> quintile	38 (16)	148 (21)	
Least poor quintile	30 (13)	159 (22)	
Mother's age			< 0.001
≤ <b> 9</b>	2(1)	129 (18)	
20 – 24	20 (9)	247 (34)	
25 – 29	61 (26)	146 (20)	
30 – 34	85 (36)	134 (19)	
≥ 35	67 (29)	64 (9)	
Number of siblings			< 0.001
None	12 (5)	175 (24)	
I	41 (17)	148 (20)	
2–3	82 (35)	196 (27)	

	-		
≥ 4	100 (43)	205 (28)	
Crowdedness, no. of people per room			< 0.001
0 – 2	43 (18)	155 (21)	
2 – 4	68 (29)	343 (47)	
4 – 6	67 (29)	142 (20)	
≥ 6	57 (24)	86 (12)	

Table I: Baseline characteristics for HIV-positive mothers and mothers from the general population (Continued)

general population. Protein-containing items such as meat, fish and eggs were given to almost half the infants over 6 months old of HIV-positive mothers, but to less than a fifth of the infants of general-population mothers.

Among infants less than 1 year of age, 3 (3%) belonging to HIV-positive mothers and 12 (2%) to general-population mothers had been given local brew or other alcohol containing liquids since birth. The alcohol content of the local brew is usually considerably lower than in e.g. beer. In children of HIV-positive mothers aged 12 – 23 months, 28 (19%) had ever received alcoholic liquids as local brew.

### Socio-economic differences

The HIV-positive mothers were poorer than the mothers from the general population. When the first factor from the principal component analysis of socio-economic status was ranked, HIV-positive had a mean rank of 399 in contrast to 498 in the general population (lowest rank indicating the poorest, Mann-Whitney-Wilcoxon Z = -4.8, p < 0.001). Using a linear regression model, both living area and HIV status were independently associated with socio-economic wealth ( $R^2 = 0.08$ , p < 0.05 for the model and each of the factors). Similarly, mother's education was associated with both living area and HIV-positive status, though the effect was small ( $R^2 = 0.05$ , p < 0.05 for the model and each factor independently). There were some regional differences in socio-economic status. Among the study participants from the areas in Kumi, 31 out of 46 (67%) belonged to the poorest quintile.

The mean number of food items given to infants aged 6 – 11 months based on 24-hour recall ranged from 3.9 (95% C.I. 3.3 - 4.5) among the poorest socio-economic quintile to 5.8 (95% C.I. 5.0 - 6.6) in the least poor group (F(4, 349) = 4.5, p < 0.001; the poorest group received significantly fewer food items than the two least poor groups). The difference was less pronounced for infants above 12 months and for those under 6 months old.

### Discussion

In contrasting these surveys of infant feeding practices among HIV-positive mothers on the one hand and the general-population mothers on the other, a number of issues arise. The first and most worrying is the fact that in several aspects of infant feeding the HIV-positive mothers seem to choose the least good option more frequently than the general population. Among the infants below 6 months of age, HIV-positive mothers chose mixed breastfeeding more often than the general population, and they were less likely to breastfeed their infants exclusively. We know from earlier studies that mixed breastfeeding is the least safe infant feeding practice for children born to HIVpositive mothers [2-5,8,9,17]. In addition, half the HIVpositive mothers had introduced staple food to their infants below the age of six months compared to a quarter of the population-based mothers. Early introduction of solid foods combined with breastfeeding has been shown to increase the risk of vertical HIV transmission four-fold [10].

Second, pre-lacteal feeding was practised by most mothers in both groups. Our prevalence is higher than was reported from Western Uganda, where 43% gave pre-lacteal feeds to their infants [26]. Pre-lacteal feeding has been associated with increased risk for neonatal deaths [27]. Among the HIV-positive mothers, pre-lacteal feeding more often included non-human milk. Maybe more of these mothers initially considered exclusive replacement feeding? Exclusive replacement feeding was ultimately chosen by some HIV-positive mothers who were diagnosed prior to birth, but hardly at all among other mothers.

On the other hand, infants over 6 months old born to HIV-positive mothers received a varied diet more often than their peers from the general population. HIV-positive mothers might have made extra efforts to give their infants good and varied diets in spite of a challenging socio-economic situation. Our impression was that nutrition was emphasised during the counselling sessions for HIV-positive mothers. The least poor mothers also gave more food items to their infants than the poorest. This may suggest that wealth influenced infant feeding. In terms of avoiding mixed feeding, mothers who were more educated or socio-economically better-off fed their infants more beneficially than their less educated and poorer peers. Similar findings associating infant feeding with education and wealth have also been described in studies from both Eastern- and Western Uganda [26,28,29]. Half the HIV-positive mothers were widowed, which may in

				Comonal o constant	
	Pre-lacteals given	Breast milk only first 3	Exclusive replacement	Pre-lacteals given	$\frac{50 \text{ mouters}}{8 \text{ reast milk only first 3}}$
	Tre-lacteals given	days	feeding	The lacteans given	days
Gender of infant					
Girl	68 (62)	31 (28)	10 (9)	200 (58)	146 (42)
Воу	82 (65)	34 (27)	10 (8)	214 (66)	166 (44)
Mother's education		*			*
None	14 (52)	3 (48)	0 (0)	36 (61)	23 (39)
Stopped in primary	87 (70)	31 (25)	7 (6)	187 (62)	114 (38)
Completed primary	25 (64)	8 (21)	6 (15)	84 (60)	54 (39)
(7 years)	20 (0.)	• (=-)	• ()		
Secondary education	21 (57)	10 (27)	6 (16)	86 (47)	97 (53)
Higher education	3 (43)	3 (43)	l (14)	21 (47)	24 (53)
(12 years and above)	0 (10)	0 (10)	. ()	21 (17)	21(00)
Father's education					**
None	8 (57)	6 (43)	0 (0)	27 (68)	13 (32)
Stopped in primary	44 (61)	25 (35)	3 (4)	2 (70)	48 (30)
Completed primary	43 (69)	13 (21)	6 (10)	94 (61)	60 (39)
(7 years)		13 (21)	0 (10)		
Secondary education	31 (62)	14 (28)	5 (10)	89 (50)	88 (50)
Higher education	19 (63)	7 (23)	4 (13)	33 (40)	50 (60)
(12 years and above)	(00)	(10)	(10)	55 (10)	
Mother is farming					**
Yes	131 (65)	56 (28)	14 (7)	308 (61)	199 (39)
No	19 (56)	9 (26)	6 (18)	105 (48)	112 (51)
Marital status					
Married or cohabiting	61 (67)	23 (25)	7 (8)	379 (57)	287 (43)
Widowed	71 (63)	32 (29)	9 (8)	4 (67)	2 (33)
Separated or divorced	16 (57)	9 (32)	3 (11)	10 (77)	3 (23)
Single	2 (50)	I (25)	I (25)	21 (51)	20 (49)
Owning land and/or					
house					
Yes	100 (62)	51 (31)	(7)	331 (59)	229 (41)
No	50 (69)	14 (19)	9 (12)	77 (50)	77 (50)
Rural	132 (6 <del>4</del> )	57 (28)	16 (8)	239 (60)	162 (40)
Urban	18 (60)	8 (27)	4 (13)	175 (54)	150 (46)
Socio-economic wealth		*			**
index	(16)	/	<b>_</b> / <b>_</b> \		
Bottom quintile	39 (60)	23 (35)	3 (5)	74 (61)	48 (39)
2 <sup>nd</sup> quintile	39 (80)	8 (16)	2 (4)	92 (65)	49 (35)
3 <sup>rd</sup> quintile	33 (63)	16 (31)	3 (6)	80 (56)	63 (44)
4 <sup>th</sup> quintile	22 (58)	10 (26)	6 (16)	84 (57)	64 (43)
Top quintile	17 (57)	7 (23)	6 (20)	76 (48)	82 (52)
Mother's age					
≤ <b>I9</b>	2 (100)	0 (0)	0 (0)	76 (59)	53 (41)
20 – 24	13 (65)	6 (30)	I (5)	136 (55)	(45)
25 – 29	38 (62)	16 (26)	7 (11)	87 (60)	59 (40)
30 – 34	54 (64)	24 (28)	7 (8)	74 (55)	60 (45)
≥ 35	43 (64)	19 (28)	5 (7)	35 (55)	28 (44)
Number of children		**			
One	6 (50)	6 (50)	0 (0)	98 (56)	77 (44)
2	24 (59)	7 (17)	10 (24)	79 (53)	69 (47)
3-4	53 (65)	22 (27)	7 (9)	117 (60)	78 (40)

