

Working Papers

12. Goat's Milk: A viable contribution in the challenge to prevent Mother-To-Child Transmission of HIV in the Mbale Region, Uganda?

Claire Scrutton, with Christine Aloit-Olaunah, Margaret Namugwanya and Professor Andrew Tomkins



No. 12

Goat's Milk: A viable contribution in the challenge to
prevent Mother-To-Child Transmission of HIV in the
Mbale Region, Uganda?

Options for action

Claire Scrutton, with Christine Alokite-Olaunah, Margaret Namugwanya and
Professor Andrew Tomkins

November 2007

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FEEDBACK

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Abbreviations and explanation of terms

WHO/UNICEF/UNFPA/UNAIDS (2003) and Ministry of Health (2006b):

ARV: Anti-retroviral drug

Acquired Immunodeficiency Syndrome (AIDS): the active pathological condition that follows the earlier, non-symptomatic state of being HIV-positive.

AFASS: acceptable, feasible, affordable, sustainable and safe replacement feeding.

Breast-milk substitute: any food being marketed or otherwise represented as a partial or total replacement for breast milk, whether or not suitable for that purpose.

Commercial infant formula: a breast-milk substitute formulated industrially in accordance with applicable Codex Alimentarius standards to satisfy the nutritional requirements of infants during the first months of life up to the introduction of complementary foods.

Complementary feeding: the child receives both breast milk or a breast-milk substitute and solid (or semi-solid) food.

Exclusive breastfeeding: an infant receives only breast milk and no other liquids or solids, not even water, with the exception of drops or syrups consisting of vitamins, mineral supplements or medicines.

Human Immunodeficiency Virus (HIV): the virus that causes AIDS. In this document, the term HIV means HIV-1. Mother-To-Child Transmission of HIV-2 is rare.

HIV-negative: refers to people who have taken an HIV test and who know that they tested negative, or to young children who have tested negative and whose parents or guardians know the result.

HIV-positive: refers to people who have taken an HIV test and who know that they tested positive, or to young children who have tested positive and whose parents or guardians know the result.

HIV status unknown: refers to people who either have not taken an HIV test or do not know the result of a test they have taken.

HIV-infected: refers to people who are infected with HIV, whether or not they are aware of it.

HIV testing and counselling: testing for HIV status, preceded and followed by counselling. Testing should be voluntary and confidential, with fully informed consent. The expression encompasses the following terms: *counselling and voluntary testing*, *voluntary counselling and testing*, and *voluntary and confidential counselling and testing*. Counselling is a process, not a one-off event: for the HIV-positive client it should include life planning, and, if the client is pregnant or has recently given birth, it should include infant-feeding considerations.

Home-modified animal milk: a breast-milk substitute prepared at home from fresh or processed animal milk, suitably diluted with water and with the addition of sugar and micronutrients.

Infant: a person from birth to 12 months of age.

Infant feeding counselling: counselling on breastfeeding, on complementary feeding, and, for HIV-positive women, on HIV and infant feeding.

IYCF: Infant and Young Child Feeding

Mixed feeding: feeding both breast milk and other foods or liquids.

MoH: Ministry of Health in Uganda

MTCT - Mother-To-Child Transmission: transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery or breastfeeding. The term is used in this document because the immediate source of the child's HIV infection is the mother. Use of the term *Mother-To-Child Transmission* implies no blame, whether or not a woman is aware of her own infection status. A woman can contract HIV infection from unprotected sex with an

infected partner, from receiving contaminated blood, from non-sterile instruments (as in the case of injecting drug users), or from contaminated medical procedures.

NGO: Non-Governmental Organisation

PMTCT - Prevention of Mother-To-Child Transmission: The prevention of the transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery or breastfeeding.

Replacement feeding: feeding infants who are receiving no breast milk with a diet that provides the nutrients infants need until the age at which they can be fully fed on family foods. During the first six months of life, replacement feeding should be with a suitable breast-milk substitute. After six months the suitable breast-milk substitute should be complemented with other foods.

TASO: The AIDS Support Organisation

UNAIDS: The Joint United Nations Programme on HIV/AIDS

UNFPA: United Nations Population Fund

UNICEF: The United Nations Children's Fund

WHO: The World Health Organization

Contents

Executive summary	I
1. Introducing Mother-To-Child Transmission and FARM-Africa	3
2. Mother-To-Child Transmission and Infant and Young Child Feeding practice: The Ugandan experience.....	7
3. Researching Infant and Young Child Feeding practices: A qualitative approach	20
4. Which Infant and Young Child Feeding options are HIV-positive mothers being offered and from which sources?	23
5. Which Infant and Young Child Feeding practices are being chosen and what factors affect their selection?.....	29
6. Is goat's milk a culturally and economically viable option?	39
7. Examining goat's milk and Mother-To-Child Transmission: Options for action	42
References	44

Executive summary

UNICEF, UNAIDS, WHO and UNFPA and the Ministry of Health of Uganda (MoH) recommends that HIV-positive mothers, who cannot afford to use an acceptable, feasible, affordable, sustainable and safe (AFASS) replacement feeding option should exclusively breastfeed for six months. If a mother does decide to exclusively breastfeed, she is advised to use an AFASS replacement feeding option as soon as she stops practising this method. However, finding a replacement feeding option that satisfies these criteria is exceedingly difficult to achieve for the majority of HIV-positive mothers in sub-Saharan Africa. They are therefore posed with a difficult dilemma. Should they breastfeed exclusively to ensure their infants receive their complete nutritional requirements but at the risk of passing on the virus, or should they opt for a replacement feeding option which eliminates the risk of passing on the virus but increases the risk of malnutrition, diarrhoea and pneumonia?

In order to address this dilemma, this report explores three main areas. First, it assesses the policy framework for the Prevention of Mother-To-Child Transmission of HIV (PMTCT) and Infant and Young Child Feeding (IYCF) in Uganda. Second, it examines the reality of how these policies are being implemented at the grassroots level in the Mbale region, Uganda, and the contribution that NGOs such as The Aids Support Organisation (TASO) can have. Finally, it explores the cultural and economic viability of HIV-positive mothers in the Mbale region using goat's milk as a replacement feeding option for their infants from when the mother stops practising exclusive breastfeeding.

This report reveals how wide the gap between policy and practice in PMTCT really is. HIV-positive mothers have limited sources of information on infant feeding and they often receive conflicting advice. Their support networks are also limited, although the TASO Mama Club is a promising example of how mothers can be offered the support they require. The mothers we spoke to are so frightened of passing on the virus to their infants that they would, and are, doing anything they can instead. The replacement feeding options being adopted are rarely, if ever truly, AFASS and so tragically mothers are leaving their infants at risk of malnutrition, diarrhoea and pneumonia. The MoH and its stakeholders have an important role to play in reducing the gap between policy and practice and reduce the impacts of Mother-To-Child Transmission (MTCT) of HIV and poor IYCF in Uganda.

In conclusion, the report explains how, in the Mbale region of Uganda, goat's milk is culturally acceptable as an infant feeding option and is in demand for its superior nutritional benefits compared to cow's milk, with some mothers already using it. Issues regarding access to goat's milk, correct preparation methods and a lack of awareness of its potential by the MoH and TASO clinic staff are also highlighted. FARM-Africa believes that these issues can be overcome through further research and collaboration with the MoH, TASO and UNICEF.