### Table 2: Feeding patterns during the first 3 days among HIV-positive mothers compared to mothers from the general population

≥ 5	67 (67)	30 (30)	3 (3)	117 (57)	88 (43)
Crowdedness, no. of people per room		*			
0-2	26 (60)	8 (19)	9 (21)	87 (56)	68 (44)
2 – 4	45 (66)	18 (27)	5 (7)	194 (57)	148 (43)
4 – 6	45 (67)	18 (27)	4 (6)	83 (58)	59 (42)
≥ 6	34 (60)	21 (37)	2 (4)	50 (58)	36 (42)
HIV-diagnosis related to infant birth		**			
HIV-diagnosis before birth	93 (62)	38 (25)	19 (13)		
HIV-diagnosis after birth	57 (67)	27 (32)	I (I)		

Table 2: Feeding patterns during the first 3 days among HIV-positive mothers compared to mothers from the general population

Exclusive replacement feeding column is removed from the general population because it was chosen by only one mother from this group \* Significance level of p < 0.05, \*\* Significance level of p < 0.01



### Figure 2

Initial feeding practices during the first 3 days comparing HIV-positive mothers diagnosed before and after birth and mothers from the general population. <sup>1</sup> Exclusive replacement feeding significantly different between HIV-positive diagnosed before birth and general-population mothers (p < 0.001). <sup>2</sup> Non-water based pre-lacteals were given significantly more often to children of HIV-positive mothers than general-population mothers.



### Figure 3

**Breastfeeding initiation time comparing HIV-positive mothers diagnosed before and after birth and mothers from the general population**. <sup>1</sup> Exclusive replacement feeding significantly different between HIV-positive mothers acquiring HIV prior to birth and general-population mothers (p < 0.001).

part explain why education of the fathers of these infants was less associated with feeding practices than was the case in the general population.

Some of the infants over 6 months old in the general population received nothing except breast milk and clear fluids, which WHO considers to be inadequate complementary feeding [30]. This was not seen among the infants of HIV-positive mothers. Inadequate complementary feeding at the age of 6 months has been shown to be a predictor for impaired growth and stunting up to at least the age of 18 months [31].

Breastfeeding duration was clearly shorter among the HIV-positive mothers, with a median duration of 12 months. The survey of the general-population mothers was not designed to evaluate breastfeeding duration, but according to the demographic health survey in Uganda the median breastfeeding duration was 19.9 months [32]. Mothers who were diagnosed HIV-positive prior to deliv-





ery breastfed their infants for a shorter time than those who were diagnosed later. We cannot measure whether this reduction in breastfeeding duration was beneficial; some reports have suggested that promoting early weaning does not reduce HIV-free survival [7].

The time of initiation of breastfeeding was similar for HIV-positive and general-population mothers except for the proportion opting to exclusively replacement-feed. In both groups, breastfeeding was commonly introduced with a delay of more than a few hours after birth. Delayed breastfeeding initiation has been reported to increase the risk of neonatal death [17]. Encouraging earlier breastfeeding initiation could thus increase survival in this setting.

There might be many reasons for these observed differences. First, the risk of transmission through breast milk might have been stressed to many HIV-positive mothers during counselling, so they might have wanted to reduce the extent of breastfeeding. Some mothers might have wanted to practise exclusive replacement feeding, but failed to do so because of social pressure, economic reasons or lack of access to formula which has been described in many different settings, including South Africa [15]. Further, these women might have been less empowered and used primary health care facilities less than women in the general population, thereby losing some of the preventive health messages provided at antenatal care units, including promotion of exclusive breastfeeding. Differences in intervention-coverage between different socioeconomic groups have been reported in other studies [33], but we found no significant association between socio-economic status and attending the PMTCT program.

We know from interviewing the health staff, including counsellors in TASO, that most of the HIV-positive mothers received the available up-to-date counselling and information in the area of infant feeding [unpublished data]. Nevertheless, it seems that HIV-positive mothers gravitate towards the worst feeding options in some of the

Food items (age categorised)	<u>HIV-positive</u> n = 235 (%)	<u>General-population mothers</u> n = 727 (%)	$\frac{\text{Chi-square}}{p(\chi^2)}$
	,		1 00 7
0 – 5 months		0.4 (22)	
VVater	20 (54)	94 (23)	< 0.001
Herbal water or gripe water	5 (17)	24 (6)	
Fruit juice, tea with sugar etc	10 (27)	68 (16)	
Non-human milks	20 (54)	146 (35)	< 0.05
Staple food (maize, beans etc)	18 (49)	60 (14)	< 0.001
Meat, egg or fish	2 (5)	8 (2)	
Number of items given last 24 hours			< 0.001
None	9 (24)	187 (45)	
I – 2	II (30)	152 (37)	
3 – 5	8 (22)	63 (15)	
6 – 9	5 (14)	(3)	
10 or more	4 (11)	I (0.2)	
6 – 11 months			
Water	43 (84)	220 (71)	< 0.05
Herbal water or gripe water	2 (4)	16 (5)	
Fruit juice, tea with sugar etc	26 (51)	142 (46)	
Non-human milks	33 (65)	171 (55)	
Staple food (maize, beans etc)	50 (98)	252 (81)	0.001
Meat, egg or fish	20 (39)	55 (18)	0.001
Number of items given last 24 hours			0.001
None	0 (0)	(4)	
I – 2	2 (4)	75 (24)	
3 – 5	19 (37)	121 (39)	
6 - 9	24 (47)	80 (26)	
10 or more	6 (12)	25 (8)	

Table 3: Nutritional items given to infants of HIV-positive mothers and mothers in the general population using 24-hour recall (age categorised)

aforementioned respects. We cannot assess how infant feeding counselling affected infant feeding practices, but the message that HIV can be transmitted through breast milk might have produced unwanted consequences. Our view is that replacement feeding should be promoted with great caution, if at all in settings where the WHO's criteria for exclusive replacement feeding is missing: acceptability, feasibility, affordability, sustainability and safety [30,34]. Exclusive breastfeeding needs to be promoted for all infants below the age of 6 months and efforts should be made to reach the least educated and poorest groups. HIVpositive mothers needs information about the importance of avoiding mixed feeding [34]. Earlier identification of HIV with diagnosis prior to birth will also make it possible to take better preventive measures [35].