We therefore propose further clinical research, involving MoH, UNICEF and TASO, to assess the effects of using goat's milk once exclusive breastfeeding has stopped being practised. This should involve recording the quantity, quality and preparation methods of the goat's milk and other foods being used, and assessing the general health condition and weight of the infants being fed the goat's milk. This should be documented over a 12-month period, in order to assess children's growth against WHO and MoH guidelines on recommended child growth rates. If the clinical research successfully shows that infants fed with goat's milk, instead of breast milk once the mother has finished practising exclusive breastfeeding, can grow up healthy, then FARM-Africa would call for MoH and UNICEF to develop IYCF counselling guidance notes to include the use of goat's milk, and offer recommendations.

It is neither viable nor ethical for a Non-Governmental Organisation (NGO) such as FARM-Africa to promote goat's milk for infants under six months old. We adhere to international and national policies on the promotion, protection and support of breastfeeding. However, in the interim, FARM-Africa could collaborate with MoH, TASO and Dr Siraje at Mbale hospital, and adopt the current guidelines for goat's milk preparation recommended by UNICEF, UNAIDS, WHO and UNFPA (2003), including the promotion of folic acid. This partnership could develop a plan which would enable FARM-Africa and TASO to encourage project beneficiaries, who are HIV-positive mothers, to use goat's milk as a replacement feeding option once a mother has stopped practising exclusive breastfeeding.

I. Introducing Mother-To-Child Transmission and FARM-Africa

Mother-To-Child Transmission (MTCT) of HIV is a severe and escalating problem (Ministry of Health (MoH), 2001, 2006a). UNAIDS estimates that 1,800 children become infected with HIV through MTCT everyday, and the majority of these occur in sub-Saharan Africa (UNAIDS, 2007). MTCT can occur at different stages of the infant's life, 15-25 per cent during pregnancy, 50-60 per cent during labour and delivery and 15-25 per cent from breast milk (MoH, 2006a), and it has been estimated that without intervention, 30-45 per cent of all babies born to HIV-infected mothers become infected (UNAIDS, 2007).

UNICEF, UNAIDS, WHO and UNFPA (2003) and the MoH (2006b, 2006c) recommends that HIV-positive mothers, who cannot afford to use an acceptable, feasible, affordable, sustainable and safe (AFASS) replacement feeding option (see Box I overleaf), should exclusively breastfeed for six months, because this is associated with a lower risk of HIV transmission than mixed feeding (Coutsoudis *et al.* 2001). If a mother does decide to exclusively breastfeed, she is advised to use an AFASS replacement feeding option as soon as she stops practising this method. However, finding a replacement feeding option that satisfies these criteria is exceedingly difficult to achieve for the majority of HIV-positive mothers in sub-Saharan Africa. They are therefore posed with a difficult dilemma. Should they breastfeed exclusively to ensure their infants receive their complete nutritional requirements but at the risk of passing on the virus, or should they opt for a replacement feeding option which eliminates the risk of passing on the virus but increases the risk of malnutrition, diarrhoea and pneumonia?

Box 1. Definition of AFASS

- **Acceptable:** The mother perceives no barrier to choosing the infant feeding option for cultural or social reasons, or for fear of stigma or discrimination.
- **Feasible:** The mother (or family) has adequate time, knowledge, skills and other resources to prepare and feed the infant, and the support to cope with family, community and social pressures.
- **Affordable:** The mother and family, with available community and/or health system support, can ably pay for the costs for the purchase/production, preparation, and use of the feeding option, including all ingredients, fuel, and clean water, without compromising the health and nutrition spending of the family.
- **Sustainable:** The mother and family have access to a continuous and uninterrupted supply, through a dependable system of distribution, for all ingredients and commodities needed to safely feed the baby using the chosen method, for as long as the infant needs it, up to one year of life or longer.
- **Safe:** Replacement foods are correctly and hygienically stored and prepared in nutritionally adequate quantities, and are fed with clean hands using clean utensils, preferably with cups.

(MoH, 2006b)

1.1 The FARM-Africa dairy goat development model and its potential to contribute to the challenge of MTCT

FARM-Africa has been successfully developing and implementing Dairy Goat and Animal Health projects in Kenya, Ethiopia, Tanzania and Uganda for the past twenty years and has been operating in the Mbale region in Eastern Uganda since 2003. The project works in Mbale, Sironko, Bududa, Manafwa and Kapchorwa districts and is based on a model that builds the capacity of both the local government extension staff and the local community to ensure long term sustainability.



A dairy goat farmer – part of the Dairy Goat and Animal Health project

The community own and manage buck stations and goat breeding units. An exotic breed of goat is brought in for its higher milk yield and higher growth rate, compared to local goats, and their adaptability to the local conditions. These exotic¹ goats are managed by the community members and cross-bred with local goats to produce generations of goats that are able to produce up to three litres of milk a day².

The Dairy Goat and Animal Health project works in collaboration with a highly reputable NGO called The AIDS Support Organisation (TASO)³. Their mission is to contribute to the process of restoring hope and improving the quality of life of persons, families and communities affected by HIV infection and disease through providing HIV counselling, testing, medical support and advocacy at the personal, family, community, national and international levels (TASO, 2007). By targeting TASO clients, FARM-Africa is able to ensure that HIV-positive people become project beneficiaries. TASO has centres all over Uganda and the Mbale centre covers the districts that FARM-Africa works in. At present, the FARM-Africa project does not specifically target HIV-positive mothers, but some are already benefiting, and there is a huge potential to develop the dairy goat development model to contribute to the prevention of MTCT of HIV, in Uganda and beyond.

In order to explore the potential in FARM-Africa's dairy goat model, the research aims to explore:

¹ Exotic means the goat is not native to the area.

² For further information on the dairy goat model and the other benefits goats can bring to the communities FARM-Africa works with, see www.farmafrika.org.uk

³ For further information, see www.tasouganda.org

- current infant feeding practices of HIV-positive women; and,
- the cultural and economic viability of promoting goat's milk as a way of preventing Mother-To-Child Transmission of HIV in the Mbale region, Uganda.

Section 2 will analyse the current situation of MTCT and infant feeding in Uganda, including the MoH policies and practices and TASO's role. It will also analyse the various definitions of animal milk, and compare the nutritional value of breast, cow and goat's milk.

Section 3 will describe the qualitative methods utilised during the research and the limitations experienced.

Section 4 will present the sources of information mothers are able to access on infant and young child feeding, what they are being offered and why.

Section 5 will explain which IYCF practices HIV-positive mothers are adopting and the reasons for these choices. It also analyses whether the replacement feeding options chosen adhere to the recommendations of being AFASS.

Section 6 will assess the viability of using goat's milk in the Mbale Region. In conclusion it will highlight the issues raised that inhibit and support the viability of promoting goat's milk as a way of preventing MTCT and suggests areas of further collaborative research.

2. Mother-To-Child Transmission and Infant and Young Child Feeding Practice: The Ugandan experience

In Uganda, Mother-To-Child Transmission (MTCT) is the second major route of HIV transmission, after heterosexual intercourse (MoH, 2006a). It is estimated that by the end of 2005, two million Ugandans had become infected with HIV, with approximately 1.438 million people living with the virus, and 950,000 people having died since 1982 (MoH, 2006a). The number of HIV-positive women, especially young women, is considerably higher than other groups (UNAIDS, 2007), and the high fertility rate in Uganda means that a high percentage of babies are being infected with HIV. Currently, it is estimated that 110,000 children under 15 years of age in Uganda are living with HIV (UNAIDS, 2007).