A comparison of two cross-sectional studies utilising analogous questionnaires in the same study setting at two nearby points in time raises certain methodological challenges. Within the time period of one year there might have been minor changes in behaviour. As there were no major changes in the feeding recommendations from WHO or national guidelines introduced in this period, we believe that the time interval did not affect the observed differences noteworthy. Our cross-sectional design also left out deceased children. From an epidemiological point of view, a case-control design could have been chosen. Pooling of data is nevertheless a cost-reducing, widelyused method, and reliable when used with caution [36]. The questionnaires were not identical, though very similar. It is well documented that 24 hour recall overestimates the prevalence of exclusive breastfeeding [37]. Bland et al. suggested the use of recurrent one-week frequency recalls for better estimation [37]. In the group of HIV-positive mothers, recall periods of one week and 24 hours were compared and gave similar results [29]. Our study may also have been influenced by socially desirable responses. Mothers who were recommended to practise certain feeding options may wish to report those practices. We did not measure this potential bias, but utilising data collectors who were not currently client counsellors probably reduced the threat. The fact that a higher proportion of urban mothers were recruited into the general-population survey may have created a somewhat unbalanced



# Figure 5

Age-specific infant feeding patterns for infants of HIV-positive mothers and general-population mothers according to 24-hour recall. <sup>1</sup> Infants aged 0–5 months: general-population mothers practised exclusive breastfeeding more frequently than HIV-positive mothers (p < 0.05), while the opposite was seen with replacement feeding (p < 0.001). Among infants aged 6–11 months the difference in frequency was different (p < 0.001).

comparison. In fact, urban mothers were more educated than those living in rural areas. Using linear regression to control for living area showed that HIV-positive status was still associated with lower education. Mothers' socio-economic status was similarly associated with HIV status. The general-population mothers were likely to include some HIV-positive cases. Consequently, differences in infant feeding practices between HIV-positive and HIV-negative mothers are likely to be slightly greater than we have reported between the HIV-positive mothers and the general population. These limitations taken into account, we believe the results presented are trustworthy.

# Conclusion

In many respects, HIV-positive mothers fed their infants less favourably than mothers in the general population, with potentially detrimental effects both on the child's nutrition and on the risk of HIV transmission. Mixed feeding and pre-lacteal feeding were widespread in both groups of mothers. The HIV-positive mothers seem to have adapted the duration of breastfeeding to their status, with a shorter duration than the general population.

Infant feeding practices were associated with both mothers' education and socio-economic wealth. Higher educational level and being socio-economically better-off were associated with more beneficial feeding practices.

# Abbreviations

ANOVA: analysis of variance; C.I.: confidence interval; DHS: Demographical health survey; HIV: human immunodeficiency virus; IQR: inter-quartile range; PMTCT: Prevention of Mother-to-Child Transmission; SPSS: Statistical Package for the Social Sciences; TASO: The Aids Support Organisation; WHO: World Health Organisation.

# **Competing interests**

The authors declare that they have no competing interests.

### **Authors' contributions**

LTF design, implementation, analysis and writing. IMSE design, implementation, analysis and writing. HW analysis and co-writing. NS implementation of the study and co-writing. TT initiation of the study, design, analysis and co-writing. JKT initiation of the study and co-writing. All authors read and approved the final manuscript.

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Lars T Fadnes

## **RESEARCH ARTICLE**



**Open Access** 

# Infant feeding counselling in Uganda in a changing environment with focus on the general population and HIV-positive mothers - a mixed method approach

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#### Abstract

**Background:** Health workers' counselling practices are essential to improve infant feeding practices. This paper will assess how infant feeding counselling was done and experienced by counsellors and mothers in Eastern Uganda in the context of previous guidelines. This has implications for implementation of the new infant feeding guidelines from 2009.

**Methods:** This paper combines qualitative and quantitative data from Mbale District in Eastern Uganda. Data was collected from 2003 to 2005 in a mixed methods approach. This includes: key-informant interviews among eighteen health workers in the public hospital, health clinics and non-governmental organisations working with people living with HIV, fifteen focus group discussions in the general population and among clients from an HIV clinic, two cross-sectional surveys including 727 mothers from the general population and 235 HIV-positive mothers.

**Results:** The counselling sessions were often improvised. Health workers frequently had pragmatic approaches to infant feeding as many clients struggled with poverty, stigma and non-disclosure of HIV. The feasibility of the infant feeding recommendations was perceived as challenging among health workers, both for HIV-positive mothers and in the general population. Group counselling with large groups was common in the public health service. Some extra infant feeding teaching capacities were mobilised for care-takers of undernourished children. A tendency to simplify messages giving one-sided information was seen. Different health workers presented contradicting simplified perspectives in some cases. Outdated training was a common concern with many health workers not being given courses or seminars on infant feeding since professional graduation. Other problems were minimal staffing, lack of resources, and programs being started and subsequently stopped abruptly. Many of the HIV-counsellors in the non-governmental organisations got extended training in counselling which seemed to be beneficial.

**Conclusions:** Health workers were faced with challenges related to workload, resources, scientific updating, and also a need to adjust to frequent changes in programs, recommendations and guidelines. The clients were faced with difficult choices, poverty, lack of education and stigma. Feasibility of the recommendations was a major concern. Systematic approaches to update health workers should be a priority.

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#### Background

Effective and feasible interventions that reduce child mortality include promotion of immediate and exclusive breastfeeding for six months, improved complementary feeding, and micronutrient supplementation with zinc and vitamin A [1-7]. Breastfeeding has been raised on the agenda of World Health Organisation (WHO) and UNI-CEF during the last two decades with initiatives as the Baby-Friendly Hospital/Health Initiative (BFHI) launched in 1991, and the Integrated Management of Childhood Illness (IMCI) launched in 1995 [8,9]. Many sub-Saharan countries adapted these programmes, and Uganda was one of the pilot countries for the IMCI-initiative [10]. Even though the BFHI and IMCI-initiatives strived towards promoting, protecting and supporting exclusive breastfeeding, numerous reports have shown widespread and prolonged breastfeeding, but limited practice of exclusive breastfeeding [11,12].

Transmission of HIV from mother-to-child through breastfeeding was identified in 1985 [13]. Since then, several reports have demonstrated confusion regarding infant feeding counselling among health workers in areas with a heavy burden of HIV [14,15]. This may have caused a spill-over effect hampering breastfeeding practices when recommendations aimed at HIV-positive mothers were adopted into the general population [16,17]. To reduce HIV-transmission, a prevention of mother-to-child transmission (PMTCT) programme was implemented in Uganda in 2000 [18]. The recommendations on infant feeding in the context of HIV changed several times with the growing knowledge, which was challenging to the counselling of infant feeding [19].

A number of studies have described improved HIV-free survival with exclusive breastfeeding compared to replacement feeding among infants of HIV-positive mothers [20-22]. For children infected with HIV, prolonged breastfeeding is associated with a better prognosis than a shorter duration of breastfeeding [23]. Still, an HIV-transmission risk exists with exclusive breastfeeding [20,21]. Recent studies have shown a reduction in HIV transmission by combining exclusive breastfeeding with antiretroviral prophylaxis [24-27]. This has led to a pivotal shift in the WHO guidelines on HIV and Infant Feeding from November 2009 [28-30]. The new guidelines are emphasising the importance of breastfeeding more than earlier, and recommend antiretroviral treatment to the mother when appropriate, and antiretroviral prophylaxis to the infant.