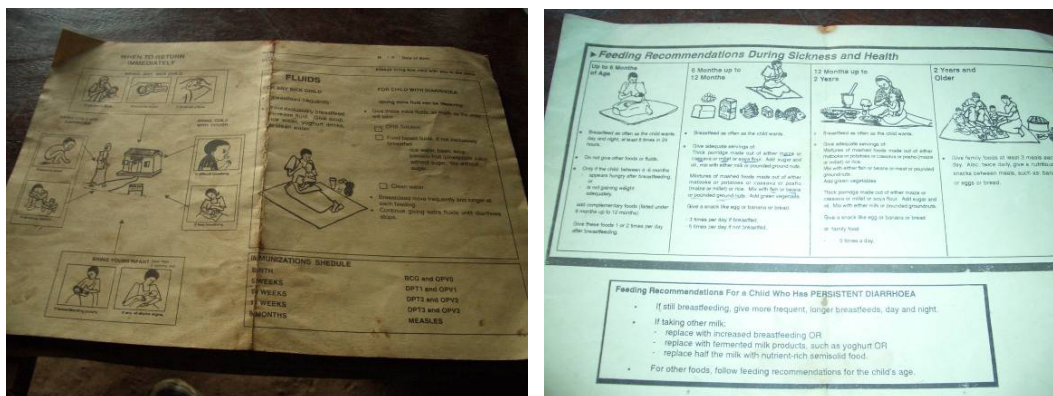
One of the mothers which took part in the research

2.1 Prevention of Mother-To-Child Transmission of HIV and Infant and Young Child Feeding policy guideline review

Prevention of Mother-To-Child Transmission (PMTCT) and Infant and Young Feeding (IYCF) policy guidelines are still a relatively new area of policy in Uganda as evidence proving the transmission of HIV through breast milk only became apparent in the mid-1990s. Initial discussions and workshops at the MoH began in 1997, which resulted in a pilot PMTCT programme being launched in 2000, which was scaled-up in 2004. In 2006 the PMTCT policy guideline was published with contributions from a wide range of stakeholders including UNICEF, WHO and TASO.

The broad objective of the policy is to reduce MTCT by 50 per cent by the year 2010, which adheres to the goals of the UN General Assembly Declaration of Commitment on HIV/AIDS. The policy outlines how this will be achieved by offering different levels of support to HIV-positive mothers at parish, subcounty and district level health centres and the main hospitals. The policy briefly states that HIV-positive women should not breastfeed

but opt for replacement feeding if it is AFASS. However, it does not define AFASS or suggest the best duration for breastfeeding. It recognises that due to social and/or economic reasons some women may still opt to breastfeed but does provide further information on how this can be practised safely.



Infant feeding guidelines for HIV-negative mothers but often given to HIV-positive mothers by local hospitals.

In 2001, the MoH published the first IYCF policy entitled 'Policy Guidelines on Feeding of Infants and Young Children in the context of HIV/AIDS', and the more recently published 'Infant and Young Child Feeding Counselling Guide' (MoH, 2006c) and the 'Feeding of Infants and Young Children in the Context of HIV/AIDS: Question and Answer Guide' (MoH, 2006b). A new National Strategy on IYCF is being developed by the MoH and UNICEF during 2007, as are the new 'Policy Guidelines on Infant and Young Child Feeding' which will include a focus on children exposed to HIV. Additionally, the 2006 'Infant and Young Child Feeding Counselling Guide' is undergoing a minor update. These developments show how committed UNICEF and the MoH are at tackling PMTCT and IYCF in the context of HIV/AIDS. Hopefully these policies and guidelines will filter down to the lower administrative levels and have a real impact on people's lives but, as will be illustrated in this study, there is still a significant gap between policy at the national level and practice at the grassroots level.

For the purposes of this study, we can only reflect on current published guidelines, which state that exclusive breastfeeding for babies under six months of age is recommended unless the mother is able to practice a replacement feeding option that is AFASS. The only exclusive replacement feeding options they recommend are modified cow's milk or infant formula.

Under MoH guidelines (2006a, 2006b, 2006c) mothers whose HIV status is negative or unknown, will be educated to feed their babies as uninfected mothers would do,

breastfeeding up to two years and mixed feeding by gradually introducing cow's milk, porridge, soft foods and then solid foods depending on what the mother has available. For HIV-infected mothers, this feeding programme of 'mixed feeding' increases the risk of passing on the virus dramatically compared to exclusive breastfeeding or AFSS replacement feeding options. HIV transmission to the infant can be increased through:

- damage to the infant's mucous membranes (e.g. by oral thrush) which increases the risk of transmission through breastfeeding;
- damage to the infant's intestinal mucosa by cow's milk or allergic reactions to complementary foods; and
- intestinal permeability caused by mixed feeding (Coutsoudis A et al, 2001).



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2.



3.



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Different IYCF practices carried out in Uganda

1. Breastfeeding
2. Feeding from a bottle
3. Feeding with a cup and spoon
4. Eating soft cabbage from a bowl

When a woman knows she is HIV-positive, and attends a government run clinic or hospital, she should be counselled on infant feeding practices. The infant feeding counsellor is expected to explain each feeding option in terms of the risks, advantages, disadvantages and costs. Box 2 overleaf and Table 1 on page 12 outline the information given to HIV-positive mothers. Box 2 describes the factors which can increase the risk of HIV transmission through breastfeeding and Table 1 illustrates the advantages and disadvantages of the infant feeding methods for infants from zero to six months old. It is recommended by MoH (2006b) that infants and young children from six to 24 months olds receive complementary feeding, whereby they are still given some form of milk, either cow's milk or infant formula, as a replacement for breast milk, but they should also begin to receive foods in addition to this. These foods should be given in small quantities to begin with, increasing as the child grows, and they include animal source foods, legumes/pulses, milk and milk products, vegetables, fruits and the staple food of the family, e.g. matoke, millet, rice, cassava, sweet and Irish potatoes and wheat.

After the counsellor and the mother have discussed each option, they should consider the home and family situation of the mother to help her decide which option is most appropriate for her. The counsellor should then support the mother in her choice, provide specific guidelines and demonstrate the chosen method. For example, if a mother chooses to breastfeed she will be taught good breastfeeding techniques and how to recognise symptoms of problems such as mastitis⁴ so she can get treatment as soon as possible. All mothers should be offered follow-up counselling and support.

⁴ Infection of the nipple.

Box 2. Factors which can increase the risk of HIV transmission through breastfeeding.

- Recent infection with HIV – a woman is more likely to transmit the virus if she has become infected during delivery or whilst breastfeeding.
- HIV disease progression – if the mother has a low CD4+⁵ count or high viral load in the plasma.
- Breast conditions – sub-clinical or clinical mastitis, cracked or bleeding nipples, or breast abscess increase the risk of infection because the baby is exposed to the mother's blood as well.
- Oral thrush/mouth sores in the infant – HIV infection is more likely to pass through open sores.
- Longer duration of breastfeeding – infants are at risk of infection as long as they are breastfed.
- Mode of breastfeeding – exclusive breastfeeding is less likely to transmit the virus than mixed feeding.

Data taken from: MoH (2006b; 2006c), UNICEF, UNAIDS, WHO and UNFPA (2003) and WHO (2004)



One of the mothers with her family and the translator, Sarah, seated on the right.

⁵ A CD4+ count is a blood test to determine how well the immune system is working in people who have been diagnosed with HIV. CD4+ cells are a type of white blood cell. CD4+ cells are also called T-lymphocytes, T-cells, or T-helper cells. HIV infects CD4+ cells and the number of CD4+ cells drops in most people infected with HIV who are not receiving treatment for the disease. A CD4+ count of 1200-600 is the average level for uninfected people. > 350 indicates a low risk of opportunistic infections. < 350 indicates a weak immune system and a high risk of opportunistic infections. 350-200 indicates an even higher risk of opportunistic infections. < 200 indicates AIDS and the highest risk of opportunistic infections. (WebMD, 2007)

Table 1. Infant Feeding Options 0-6 months

	Advantages	Disadvantages
Exclusive breastfeeding under 6 months of age	<ul style="list-style-type: none">• Breast milk is the perfect food for babies, it contains all the nutrition and water they need and it protects them from many diseases, especially diarrhoea and pneumonia.• Breast milk is free and always available and does not need special preparation.• Exclusive breastfeeding may lower a baby's chance of HIV infection compared to mixed feeding.• Exclusive breastfeeding helps a mother recover from childbirth and can help protect her from getting pregnant again too soon.• Many women breastfeed their babies so people will not wonder why she is breastfeeding.• Breastfeeding builds an everlasting relationship between mother and baby.	<ul style="list-style-type: none">• As long as the woman breastfeeds, her baby is being exposed to HIV. The risk is even higher if the mother develops symptoms of AIDS or if she is re-infected with another strain of the virus while breastfeeding.• The woman cannot mix breastfeeding with other foods or liquids when the baby is less than 6 months old because this will increase the risk of passing HIV to her baby.• People may pressure the woman to give her baby water, other liquids or food while she is breastfeeding, and it may be difficult to say 'no'.• Continuing to exclusively breastfeed her baby may be difficult if the woman has to be away from the baby while she works.• Breastfeeding her baby may be difficult if the woman gets very sick.

<p>Home modified animal milk (cow's milk)</p>	<ul style="list-style-type: none"> • There is no risk of passing HIV to the baby through cow's milk. • Cow's milk costs less than infant formula. It is usually easily available. • Other caregivers can help feed the baby. 	<ul style="list-style-type: none"> • Unlike breast milk, cow's milk does not contain antibodies and other substances that protect the baby from infection. • Fresh cow's milk is hard for babies to digest and does not contain everything that babies need to be healthy, such as vitamins, minerals and fatty acids. Fresh cow's milk needs to be boiled. The right amounts of boiled water and sugar need to be added and these are: 0-1months old 40ml milk, 20ml water with 1 level spoon of water per feed, 1-2 months old 60ml milk, 30ml water with 1 rounded spoon of sugar. From 3-4 months old, 120ml milk, no water but 2 spoons of sugar per feed and 5-6 months 150ml milk, no water but 2 teaspoons of sugar per feed. An infant below 6 months of age who is fed on cow's milk also needs a multivitamin syrup or tablet, iron and folic acid. • The baby fed with cow's milk is more likely to get sick from diarrhoea, chest or other infections, and malnutrition, especially if the cow's milk is not prepared correctly or is previously contaminated. • Cow's milk takes time to prepare and must be made fresh each time the baby is fed if there is no refrigerator. • The baby will have to drink from a cup as bottles are difficult to clean and are easily contaminated with germs. • The baby needs about 130 litres of milk for the first six months. The mother will also need to buy sugar and a micronutrient supplement (¼ tablet of iron and ¼ table of folic acid daily). All these will cost approximately Ush82,700 to121,700 (£36) for the first 6 months. • The mother should not breastfeed the baby at all. If she does, the chances of passing HIV to the baby are greater. • The mother needs a reliable supply of clean boiled water, fuel and soap. • People may wonder why the woman is using cow's milk instead of breastfeeding. This could cause them to suspect that she is HIV-positive, and therefore could cause stigma and discrimination. • Women who use cow's milk do not benefit from exclusive breastfeeding's natural protection against getting pregnant too soon.
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<p>Commercial Infant formula</p>	<ul style="list-style-type: none"> • There is no risk of passing HIV to the baby through the infant formula. • Most of the nutrients that a baby needs have already been added to the formula. • Other caregivers can help feed the baby and the mother can have time for herself. 	<ul style="list-style-type: none"> • Unlike breast milk, infant formula does not contain antibodies and other substances that protect the baby from infection. • The baby is likely to get sick from diarrhoea, chest or other infections, and become malnourished if the infant formula is not prepared correctly. • Infant formula is expensive and the mother or caregiver must always have enough on hand. A baby needs a total of forty 500g tins of formula during the first 6 months. This will cost about Ush56,000 per month (£17). Babies, who are 6-to-24 months old, still need infant formula or some kind of animal milk. • Infant formula takes time to prepare, and it must be made fresh for each feed if there is no refrigerator. • The baby will have to drink from a cup as bottles are difficult to clean and are easily contaminated with germs. • The mother should not breastfeed the baby at all. If she does, the chances of passing HIV to the baby are greater. • The mother needs a reliable supply of clean water (that has been boiled), fuel and soap. • People may wonder why the woman is using infant formula instead of breastfeeding. This could cause them to suspect that she is HIV-positive, and therefore could cause stigma and discrimination. • Women who use infant formula do not benefit from exclusive breastfeeding's natural protection against getting pregnant too soon.
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4.



Preparation of goat's milk as an IYCF option

1. Boiling the milk

2. Sieving the milk

3. Re-warming the milk by submerging it in hot water from a flask. A method used in the night

4. Feeding the baby using a cup and spoon

2.2 TASO and its role in Prevention of Mother-To-Child Transmission

TASO does not explicitly offer PMTCT services so they refer HIV-positive mothers to their nearest government hospital or health centre. However, as TASO has regular contact with these mothers during clinic visits, counselling sessions, drug, ARVs or food aid distribution, and home visits, they are in a prime position to counsel them on PMTCT and IYCF.



TASO Mamas Club in Bukedea

TASO counsellors in Mbale are at the forefront of PMTCT and along with the main Mulago centre, they are the first centre to set up a Mama Club. The aim of the Mama Club is to provide a forum for HIV-positive mothers who are either expecting or have children of two years of age or under. They are able to discuss their own experiences of living with HIV as a mother, to offer support and advice to each other and to participate in sessions about personal hygiene, infant feeding, counselling, family planning and the importance of delivery from hospital instead of a home birth. They are also taught about the implications of being pregnant and looking after an infant as an HIV-positive woman because it can further weaken the immune system and even be/or is fatal. A further aim of the group is to develop the group member's income generating, business and group savings skills. The first Mbale Mama Club meeting was held in December 2006 after a period of recruiting and registering 100 participants from Bududa, Budadiri, Manafwa, Bukedea, Mbale, Sironko and Kapchorwa districts.

Discussing personal issues such as HIV status can be extremely difficult for the majority of people, and this is especially relevant in Uganda due to a variety of factors. First, many

people fear to talk openly about their HIV status as stigma still exists in many communities although it is reducing as more people are being educated. Second, the majority of community members are not specifically educated on the infant feeding practices that HIV-positive women should follow so there is often no one for an HIV-positive mother to talk to. Third, in Ugandan culture, people tend to keep their personal issues private and do not discuss them widely.

One of the main objectives of TASO is to build the confidence of the client and to encourage them to disclose their status to their family, friends and community as it helps clients to come to terms with their status, to educate others on HIV and to ensure they have support as a person living with HIV. The people who have the courage to go to TASO have an advantage, as the majority of people are either unaware they might be at risk of HIV infection or are too frightened to get tested and receive the medication, support and education they need to be able to live with HIV. In the rural areas not all mothers attend antenatal clinics, and for those that do, not all clinics have the facilities or resources to test for HIV, so there are mothers giving birth who do not know they are HIV-positive. It is important to realise that it is only the minority of HIV-positive mothers who know their status, have come to terms with it and have received the correct advice and support.

TASO follows the MoH guidelines, with the exception that they mainly promote exclusive breastfeeding up to three months, and only recommend exclusive breastfeeding up to six months for mothers from very poor households. TASO states that through experience of working directly with HIV-positive mothers they have learnt that the majority of them do not want to breastfeed for very long, and often believe they are not able to produce enough milk to exclusively breastfeed for six months. This often means that the mother will resort to a programme of 'mixed feeding' to ensure the baby does not go hungry, which as discussed in section 2.1 can increase the risk of HIV transmission.