Sub-optimal infant feeding practices in Eastern Uganda has recently been shown, both in the general population and among HIV-positive mothers [11,31-33]. Health workers' counselling practices are key factors to improve the feeding practices [14]. How did the health workers' counselling practices influence infant feeding

practices in this area? The aim of this paper is to assess how infant feeding counselling was done and experienced among counsellors and mothers in Eastern Uganda in the context of previous guidelines. This has implications for implementation of the new guidelines.

#### Methods

The infant feeding counselling situation was assessed with a mixed-method approach including both qualitative and quantitative data from health workers and health clients in the same study catchment area of Mbale District, Eastern Uganda. The data collection period between 2003 and 2005 was a period of changes in infant feeding guidelines, and can therefore provide useful information on adaptations to changes in guidelines.

#### Mixed methods approach

In line with the 'concurrent nested' design described by Cresswell et al [34], this paper combines both qualitative and quantitative data which have been carried out in parallel and integrated in the design, implementation and analysis phase. This study emphasises findings from the qualitative data which is triangulated with quantitative data. Detailed descriptions of the quantitative data packages exist elsewhere [11,31]. The multilevel designs framework which in this case involves key informant interviews for health workers and focus-group discussions for mothers has been well described by Tashakkori and Teddlie [35]. A list of the different data packages (DP) is presented below:

#### Data packages in the study

DP 1 Thirteen key informant interviews with health workers from nine public sector institutions comprising nurses, midwives and clinical officers working with child health and infant feeding guidance were conducted in 2003 and 2005.

DP 2 Five key informant interviews among health personnel working with HIV positive people from a public hospital and in non-governmental organisations were carried out in 2005.

DP 3 Seven focus-group discussion among HIV-positive people were held at an HIV-clinic in 2005: 5 groups involving mothers below 35 years of age, one group with HIV-positive men, and one with HIV-positive women above 35 years of age.

DP 4 Eight community-based focus group discussions from 2003 highlighting the views of toddler parents regarding infant feeding practises (in press).

DP 5 A community-based cross-sectional survey was conducted in 2003 where 727 mothers were interviewed. This is analysed with regard to infant-feeding practices and growth determinants [11,32].

DP 6 A cross-sectional study was conduced in 2005 where 235 HIV-positive mothers-child pairs recruited from an HIV-clinic were interviewed. This is analysed with respect to feeding practices and predictors of feeding behaviour [31,36].

Some findings have been published from data package 4, 5 and 6, but this paper will focus on hitherto unpublished findings. The data packages will hence be referred to with superscript <sup>[DP]</sup>.

#### Study setting

Mbale has a population of 403,100 inhabitants [37]. The district is predominantly rural which is reflected in a 59% proportion of home deliveries (2008), but an antenatal attendance of 95%. The infant mortality rate is 76 per 1000 live births. The regional HIV-prevalence among fertile women was 6.2% (2004-5) [38]. Nearly all mothers practiced breastfeeding [11]. The Ugandan health system is characterised by a hierarchical structure, with a national referral hospital at the top level, followed by a regional hospital, health centre IV, health centre III at sub-country level and health centre II at the parish/community level. In Mbale District there was one regional hospital, one district hospital, and the majority of the sub-counties had a health centre III. Most women lived within 1-2 hours walking distance to a health centre II or III.

#### Context of health education

Health education sessions were conducted in all public health facilities that were included in this study <sup>[DP1,2]</sup>. The sessions usually lasted for 30-60 minutes. The topics being taught in the public health services and the way the sessions were organized varied. Feeding of infants was one of many themes that were covered during health education sessions. Other common themes were care during pregnancy, nutrition of pregnant women, postnatal care, sexually transmitted diseases including HIV, family planning, prevention of malaria, use of medicines, hygiene, first aid of conditions like diarrhoea with oral rehydration, and immunization of babies. The number of clients attending health education in the public health facilities ranged from around 10-200 per day, typically involving 20-50 mothers in each health education session. In the non-governmental organisations, individual counselling had a stronger stand. Regarding HIV, the public health services were moving towards the 'provider-initiated routine HIV counselling and testing algorithm' [39].

#### Interviews

Key informant interviews were conducted with health personnel and 18 key informants were purposely selected. The main selection criterion was that the health workers participated in health education. The participants were recruited by approaching most public health facilities within Mbale Municipality and surroundings which could be reached within a one hour minibus drive. The informants comprised men and women within the age range 20-60 years. The mean duration of the interviews was one hour. The two first authors conducted the interviews with the health workers in English, tape-recorded and transcribed them. The first author was responsible for data package 2, 3, and 6, and the second author for 1, 4 and 5.

Mothers from the same area were interviewed in focus groups containing 5-11 participants and lasting about one hour. The focus groups were moderated by trained research assistants under supervision of the two first authors, and were conducted in the local language Lumasaaba, tape recorded, translated and transcribed. In the quantitative data packages, structured interviews were performed by data collectors.

#### Analysis

Inductive thematic content analysis was chosen [40-42]. Systematic reading, coding and re-categorisation were performed by the two first authors. After identification of themes, inter-consistency checks were done. The following main themes emerged: 1) *The context influencing infant feeding teaching*; 2) *Feeding of severely ill children*; 3) *Challenges related to breastfeeding*; 4) *The counselling process*; 5) *Simplifying messages*; 6) *HIV-infected mothers' disclosure and choice*; 7) *Feasibility and capacity challenges*. These themes will be mirrored from the different data packages, and are summarized in table S1 (additional file 1).

#### Ethics

All participants signed informed consent. Ethical approval was obtained from Makerere University, Faculty of Medicine Ethics and Research Committee, and the Uganda National Council for Science and Technology.

#### **Results and discussion**

#### The context influencing infant feeding teaching

Although systematic approaches were described in some clinics, teaching in the public health system often appeared to be improvised according to the perceived needs of the clients, or the planned activities in the units <sup>[DP1,2]</sup>. Most of the health workers in the public health services had their current knowledge on infant feeding guidelines from their training as professionals. Some of the health workers had attended specific workshops on infant feeding, including one who was trained within the IMCI framework of WHO. The infant feeding messages varied depending on whether the health workers had updated knowledge.

Infant feeding teaching and health education were regarded as important among health workers <sup>[DP1,2]</sup>. In most cases the health educators got positive feedback as *'we have not known this.'* Women being busy with work who just came for treatment did pay less attention to the teaching, while those *'who come with malnourished children - they usually pay much attention.'* Great interest was expressed as motivating for the health workers. A factor opposing this enthusiasm was a heavy work load. *'The number of services is increasing, but we still have the same number of staff.'* 

Regarding infant feeding, the health workers in the public services stressed the importance of breastfeeding and complementary feeding from six months. Terms like *'breastfeeding on demand'* and *'frequent breastfeed-ing'* were often referred to.

Many health workers had pragmatic approaches to infant feeding teaching, knowing that numerous mothers had challenges related to the feasibility of the infant feeding guidelines <sup>[DP1,2]</sup>. As an example, women were taught how to dilute cow's milk and boil water for the baby when the health workers were informed that the mother had to leave the baby during daytime and could not manage exclusive breastfeeding.

The hygienic hazard of bottle feeding was often emphasised during the counselling sessions <sup>[DP1,2]</sup>. The importance of hygiene in general and the hazard of some of the traditional practices were frequently underlined by the health workers. Many women and some men believed breasts had to be cleaned before breastfeeding, and told that this practice was encouraged by local health institutions <sup>[DP4]</sup>. The health workers in contrast reported to encourage cleaning of the breasts only when the mothers had applied local medicines on the breasts.