2.3 ARVs and Septrin

All HIV-positive mothers, from subcounty level upwards, should also be offered Nevirapine, which is a short course antiretroviral drug (ARV) that is given to the mother during delivery and to the infant within 12 hours of birth and significantly reduces the rate of MTCT (Stringer et al, 2003). Additionally, it is both cost-effective and easy to administer in comparison to other available ARVs. Long term ARVs are only offered to HIV-positive

mothers with a CD4 count below 250 but these are only available at district level health centres and hospitals.

In comparison, TASO is able to offer long term ARVs to all of their clients with a CD4 count below 100. A person on ARVs must continue them for the rest of their life and is meant to have a fulfilling and nutritious diet to ensure they work effectively. TASO therefore distributes food aid⁶ from the World Food Programme every month to these people. Unfortunately due to limited resources a person is only eligible for food aid for approximately six months before someone in greater need comes along. TASO is also able to offer Septrine, an antibiotic which prevents opportunistic infections, to all of its clients regardless of their CD4 count.

2.4 Defining Animal Milk

According to UNICEF, UNAIDS, WHO and UNFPA (2003) modified animal milk can include cow, goat and camel's milk, which can be prepared the same way, and also buffalo and sheep's milk, which must be diluted further due to the higher fat and energy content. Interestingly, in the 2001 'Policy Guidelines on Feeding of Infants and Young Children in the context of HIV/AIDS', the term 'modified animal milk' is also used without a clear definition, although cow's milk is the only example of animal milk provided. In the 'Infant and Young Child Feeding Counselling Guide' (MoH, 2006c) they also refer to animal milk, providing cow's milk as the main example, apart from one example on page 72 where it states that goat's milk may also be prepared and used like cow's milk.

During discussions with UNICEF they explained how they were hesitant to promote goat's milk because there is lack of research into its use for infants and young children in the Ugandan context and that there is a lack of awareness of how many people in Uganda have access to it. In contrast to this, Dr Siraje, felt that the term animal milk includes both cow and goat's milk. This shows that goat's milk is not widely promoted throughout Uganda as a type of animal milk in infant feeding, but is on an international basis.

⁶ Food aid is supposed to feed the whole family for one month however, during the research, everyone the research team met who received food aid said it lasted for only two weeks. They receive 1litre cooking oil, 15kg maize flour, 10kg soya flour, and beans/peas per person per month.

2.5 Comparing goat, cow and breast milk

Breast milk is superior to cow and goat's milk and provides the infant with all its nutritional requirements up to six months of age (MoH, 2001, 2006a, 2006b, 2006c; UNICEF, UNAIDS, WHO and UNFPA 2003; WHO, 2004), and comparative studies (Clark, 2007; Haenlein, 2004) reveal that goat's milk has superior nutritional qualities to cow's milk because:

- It has a higher fat and essential fatty acid content which are beneficial to human health;
- It is easier to digest because it does not contain agglutinin, which prevents the fat globules from clustering together;
- The protein forms a softer curd so is easier to digest;
- It contains seven per cent less lactose than cow's milk;
- It is less allergenic because it contains only trace amounts of the allergenic casein protein, alpha-SI, found in cow's milk. Goat's milk casein is more similar to breast milk;
- It has a similar mineral content to cow's milk, although goat's milk contains 13 per cent more calcium, 25 per cent more vitamin B-6, 47 per cent more vitamin A, 134 per cent more potassium, 400 per cent more copper and three times more niacin;
- It contains more of the antioxidant selenium than cow's milk and breast milk; and,
- It contains the same important bioactive components as breast milk. These bioactive components are able to stop the growth of harmful organisms, and to protect the health of the person consuming them.

The only area that cow's milk supersedes goat's milk is that it contains five times as much Vitamin B-12 and ten times as much folic acid. Therefore, it is recommended by UNICEF, UNAIDS, WHO and UNFPA (2003) that infants given goat's milk should also be given folic acid supplements. Therefore this must be considered an important factor in the viability of using goat's milk as a method of preventing MTCT. There is, disconcertingly, rather little evidence of infant growth and health on exclusive cow or goat's milk feeding.

This section has presented a broad background to MTCT and ICYF in Uganda, including MoH and TASO's roles. The following section sets out the research framework.

3. Researching Infant and Young Child Feeding practices: A qualitative approach

During late 2006, Claire Scrutton, Christine Alokita-Olaunah and Margaret Namugwanya, from FARM-Africa, and Professor Andrew Tomkins, from the Institute of Child Health, collaboratively designed the research questions, framework, and focus group and interview schedules. Christine Alokita-Olaunah and Margaret Namugwanya, both based in Mbale, were also responsible for making the necessary field work arrangements. Claire Scrutton was responsible for collecting the secondary and primary research data, analysing the data and being the lead author of the final report. The field work stage took place between mid-January and mid-February 2007.



Claire Scrutton and Sarah with the Bududa Mamas Club Group

In total, 60 members of TASO Mbale Mama Club participated in the research, and each mother was either pregnant, had a child under two years old or both of these. The majority of them had given birth to other children before and after they became HIV-positive. During the research we therefore asked mothers to discuss the infant feeding practices of children they had given birth to whilst being HIV-positive and to discuss their intended infant feeding practices of any unborn children. In total the research is based on 67 infants from 60 mothers.

The research consisted of six focus group discussions with ten mothers in each. During the focus groups we were able to obtain information on socio-economic data and an overview of the different infant feeding options being practiced by the mothers. We were then able to use this information to purposively select ten mothers that were representative of the entire group, for home visits and semi-structured interviews. We also carried out semi-structured interviews with an elder female relative⁷ if they were available and willing to talk to us. In addition to this we carried out semi-structured interviews with UNICEF, TASO Mbale, Dr Siraje, and antenatal clinic staff from district and subcounty level health centres and hospitals.

3.1 Limitations



Margaret the translator

As a consequence of previous research trips to the Mbale region, Clarie Scrutton had a basic grasp of the languages which are spoken, which enormously helped to build rapport with the mothers. As Margaret Namugwanya was only able to speak some of the languages spoken by the mothers, and was unable to attend all of the focus groups and interviews, it was essential to use a translator. TASO introduced Claire Scrutton to two of their clients to be her translators, who were also HIV-positive mothers, but who were not in the Mama Club or from the same areas as the Mama Club members. The researchers would have preferred to use just one translator but they were

unable to find one who spoke all of the languages and dialects, so they had a second translator in Bukedea. This is a common problem when working in Uganda due to the variety of languages and dialects spoken throughout the country. For the first few focus groups, the researchers asked the Bukedea translator to sit in with us to ensure continuity.

At first the mothers were reluctant to open up, because these issues are not normally discussed in a group situation or in front of a stranger. Having a translator who was also from TASO helped immensely and we did everything possible to make the mothers feel relaxed. Our approach was successful because as soon as one mother began talking, the rest

⁷ The term 'elder female relative' includes mothers, grandmothers, great-grandmothers, aunts, older sisters and mother-in-laws.

followed on. They seemed to really enjoy being able to openly discuss these issues and to find out that there are mothers in similar situations to themselves. During focus group discussions it became apparent that some of them had only found out they were HIV-positive within the last month and it was admirable to see them participating in the group discussion, talking openly about their status and their infant feeding practices.

4. Which Infant and Young Child Feeding options are HIV-positive mothers being offered and from which sources?

This section aims to illustrate the different sources of information and the most and least common options being offered, and concludes by discussing the reasons for the diversity in the options.