The majority of the known HIV-positive mothers had discussed infant feeding with health personnel, 159 of 235 mothers (68%) <sup>[DP6]</sup>. The counselling content that was reported most often was the question on when to introduce liquids and solids to infants. In the general population, the proportion reporting to have discussed infant feeding with health personnel was considerably lower, 107 of 727 mothers (15%) [DP5]. The topic most often reported from the counselling sessions was breastfeeding technique. Some of the differences between the groups may be attributed to the fact that the recruited HIV-positive mothers received regular follow-up by health workers. Qualitative data from mothers in the general population revealed that mothers were informed about exclusive breastfeeding as a preferred practice, but they were equipped with limited strategies to maintain the practice <sup>[DP4]</sup>.

## Feeding of severely ill children - an entry portal to infant feeding teaching

Although group teaching was dominating in the public services, they mobilised some extra teaching capacities to targeted individuals <sup>[DP1]</sup>. Undernutrition was seen as an entry portal to discuss nutrition on an individual basis. 'Sometimes when a mother comes with a child who is malnourished, we have to health-educate that mother.' Harmful feeding practices were also discovered while treating children for other diseases. 'There are some who think that when a child is sick and just does not want to eat - they just stop there. For example if a child has measles, many people think that giving that child milk will worsen the condition. So when we talk with them about nutrition, food is part of the treatment.'

Most health workers were referring children with severe undernutrition and clinical manifestations like kwashiorkor and marasmus on a monthly basis to the nutrition unit of the regional hospital. Referral itself was not necessarily the solution to undernutrition. 'You can tell the mother to go to the main hospital, and then she doesn't. She just goes back home. She doesn't have the money, and the (other) children are at home.' The health workers related malnutrition to poverty, being sick with malaria, diarrhoea or cough, unawareness of nutritional values of food, poor hygiene, and the fact that young school girls often left their babies to grandmothers who did not manage substituting breast milk adequately. High birth rates were also considered to be partly responsible for the difficult situation many were facing. 'This malnutrition comes out of what? Poor family planning - you produce many (children), and cannot afford to feed them well and bring them up properly. So we also talk about family planning.' Health workers struggled to counsel feasible alternatives for the infants: 'Most of these mothers don't have the food you ask them to give - some children come malnourished. Look at some kids - they are thin, they are wasted. Feeding down there is a very big problem.' These problems seemed to affect many, and a study from the same area confirmed that numerous children were stunted and wasted [32]. This can have detrimental effects for the children in terms of increased morbidity and mortality [1].

#### Challenges related to breastfeeding

Even if breastfeeding was regarded as the best infant feeding practice in the health institutions, some situations were reported where breastfeeding was debated, either among the mothers or among the health workers <sup>[All DP's]</sup>. One such reason was new pregnancies. A pregnancy was a common reason to stop breastfeeding among mothers <sup>[DP4]</sup>, but health workers on the contrary encouraged women to continue breastfeeding during new pregnancies <sup>[DP1,2]</sup>. 'We are telling the mothers to breastfeed their children as much as possible and as long as possible.' The belief that breastfeeding during pregnancies can be harmful has been reported from a study in Western Uganda [43]. That study described the belief that breastfeeding during pregnancy could cause kwashiorkor for the breastfed infant.

Both community members and health workers typified the group of busy mothers occupied with work and studies to often avoid breastfeeding <sup>[DP1-4]</sup>. This was regarded as challenging for the health workers, but they had many pragmatic suggestions on how to overcome this challenge, such as having the baby brought to the mothers during working hours.

A challenge that many health workers faced, was the perceived lack of milk that some mothers experienced. In most cases the health workers would advise the mothers to have a varied diet and drink enough fluids to overcome the shortage of breast milk. They also acknowledged psychological stress as a factor contributing to breast feeding problems. Reasons why some mothers were suffering mentally were often related to economic worries and unstable family relations. The health workers showed great empathy for the extremely difficult situations many mothers bore when feeding their children.

Although a breastfeeding dilemma was observed in different situations, the HIV-positive mothers stood in the heart of this discussion. Avoiding breastfeeding was in many cases promoted as the ideal option for HIVpositive mothers from several of the health workers, both in the public health sector and among those working directly with HIV-positive mothers in the PMTCT programmes <sup>[DP1,2]</sup>. Breastfeeding was thereby mainly regarded as an option for those who could not afford or manage replacement feeding. Many health workers acknowledged that their clients had economical constraints and therefore advised mothers to practice exclusive breastfeeding. When mothers had chosen a feeding option, some health workers highlighted the importance of sticking to the chosen option to avoid mixed feeding. When the HIV-positive mothers were asked what the health workers had told them related to breastfeeding, some reported that the transmission risk of breastfeeding was underlined, while other told that they were given advice on practical aspects of breastfeeding <sup>[DP3]</sup>.

Mothers not breastfeeding were often suspected to be HIV-positive by their communities peers <sup>[DP2-4]</sup>. Other illnesses like malaria and mental disorders were also held as likely explanations why mothers avoided breast-feeding. The choice to avoid breastfeeding was regarded as culturally highly controversial <sup>[DP3,4]</sup>. Another view held by numerous young mothers as well as groups of

men and older women, was that mothers not breastfeeding were immature and irresponsible. 'Some are mothers who lack responsibility and just want to enjoy their life.'

There were mixed perceptions on exclusive breastfeeding. Among 235 HIV-positive mothers, 70% considered exclusive breastfeeding for several months to be harmful, while 30% considered it as beneficial <sup>[DP6]</sup>. Water was regarded as a necessary addition to breastfeeding among 219 (93%) of the mothers, and exclusive breastfeeding was seen as insufficient for children <sup>[DP3,6]</sup>. Regarding infant feeding practices, HIV-positive mothers breastfed shorter than mothers in the general population <sup>[DP5,6]</sup> [33]. Mixed feeding during the first half of infancy was widespread in both groups [11,31]. It seems like the message from the guidelines about the benefits of exclusive breastfeeding had not reached this population fully.

#### The counselling process

Many of the health workers put much effort into communication and having a good, caring and empathic attitude <sup>[DP1,2]</sup>. '*They have the potential, but they have not explored it. Our job is to open their minds.*' One-to-one counselling was a prioritised strategy in non-governmental organisations working with HIV-positive people, and often included teaching on infant feeding to parents when relevant. In order to ensure high quality of the counselling process, some health workers were concerned about not to have too many counselling sessions per day: '*if you counsel more than 10 people (each day), it is not effective counselling.*'

Some counsellors emphasised that they provided information to empower clients to take well informed choices <sup>[DP2]</sup>. With this strategy, they stressed the importance of not making decisions for their clients. The clients themselves acknowledged this <sup>[DP3]</sup>. 'We talked about very many things. So it was our own decision - we as individuals to decide what to do now.' The topics discussed were often chosen in an interactive process between the clients and counsellors <sup>[DP2]</sup>. 'So we allow them to tell their stories.' Also some of the providers in the public sector used an interactive counselling strategy characterised by questions and answers <sup>[DP1]</sup>.

Many of the HIV-counsellors in the non-governmental organisations got extended training in counselling <sup>[DP2]</sup>. This type of training in communication skills seemed to improve teaching and counselling and could be beneficial also for an extended range of health workers conducting infant feeding teaching in the public sector.

#### Simplifying messages

A tendency to simplify messages and exaggerate some perspectives at the expense of other perspectives during infant feeding counselling was observed <sup>[DP1,2]</sup>. This may have been an effort to reach the audience, and was

probably based on their interpretations of recent guidelines. An illustrating quote from a counsellor focusing on the hazards of breastfeeding was: 'When a mother is HIV-positive and breastfeeds her child, the child is likely to catch HIV.' A similar simplistic message from a counsellor focusing on exclusive breastfeeding was: 'if you give any other feeds than breast milk, this means that the baby's alimentary canal will be infected.'

This tendency of simplifying may have the advantage of not overwhelming the clients with complexity. Unfortunately it also carries the danger of confusing the listeners with incomplete information as many different health workers showed different parts of the picture. Some health workers were stressing the fact that HIV can be transmitted through breastfeeding, while others were focusing on the beneficial effect of exclusive breastfeeding. Clients who got contradictory simplistic messages may have had difficulties putting the pieces together to make informed choices. This way of informing clients in addition to varying routines and content of the infant feeding counselling, may have contributed to increase the amount of mixed feeding. Related issues have been pointed out in some Sub-Saharan countries. Chopra et al described counselling among health workers in Botswana, Kenya, Malawi and Uganda, and concluded that many overestimated the risk of HIVtransmission [19]. Similarly, Doherty et al described confusion among health workers in South Africa resulting in mixed feeding [14].

#### HIV-infected mothers' disclosure and choice

Disclosure of HIV-status was a challenge to optimal feeding in many cases <sup>[DP1,2,3]</sup>. In some cases, mothers breastfed their children when seen by others, while they were avoiding breastfeeding when being alone. 'I'm sorry, I can't (give replacement feeds) because the man will know (my HIV status), and he will send me away and will not even buy milk for this child. How am I then going to care for this child?' Similarly, some HIV-positive men not having disclosed their status asked their wives not to breastfeed. This resulted in replacement feeding when the mother was seen by the husband, but breastfeeding when the husband was absent. The least fortunate infant feeding practice, mixed feeding during the first half of infancy, was thus often a consequence of not disclosing HIV-status. Not disclosing HIV-status has been reported to increase mixed feeding also in two South African studies [14,44]. However, the quantitative data did not show any significant differences in infant feeding practices between mothers having disclosed their HIV-positive status in their respective community compared to those who had not disclosed <sup>[DP6]</sup>.

Disclosure of HIV may not be an easy choice as some women may have to pay a high price for disclosing their

HIV status. Several of the HIV-positive people who disclosed their status told stories of being excluded from the family, being treated badly, losing their property or work, and being sent away from their homes <sup>[DP3,6]</sup>. On the other hand, many who disclosed their HIV-status reported that they had been encouraged and supported by their communities. Some health workers reported a trend of improvement regarding stigma: 'Initially it was stigma, but stigma is dying.' Studies from South Africa suggest that the mothers experiencing negative outcomes from disclosure are the exceptions rather than the rule [44-47]. Many report more support from family and friends when disclosing their HIV status. The weight of the stigma burden may be related to how well each setting has adapted to HIV, which in many settings seems to require some maturation time. As numerous settings still struggle with these adaptations, many HIVpositive people still face stigma as a heavy burden.

#### Feasibility and capacity challenges

Health workers also brought up program changes as a factor that complicated their work <sup>[DP2]</sup>. One example was a program supplying infant formula to HIV-positive mothers before it suddenly stopped. The mothers then asked the health workers what to do as they could not afford to buy replacement food. '*I don't have flour to make porridge. I can't afford milk.*' The counsellors found this hard to handle. 'So you find that the food the mother have at home is really not opted for the child - so you really fail to understand how to help them out of their situation.' It has also been described that replacement feeding is opposing the view of motherhood, which can partly explain that it is often perceived as an unacceptable alternative [48].

In addition to acknowledging the mothers' challenges, many health workers in the public health sector expressed a deep concern for the situation of their institutions <sup>[DP1]</sup>. Major concerns which made daily performances difficult were inadequate facilities including lack of separate rooms for deliveries, absence of soap, clean water, electricity, and drugs in stock. This was reported to be most precarious in the remotest areas. Inadequate facilities are a burden to the health workers and may impede counselling. These obstacles came in addition to their own perceived needs for refreshing courses, workshops and teaching material. A few of the health workers expressed a need for demonstration kits to ease the infant feeding sessions. The need for more staff was also pointed out by several health workers.

#### Key principles discussed

This study has described the circumstances around infant feeding teaching and counselling in Mbale District, Eastern Uganda. It has highlighted variation in counselling and messages. Further, the study has highlighted some of the challenges and opportunities existing. Major challenges existed both in the health system and on the client level. Lack of resources, minimal staffing, inadequate training and follow-up, as well as meeting the clients challenges, were frequently reported from the health workers. The clients on the other hand were faced with poverty, difficult choices and stigma. Large counselling groups with ad hoc curriculum and irregular sessions might explain why mothers had heard about exclusive breastfeeding, but not integrated the messages. Health workers were concerned with feasibility of exclusive breastfeeding, and often suggested pragmatic solutions when they were faced with mothers who did not manage to practice the ideal options.

The economic situation of the public health services will unfortunately impede individualised counselling to the same extent as practiced in some non-governmental organisations. If more is invested in the public health system to upgrade the infant counselling services, it may be possible to improve the feeding situation [49]. A review on interventions to change health workers' behaviour identified workshops as one of the potent strategies [50]. Similarly, a Tanzanian and a Sudanese study trying to change health workers' practices showed substantial benefits of short seminars [51,52]. To maintain the knowledge, it was necessary to have follow-up or refreshing seminars. Based on the shortcomings observed in this study, it could be beneficial with short updating workshops for health workers on a regular basis to keep them up to date without taking too much valuable time. If different topics relevant for antenatal care could be integrated into e.g. annual workshops, important updates on guideline changes and changes in patient management could be provided. This could potentially streamline the health education and reduce the risk of confusion.

Counselling was given high priority in the HIV-positive population, but contradicting and simplified messages might have hampered some of the effects of the counselling on infant feeding. The new guidelines from 2009 advocate for '*informing mothers known to be HIVinfected about infant feeding alternatives*' [28]. Avoiding simplistic and diverging messages might be important to fulfil this objective. How the information is conveyed is likely to determine the choice of the mother. Many HIV-positive mothers will still face disclosure challenges in their respective communities. Without strategies in place to support them, it is difficult to avoid unfavourable feeding practices.

Experiences from this study can shed light on some aspects of implementation of the new guidelines on HIV and infant feeding [28]. These guidelines promote exclusive breastfeeding in contexts with a high HIV prevalence more than earlier guidelines did, and emphasise not to compromise breastfeeding in the general population. As implementation of guidelines and programs not always reach the aims that have been set, ongoing evaluation during implementation is essential [53,54]. There seems to be a need to promote, protect and support exclusive breastfeeding more; with increased emphasis in the public health system. Individualised and group peer-support of breastfeeding are promising strategies [55,56].