4.1 Sources of Infant and Child Feeding information

The main sources of information are from TASO and government-run antenatal clinics, at either subcounty or district level, or at Mbale hospital. The mothers also use radio as an additional source of information. High level support in the home is rare and only the minority of them had a friend or relative who had some level of training or experience in IYCF for HIV-positive mothers.

'My sister-in-law was sick and gave birth and breastfed the baby, the baby got sick and died. But then she was given advice and the next child was not breastfed and it is now healthy and grown up.'

Mother from the Mbale TASO Centre Focus Group

In Ugandan culture, knowledge regarding infant feeding is traditionally passed down the maternal line in families. However, since HIV has become an issue, HIV-positive mothers have begun to seek knowledge from different sources. The mothers spoken to all confirmed that they were originally taught about infant feeding from their own mothers and they followed this advice until they knew their HIV status had changed. It was only the minority of them who said their own mother had also been educated in infant feeding for HIV-positive mothers and so was able to carry on assisting them. For the majority of them, the role of transferring knowledge regarding infant feeding has now reversed and daughters are educating their mothers.

'We are the ones who talk to them.'

Mothers from Budadiri Focus Group

Overall, it can be said that HIV-positive mothers are reliant on a limited range of sources, which can often only be accessed at certain times.

4.2 Options for Infant and Young Child Feeding being offered

HIV-positive mothers are not receiving the same messages as each other on IYCF. In practice, mothers are being offered a range of recommendations that might include one, two, three or four of the options described below in Box 3. The least common are outlined in Box 4. These options are not ranked.

Box 3. The most common infant feeding options offered up to 6 months of age

- A) Exclusive breastfeeding up to 0-6 months.
- B) Exclusive breastfeeding up to 0-3 months followed by either D or E.
- C) Replacement feeding from 0-3 months with cow's milk, water and sugar, varying from pure milk without sugar to 1 cup of milk mixed with 1 cup of water with ½ tablespoon of sugar, followed by either D or E.
- D) Replacement feeding from 3-6 months with either cow's milk, varying from pure milk with sugar to 1 cup of milk mixed with ½ cup of water with no sugar to 1 cup of milk mixed with 1 cup of water with 1 tablespoon of sugar.
- E) Replacement feeding from 3-6 months with cow's milk, porridge, water and sugar, varying from porridge with just water and minimal sugar to porridge with water, milk and sugar. If the mother cannot afford to use just cow's milk, water and sugar, she is told to give watery porridge, in comparison to adult porridge, and add as much milk as she can afford to.
- F) Replacement feeding from 0-6 months with cow's milk, water and sugar, varying from pure milk to 1 cup of milk mixed with 1 cup of water with 1 tablespoon of sugar.

Box 4. The least common Infant Feeding Options offered up to six months of age

- A) Exclusive breastfeeding up to 0-2 months followed by 2-6 months of cow's milk.
- B) Replacement feeding from 0-6 months with infant formula.
- C) Replacement feeding from 0-6 months with goat or cow's milk.
- D) Exclusive breastfeeding up to 3 months followed by 0-5 months of cow's milk, porridge, or ground up beans, or ground nut sauce with cow's milk.
- E) Replacement feeding from 0-5 months millet porridge with cow's milk, water and sugar and pure cow's milk at night followed by replacement feeding from 5-8 months of millet porridge with cow's milk, water and sugar and diluted cow's milk at night.

Some mothers were offered four of the most common options, whereas some were offered more case-specific recommendations of just one of the least common options. In contrast to the recommendations of UNICEF, UNAIDS, WHO and UNFPA (2003) and the MoH (2006b, 2006c), only 60 per cent of mothers were ever offered exclusive breastfeeding for up to six months as an option and one mother reported to have not even been offered this option. They were often given conflicting advice, for example, one mother was told by Budadiri hospital to exclusively breastfeed for up to two months, but TASO told her to exclusively breastfeed for up to either three or six months depending on what she could afford. All mothers were given different methods to prepare the home modified animal milk. This is compounded by the fact that the staff at TASO, Dr Siraje and the antenatal clinic staff also gave the researchers conflicting recommendations for animal milk preparation.

There was less diversity for IYCF practices from six to 24 months old where mothers were advised to choose a replacement feeding option of porridge with sugar (mixed with cow's milk if she can afford it), cow's milk (if she can afford it) and soft food and fruit, e.g. mashed-up potatoes, matoke, green vegetables, egg, pawpaw and avocados. When the child reaches 12-24 months old, they should be fed on exactly the same food that the other older children and family eats. There was no recognition that a replacement feeding option should continue up to two years of age as MoH (2006b, 2006c) recommends.

It is important to note the discussions held with the elder female relatives of the HIV-positive mothers, because only 20 per cent of them said they would advise exclusive breastfeeding for up to six months, stating that this was an option for only very poor mothers. As a first option, for an infant up to three months old, 60 per cent said they would advise using cow's milk, because it is nutritious and there is no risk of HIV transmission, the second option would be a mixture of porridge⁸ and milk because it was less nutritious than just cow's milk, but there was still no risk of HIV transmission. Finally they would offer breastfeeding as the last option because of the risk of HIV transmission. Interestingly, 20 per cent of elder female relatives of the HIV-positive mothers did not feel they had enough knowledge to offer any advice at all.

⁸ The term porridge includes soya, maize and millet varieties made up to a watery consistency, compared to adult porridge which is thick. It will usually have some animal milk added to it but not always, depending on what is available at that time. The mother may also give just animal milk to the infant, e.g. during the night, depending on what the mother can afford, but usually it is mixed with porridge.

4.3 Understanding the diversity in options being offered

Counsellors at TASO and infant feeding counsellors at subcounty, district and regional health centre level are trained to provide mothers with all the available IYCF options, but as illustrated, there is a significant diversity in the options offered and the advice given. The options offered are dependent on factors such as:

- the type of clinic/hospital visited;
- the level and quality of training and experience the person offering IYCF advice had received;
- the area the mother lives in;
- her socio-economic status; and,
- if she received the information verbally or written.

First, the type of hospital or clinic visited has a significant impact. Interviews with antenatal clinic staff and infant feeding counsellors from district and subcounty level health centres and hospitals, and those based at TASO, revealed that only 40 per cent of them offer/encourage exclusive breastfeeding up to six months, and usually it is only for very poor mothers. Mbale hospital encourages exclusive breastfeeding for up to six months as an option to non-working mothers only, and working mothers are educated to exclusively breastfeed for up to three months only because she will be unable to breastfeed once she returns to work. The majority of clinic staff (60 per cent), including all of those at TASO, do not encourage exclusive breastfeeding for up to six months, because most HIV-positive mothers do not produce enough breast milk for the baby from three to six months old. The baby may still be hungry after feeding and this might force the mother to mix feed, which dramatically increases the risk of HIV transmission. Therefore, the option of exclusive breastfeeding for up to three months is offered as an alternative.