#### Strengths and limitations

The strength of this study was the combined use of qualitative and quantitative data to shed light on the teaching, counselling and infant feeding situation in Eastern Uganda. This enabled a discussion of challenges related to choice of infant feeding and feasibility which is highly relevant to the new infant feeding guidelines in the context of HIV. There are inbuilt limitations with the design of the study: the integration of data was done post hoc and there are few descriptions on how this can be done as objective as possible [34]. For this reason, some of the discrepancies between messages from the health providers and the health clients observed while integrating the data, cannot be elaborated on. An example was the discrepancy reported on 'cleaning of breasts' from the health workers and the mothers. Some topics from the key-informant interviews could not be triangulated with quantitative data from the health clients. Still, the mixed triangulation approach enabled us to present and compare overlapping and diverging findings.

Regarding the qualitative data and the selection of informants, all interviewed health workers performed counselling or health education, but not all had it as their principal responsibility. Even though having tried to recruit informants from all relevant health providing institutions in the area, not all were reached. Traditional birth attendants may also have given counselling to some mothers. However, they were not included in this study. Although emphasising to the respondents that the information they gave could not be linked to them, respondents may have given socially desirable responses. Limitations of the quantitative data have been elaborated on elsewhere [33].

#### Conclusions

This study showed that the quality of infant teaching and counselling might be compromised when adjusting to frequent changes in programs while experiencing a heavy work load. Major challenges for the health workers were lack of resources and minimal staffing, inadequate training and follow-up, as well as meeting the complicated situations of the clients. The clients were faced with difficult choices often associated with poverty, feasibility, stigma and disclosure of HIV. With the new guidelines on infant feeding in the context of HIV from late 2009 being implemented, it is important not to repeat previous missteps. New guidelines need to be integrated in all relevant levels of the health system to reach out to the clients. The clients should experience a more streamlined education with confident health educators. Systematic approaches to update health workers should be a priority. More resources to the public health service in low-income country must be an aim.

Nevertheless, it is also important that future operational research evaluate acceptability and feasibility of infant feeding guidelines, and the effect of the recommendations on behavioural changes. Earlier experiences have taught us that research must go hand in hand with implementation of new guidelines. This could detect confusion among health personnel and health clients, and suggest early adaptations to increase acceptability and feasibility.

#### Additional material

Additional file 1: Table S1: Summary of main findings from the different data packages sorted under themes [DP1-6].

#### Abbreviations

BFHI: baby-friendly hospital initiative; DP: data package; HIV: human immunodeficiency virus; IMCI: integrated management of childhood infections; PMTCT: Prevention of Mother-to-Child Transmission; WHO: World Health Organisation.

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#### Authors' contributions

LTF and IMSE: design, implementation, analysis and writing. JN and KMM: co-writing. TT and JKT: design and co-writing. All authors approved the final manuscript.

#### **Competing interests**

The authors declare that they have no competing interests.

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## Article 4

Lars T Fadnes, Victoria Nankabirwa, Ingunn MS Engebretsen, Halvor Sommerfelt, Carl Lombard, Sonja Swanevelder, Jan Van den Broeck, Thorkild Tylleskär, James K Tumwine, for the PROMISE-EBF Study Group:

Growth outcomes at 2 years from a cluster-randomised controlled trial promoting exclusive breastfeeding for six months in Uganda. *Manuscript*.

Lars T Fadnes

The article will be made available when published

Lars T Fadnes

## **Appendices**

The questionnaires, consent forms, focus group discussion guides, and key informant interview guides can be found through the following links.

## Direct links to quantitative questionnaires and consent forms:

# Infant Feeding Practices among HIV-positive mothers in rural Uganda 2005, consent form:

Consent form for study from <u>http://questionnaires.fadnes.net/Quantitative-2003-2005/Consent-form-2005.pdf</u>

# Infant Feeding Practices among HIV-positive mothers in rural Uganda 2005, questionnaire (English):

http://questionnaires.fadnes.net/Quantitative-2003-2005/Infant-Feeding-Practicesamong-HIV-positive-mothers-in-rural-Uganda-English-2005.pdf

# Infant Feeding Practices among HIV-positive mothers in rural Uganda 2005, questionnaire (Lumasaaba):

http://questionnaires.fadnes.net/Quantitative-2003-2005/Infant-Feeding-Practicesamong-HIV-positive-mothers-in-rural-Uganda-Lumasaaba-2005.pdf

# Infant Feeding Practices and Nutrition Status of Infants 2003, questionnaire (English):

https://bora.uib.no/bitstream/1956/4319/1/Appendices\_Errata\_Engebretsen.pdf

## **Questionnaires from the PROMISE EBF trial:**

Contact Thorkild Tylleskar: http://www.uib.no/persons/Thorkild.Tylleskar#profil

## Direct links to focus group discussion documents:

### Focus group discussion consent form:

http://questionnaires.fadnes.net/Focus-group-discussions/Consent-form-FGD-2005.pdf

## Focus group discussion guide 2005:

http://questionnaires.fadnes.net/Focus-group-discussions/Focus-group-discussionguide- 2005.pdf

## Focus group discussion guide 2003:

http://questionnaires.fadnes.net/Focus-group-discussions/Thematic-Focus-Group-Discussion-Guide-2003.pdf

## Direct links to key informant interview documents:

## Key informant interview consent form 2005:

http://questionnaires.fadnes.net/Key-informant-interviews/Consent-form-KII-2005.pdf

## Key informant interview guide -HIV-clinic-2005:

http://questionnaires.fadnes.net/Key-informant-interviews/Key-informant-interview-guide-AIC-2005.pdf

## Key informant interview guide – HIV-positive mothers 2005:

http://questionnaires.fadnes.net/Key-informant-interviews/Key-informant-interview-guide-HIV-positive-mother-2005.pdf

## Key informant interview guide – hospital maternity ward 2005:

http://questionnaires.fadnes.net/Key-informant-interviews/Key-informant-interviewguide-maternity-ward-2005.pdf

## Key informant interview guide – hospital PMTCT clinic 2005:

http://questionnaires.fadnes.net/Key-informant-interviews/Key-informant-interview-guide-PMTCT-2005.pdf

## Key informant interview guide –HIV-clinic 2005:

http://questionnaires.fadnes.net/Key-informant-interviews/Key-informant-interview-guide-TASO-2005.pdf

## Direct links to ethical approvals:

 $\underline{http://questionnaires.fadnes.net/Ethical-approvals/PROMISE-EBF-amendments-to-protocol-2008.pdf}$ 

## Corrections and notes

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## Corrections

## Thesis

- Page 20: Additional reference (together with reference 20): Barker DJ, Gluckman PD, Godfrey KM, Harding JE, Owens JA, Robinson JS: Fetal nutrition and cardiovascular disease in adult life. *Lancet* 1993, 341(8850):938-941.
- Page 30 (figure 4): Trial profile for the PROMISE-EBF follow-up
  - o Intervention arm: 18 excluded due to 'Other' reasons (not 17)
  - Control arm: '*Recruited pregnant mothers*' was 421. 26 excluded due to '*Other*' reasons.
  - *'Total'* will then be 46 and 52, and included *'Included mother-infant pairs'* 396 and 369 in the intervention and control arm, respectively
- Page 57
  - "There is limited literature on long-term outcomes of exclusive breastfeeding" should read "There is limited literature on long-term outcomes of exclusive breastfeeding promotion"

## Article 1

- Page 8  $(3^{rd} \text{ last sentence})$ :
  - "diseased" should say "deceased"
- o Table 1:
  - In the right column "<sup>2</sup>" should read " $\chi^{2}$ " (chi squared)

## Notes and clarifications

## Paper 1 and 2

It is worth noting that the discussion of article 1 and 2 related to breastfeeding duration among HIV-positive mothers that present a short duration of breastfeeding as beneficial is outdated due to a paradigmatic shift in the existing knowledge (see introduction of the thesis).

There is also a statement in paper 1 which might look odd and could need a short explanation: "Another explanation for the dominance of complementary feeding including breast milk may be the fear of making the infant totally reliant on breast milk, which could be particularly true for HIV-positive mothers [32]" This is referring to some of the qualitative interviews that is presented more thoroughly in paper 3 where some families indicated that they tried to avoid that the breast milk was the only source of the infant nutrition which was believed to make the children even more vulnerable in case the mother had an accident, became ill or died. Brestfeeding exclusively was thus considered to increase the vulnerability. This view has also been reported in another study from Zambia that was referred to [32].

Regarding representativeness of the HIV-positive participants recruited from the The Aids Support Organisation (TASO):

A study by Karamagi et al conducted in the same area (Mbale) in 2003 [1], indicated that the prevalence of antenatal HIV testing was only 10%. This might indicate that only a small proportion of the women who were HIV-positive knew their HIV status. A large proportion of those who sought support and treatment for their HIV-status, did it at TASO which was the largest organisation providing such care. Thus, paper 2 is comparing the general population with few identified HIV-positive mothers with those who live with a <u>known</u> HIV-positive status. It is also important to note that the proportion knowing their HIV-status has improved since that time.

1. Karamagi CA, Tumwine JK, Tylleskar T, Heggenhougen K: Antenatal HIV testing in rural eastern Uganda in 2003: incomplete rollout of the prevention of motherto-child transmission of HIV programme? *BMC Int Health Hum Rights* 2006, **6**:6.

The feeding patterns described among the youngest infants of the HIV-positive mothers during the first half of infancy is based on a small number of children (37), and hence the precision of these estimates are low. Care must thus be taken when interpreting these estimates.

As there were differences in the mean age of the infants from the general population and infants born to HIV-positive mothers that are compared in paper 2 at the time of the interview, it can be argued that this involves a risk of information bias as the HIV-positive mothers in average have longer recall period than the general population.

## Paper 4

Cluster adjustment was done with the cluster command in Stata which corrects the standard error.

Inverse-probability proportional weighting does not involve value imputations. It gives more weight to the cases that are more likely not to be measured.

It can be noted that there is a small difference between the anthropometric measurements already at 3 weeks between the control and intervention arms.

## Thesis

The following sentence (page 60) might have been unclear: 'On the other hand, governments have several good reasons to reduce their own contribution to a sector and smoothen the budget when they get earmarked aid, as aid often is unreliable'.

Cuts in aid and even such rumours can make planning unpredictable for nations, and thus many tend to smoothen out the effects of aid that fluctuates [1-2]. A common situation is that earmarked aid is given with the aim to strengthen e.g. treatment of people with HIV. Governments might then re-allocate some of the financial resources that were initially assigned for that purpose to other sectors [1]. This makes the budgets less vulnerable to extreme changes.

- Ooms G, Decoster K, Miti K, Rens S, Van Leemput L, Vermeiren P, Van Damme W: Crowding out: are relations between international health aid and government health funding too complex to be captured in averages only? *Lancet* 2010, 375(9723):1403-1405.
- 2. <u>http://www.guardian.co.uk/global-development/poverty-matters/2011/apr/08/us-federal-budget-cuts-aid-certain-casualty</u>

# Summary of the current and past guidelines on HIV and infant feeding from WHO

Over the last 10 years, there has been a gradual shift in how the guidelines from the World Health Organisation (WHO) has recommended infant feeding in the context of HIV [1-8]. In 2001 [1], it was emphasised that children should not be breastfed when replacement feeding was acceptable, feasible, affordable, sustainable and safe (AFASS). It was also stated that otherwise, exclusive breastfeeding for the first few months of life was recommended, but should be discontinued as soon as feasible.

Unfortunately, the interpretation of the so-called AFASS criteria were interpreted more leniently among several health workers than they were probably intended to be [9]. With increasing acknowledgement of the problems associated with early cessation of breastfeeding or not breastfeeding in contexts where it was considered to be possible with replacement feeding, more and more emphasis was put on breastfeeding as the main infant feeding option [4-7, 10].

The guidelines from 2009 and 2010 also emphasises the importance of using antiretroviral prophylaxis as the main strategy to reduce HIV-transmission from mother-to-child [5-7]. Thus, differences in feeding strategies between children born to HIV-positive mothers and children born to HIV-negative mothers are less pronounced in the current guidelines with the exception of the antiretroviral prophylaxis/ therapy.

The current guidelines from 2010 also emphasises that HIV-positive mothers should receive the care they need – including antiretroviral drugs if that is indicated for the mothers' own health, or as prophylaxis to their children during pregnancy and delivery [7]. The importance of prolonged antiretroviral protection also during the complete duration of breastfeeding is underlined, either as treatment to the mother or prophylaxis to the child. The necessity of adequate complementary feeding of the children is also highlighted.

## References

- 1. World Health Organization (WHO): New data on the prevention of mother-to-child transmission of HIV and their policy implications: Conclusions and recommendations. Technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS inter-agency task team on mother-to-child transmission of HIV. . Geneva: WHO; 2001.
- 2. World Health Organization (WHO), UNICCEF, UNFPA, UNAIDS, WORLD BANK, UNHCR, WFP, FAO, IAEA: **HIV and Infant Feeding Framework for Priority Action**. *wwwwhoint/child-adolescent-health/New\_Publications/NUTRITION* 2003.
- 3. World Health Organization (WHO), UNICEF, UNAIDS, UNFPA: **HIV and infant feeding. Guidelines for decision-makers**. 2003, http://www.who.int/child\_adolescent\_health/documents/9241591226/en/.
- 4. WHO, UNICEF, UNFPA, UNAIDS: HIV and infant feeding: new evidence and programmatic experience: Report of a technical consultation held on behalf of the Inter-agency Task Team (IATT) on Prevention of HIV infections in pregnant women, Mother and their Infants, Geneva, Switzerland, 25-27 October 2006 [http://www.who.int/child\_adolescent\_health/documents/9789241595971/en/]
- 5. World Health Organisation: **Rapid advice: infant feeding in the context of HIV**. 2009.

- 6. World Health Organisation: **Rapid advice: use of antiretroviral drugs for treating pregnant women and preventing HIV Infection in infants**. 2009.
- 7. World Health Organization (WHO), UNICEF, UNFPA, UNAIDS: Guidelines on HIV and Infant Feeding 2010: Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. 2010.
- 8. Moland KM, de Paoli MM, Sellen DW, van Esterik P, Leshabari SC, Blystad A: Breastfeeding and HIV: experiences from a decade of prevention of postnatal HIV transmission in sub-Saharan Africa. Int Breastfeed J 2010, 5:10.
- 9. Doherty T, Chopra M, Jackson D, Goga A, Colvin M, Persson LA: Effectiveness of the WHO/UNICEF guidelines on infant feeding for HIV-positive women: results from a prospective cohort study in South Africa. *AIDS* 2007, **21**(13):1791-1797.
- Kuhn L, Aldrovandi GM, Sinkala M, Kankasa C, Semrau K, Mwiya M, Kasonde P, Scott N, Vwalika C, Walter J, Bulterys M, Tsai WY, Thea DM: Effects of early, abrupt weaning on HIV-free survival of children in Zambia. N Engl J Med 2008, 359(2):130-141.