Second, the level and quality of training and experience the person offering IYCF advice has received has a considerable impact. Most staff had been trained in infant feeding techniques before HIV became such an issue but now it is current policy that all antenatal staff are trained in PMTCT. At Mbale hospital, there are 13 trained infant feeding counsellors, who have received MoH training in the form of workshops during mid-2006. They had also been given the 'Infant and Young Child Feeding Counselling Guide' (MoH, 2006c) and the 'Feeding of Infants & Young Children in the Context of HIV/AIDS: Question and Answer Guide' (MoH, 2006b). At district level hospitals there are only a few trained infant feeding counsellors, for example there are three in Aturtur hospital and two at Bududa hospital. The

Aturtur hospital staff explained that whenever TASO visited the area they would educate the midwives as much as possible. However, it was not until early 2006 that they started receiving MoH pamphlets and orientation courses by the District Health Service. In July 2006, they were invited for MoH training with other district midwives in Mbale. Before 2006, the Bukedea hospital midwives had to refer HIV-positive mothers to TASO or to Mbale hospital for IYCF. At the subcounty level, there are even fewer trained infant feeding counsellors. In Bududa district, there were only two at sub-county level, one of whom worked for TASO on a part-time basis. When the nurse was recruited by TASO as a community nurse in late 2005, she received training on working with HIV-positive people, including IYCF, and then received further training from the MoH in December 2006. Staff at TASO began receiving training on IYCF in 2003 and have received regular updates from MoH. They also learn through in-house training, publications, the internet, and through training from the Centre for Disease Control, an international research organisation.

One case study mother explained how staff at a village level clinic could not understand why she was not breastfeeding and she had to educate them. This illustrates how slow the process can be from transferring policy into practice at the grassroots level. Discussions with Dr Siraje revealed that in his opinion, apart from at Mbale hospital, antenatal clinic staff in the Mbale region have not received sufficient training on IYCF and nutrition to be able to offer the best advice. Part of his role is to visit and follow-up some of the staff who have been trained by MoH but due to limited time and resources he has been unable to go.

The majority of TASO and antenatal clinic staff did not feel confident in discussing the use of goat's milk in IYCF as it had not been included in their training and that it is less commonly used. It was only Dr Siraje who included goat's milk in the term animal milk and understood how it compared to cow and breast milk. The use of goat's milk as an option heavily depends on the person's level of training and understanding of goat's milk.

Third, instead of every mother receiving the same options regardless of socio-economic status, it appeared that some counsellors and nursing staff were pre-judging mothers on their socio-economic status and selecting which options would be appropriate for them.

Fourth, the area the mother lived in can determine the options she is offered because she might have access to only a small clinic where staff might have had little or no specific IYCF training, or she might have access to a large hospital or TASO clinic where staff have received specific IYCF training. Each TASO counsellor is allocated a specific location to

work in. Although TASO tries to standardise the advice and support it offers, it is possible that women in one area might receive slightly different advice from women in another area, depending on who is passing on the information.

Finally, mothers are rarely given information booklets to take away with them, or have the resources or even the ability to write down what they have been told. Only one of the case study mothers had a MoH leaflet on PMTCT. For anyone in the same situation it would be easy to forget or misinterpret which various options and methods of preparation they had been told. Additionally, when the mother returns home she often lacks the support to be able to discuss these options and check whether she is implementing them properly.

In conclusion we have seen how the options can differ between mothers and some reasons to explain this diversity. This illustrates how a clear transfer of knowledge regarding infant feeding is crucial for PMTCT. In Section 5 we will examine how mothers use this advice and if they adhere to MoH guidelines.

5. Which Infant and Young Child Feeding practices are being chosen and what factors affect their selection?

Of the 60 mothers and 67 infants and young children included in the research, 55 per cent of them were breastfed at some stage, and 27 per cent of them were never breastfed. We were unable to discuss the feeding practices of 18 per cent of infants, due to time limitations, although the majority of them were still unborn.

Sections 5.1 and 5.2 illustrate the options chosen by mothers depending on whether breastfeeding took place at any stage. Due to the diversity of choices, we have included specific reasons as to why each method was chosen, as well as more general lists of reasons as to why a mother might choose to breastfeed and then change to a replacement feeding option or decide to opt for replacement feeding options from birth.

5.1 Breastfeeding followed by replacement feeding options

The study looked at when and the reasons why 55 per cent of those mothers who breastfed transferred to replacement feeding options (see Table 2 overleaf). An HIV-positive mother in the Mbale region might choose to exclusively breastfeed for one or many of the following reasons. They are in no particular order, except poverty which was the most significant reason given. It is important to note that of the 55 per cent who breastfed, only one mother did not breastfeed exclusively. She adopted a practice of exclusive breastfeeding for the first three months and then began mixed feeding with cow's milk at three months and will continue up to six months until she stops breastfeeding entirely. She received advice from TASO and her local hospital who advised her to exclusively breastfeed up to six months but her neighbour advised her to exclusively breastfeed up to three months and then mixed feeding up to six months before stopping breastfeeding. She followed her neighbour's advice because she had never been taught about the effects of mixed feeding and because she had greater trust in her neighbour.

'I have a neighbour who is HIV-positive and she has experience of feeding babies and her baby is healthy. The neighbour said from 0-3 months to breastfeed and then three to six months to mix feed ...I don't have enough milk in the breast.'

Case study mother Bukedea

Table 2. Replacement feeding options for infants who were breastfed

Duration of Exclusive Breastfeeding	Number of Infants fed for this duration	The mother's reasons for cessation of breastfeeding
0-3 weeks old	1	The mother stopped because her breasts were swollen, otherwise she would have continued up to 3 months.
0-2 months old	1	The mother was educated by the hospital to stop at 2 months.
0-3 months old	17	Through the mother's choice or because they could not afford to stop earlier.
0-5 months old	3	One mother had twins and had not been educated properly and another could not afford to stop earlier.
0-6 months old	8	Six mothers could not afford to stop earlier, and only two mothers chose this as their preferred option. Interestingly, three mothers were all from the same area and two of them were sisters who lived together.
0-7 months old	1	The mother could not afford to stop and was going to continue for the time being.
0-9 months old	1	The mother did not know her HIV status but stopped when she found out she was positive.
0-10 months old	1	The mother was bedridden and had no support in feeding her baby, so she was forced to breastfeed.
0-12 months old	2	One mother did not know her HIV status and the other mother could not afford a replacement feeding option and so waited until the infant was one year old when she could begin using solids.
0-18 months old	1	She did not know her HIV status and then she could not afford to remove the baby from the breast when she found out she was HIV-positive.

Box 4. Reasons why a HIV-positive mother in the Mbale region might choose to exclusively breastfeed

- Poverty. Factors that increase poverty are: being too weak/sick to work due to HIV status; being a widow; other family members dying; boyfriend leaving them without support; having a large family with many children to support; stigma within the community which might result in a decrease in social support networks.

'I personally lost my husband and got another husband. When I got pregnant he denied it was his so I didn't have much support. I decided to breastfeed the baby.'

Mother from Bududa focus group

- It will give the mother time to plan and save money for buying cow's milk when she stops breastfeeding.
- She has been educated on the benefits and risks of all infant feeding options and has made an informed choice.
- Lack of knowledge/education that exclusive breastfeeding is preferable to mixed feeding.
- Baby refuses to eat anything else.
- She is afraid to reveal her HIV status by using replacement feeding.
- Pressure from the community/mother-in-law to breastfeed as it is common practice.
- She does not know her HIV status.

Facilitator: Are there any women who breastfed for longer than three months?

Mothers from Budadiri focus group: 'Yes, up to nine months. My husband was sick and did not tell me'. 'Yes, for one year and three months, as my husband was sick and he did not tell me'.

- She is in denial of her HIV status and so feeds her baby as a HIV-negative mother would.
- She does not own a flask so cannot properly store mixed food for the baby at night so therefore risks providing mixed feeding to the child.
- It is easier than replacement feeding options as there is no preparation needed.
- It is cheaper than replacement feeding options as you do not have to buy ingredients, fuel or equipment.
- She believes that breast milk is more nutritious than replacement feeding options.
- Does not have to worry about ensuring the water and milk have been boiled properly and the cups, bottles, spoons and saucepans are clean enough for the baby.
- She does not receive food aid and so there is less food available for the family.
- An AFASS replacement feeding option is not available.



Mother with twins who took part in the research study with Sarah, the translator, on the right

Mixed feeding is a real concern and mothers commented that it was common amongst HIV-positive mothers outside of TASO mainly due to a lack of correct information and poverty. TASO and antenatal staff are aware it is a problem and educate people on this.

'Mixed feeding is common due to economic status, as soon as she gets money she buys milk for one day then she is back on the breast the next day. They chop and change.'

Sister Stella, Mbale Hospital

Even within TASO there are others cases of mixed feeding, one case study mother explained:

Case Study Mother: *'I have a friend doing it and she's also in TASO'.*

Facilitator: *'Why is she doing it?'*

Case Study Mother: *'She can't manage to buy enough cow's milk so she has to feed it with anything she can find, breast milk, cow's milk, whatever'.*

Facilitator: *'What do you think about this?'*

Case Study Mother: *'I saw someone who was mix feeding and her baby got infected. TASO teaches us it's bad.'*

Throughout the focus groups and interviews it became apparent that the benefits of breastfeeding were not being advocated enough by TASO and government-run clinics and hospitals, as recommended by UNICEF, UNAIDS, WHO and UNFPA (2003) and the MoH (2006b, 2006c). Mothers often said:

'They say you are not to breastfeed even if you are very, very poor.'

Case Study mother from Bududa

Mothers often sounded embarrassed and ashamed for having to exclusively breastfeed for even just three months, as if they felt they were failing themselves and their children. This is a critical issue that MoH, UNICEF and TASO need to address in their policies and guidelines and dissemination. The replacement feeding options that mothers adopt will be discussed below, and more importantly, a discussion on whether they are ever truly AFASS.

Box 5. Reasons why a HIV-positive mother in the Mbale region might choose a replacement feeding option

- She has been educated on the benefits and risks of all infant feeding options and has made an informed choice.
'They told me if you breastfeed a baby can get infected through the milk. I decided not to breastfeed.' Case study mother from Bududa
- She wants to reduce the chances of passing on the virus to her baby.
- She can afford to do so, either by herself or because she is being supported.
'My brother supported me to buy milk for up to six months but no more, now the baby is on porridge'. Mother from the Mbale TASO Centre Focus Group
- She is strong enough to work e.g. dig in her own or other people's gardens and earn money. TASO counsels its clients on how to look after themselves and eat properly which helps. Mothers also commented that Septrin and ARVs made them feel stronger than before they went on them.
- She is unable to exclusively breastfeed because she is not supported by her family so she might not trust them to look after the baby properly whilst she works.
- She believes that it is an acceptable, feasible, affordable, sustainable and safe (AFASS) replacement feeding option.
- She is receiving food aid and so has extra food for the child.
- She is open about her HIV status and does not have to hide the fact she is not breastfeeding.
- She is able to clean the cups, bottles, spoons and other infant feeding equipment properly.

5.2 Replacement feeding options without exclusive breastfeeding

Of the 27 per cent of infants who were never breastfed:

- Eight infants were fed on cow's milk from 0-3 months old
- Three infants were fed on goat's milk from 0-3 months old
- One infant was fed on cow's milk from 0-4 months old
- One infant was fed on cow and goat's milk⁹ from 0-6 months old
- One infant was fed on infant formula from 0-3 weeks old
- Three infants were fed on a mixture of porridge and cow's milk from 0-3 months old
- One infant was fed on a mixture of porridge and cow's milk from 0-6 months old

An HIV-positive mother might choose a replacement feeding option for the following reasons: HIV-positive mothers are struggling to do all they can to protect their children from HIV but there are serious questions to be asked about the beneficial effects this is having on the infants themselves.

5.3 Are the replacement feeding options ever acceptable, feasible, affordable, sustainable and safe (AFASS)?

As previously discussed, UNICEF, UNAIDS, WHO and UNFPA (2003) and the MoH (2006b, 2006c) recommends that HIV-positive mothers, who cannot afford to use an acceptable, feasible, affordable, sustainable and safe (AFASS) replacement feeding option should exclusively breastfeed for six months. The MoH put forward its own definitions of AFASS, and these will form the basis of analysing if the replacement feeding options are AFASS or not.

Acceptable:

The mother perceives no barrier to choosing the infant feeding option for cultural or social reasons, or for fear of stigma or discrimination.

The HIV-positive mothers in the research have all received counselling on dealing with stigma, but they felt they were all strong enough to rise above the discrimination due to the support TASO gives them. However, they felt that HIV-positive mothers who do not receive support from TASO are more likely to change their infant feeding option for fear of stigma or discrimination.

⁹ Not physically mixed together.

'Before they used to (discriminate) and point fingers, but now they have stopped and we live together.'

Bududa focus group

Feasible:

The mother (or family) has adequate time, knowledge, skills and other resources to prepare and feed the infant, and the support to cope with family, community, and social pressures.

Although, in many situations, the husband and family members were able to support the mother and assist with feeding, some mothers commented that they did not trust other people to feed their child correctly. Therefore they did not leave the child alone or selected who they left them with.



The different utensils the mothers use to feed their infants and young children.
Note the different levels of hygiene.
The small tube of Soltan cream has been photographed to show perspective.

Affordable:

The mother and family, with available community and/or health system support, can ably pay for the costs for the purchase, production, preparation and use of the feeding option, including all ingredients, fuel, and clean water, without compromising the health and nutrition spending of the family.

Many of the mothers were widows or single mothers, and in families where many of the adults were also HIV-positive or had already died of AIDS, or they had been abandoned by the father of the child. Many of the mothers had lost their jobs due to prolonged periods of sickness, or had been forced to reduce the amount of time they were able to spend in their gardens growing food for consumption and sale. The counselling and medicines that TASO provides does enable people to stay stronger and healthier for longer but food security and poverty are major problems these mothers face on a daily basis. Many end up completely reliant on other people for support. Infant formula is too expensive for HIV-positive mothers in the Mbale region, and the majority of mothers cannot afford the amounts of milk recommended so they dilute it further with water or add porridge as a substitute. After the mother has chosen an initial feeding option, as outlined in sections 5.1 and 5.2, they usually change to this method of diluting milk with porridge and water and introducing soft foods as early as possible. Section 5.2 illustrated how four of the infants were given porridge with milk from birth. These findings are alarming as it is standard practice that porridge or any soft food is not meant to be introduced into an infant's diet until six months of age. A mother from Mbale TASO Centre focus group was recommended to exclusively breastfeed her infant up to three months, and then use cow's milk up to six months, so she did exclusively breastfeed up to three months but then could not afford the cow's milk, so resorted to using mainly porridge 'I cannot afford milk, so I feed her soya porridge, but if I get some money then I buy her some milk.' The MoH (2006b, 2006c) also recommends that all infants and young children on replacement feeding should be given micronutrient supplements, or folic acid if using goat's milk. However, none of the mothers the researchers spoke to were doing this, as they are not trained to use them, they are not commonly used or they are an extra expense they cannot afford.

Sustainable:

The mother and family have access to a continuous and uninterrupted supply, through a dependable system of distribution, for all ingredients and commodities needed to safely feed the baby using the chosen method, for as long as the infant needs it, up to one year of life or longer.

Cow's milk is either sourced from the family's cow(s) or from the local market. The majority of mothers did not have access to cow's milk at home so they had to buy it. They all commented on how, even when they requested pure cow's milk, they would normally be sold diluted milk. This is a common problem and leaves mothers unable to prepare the milk to the exact concentration they want. Goat's milk was being sourced from more trusted sources, in both cases they came from neighbours they had a good relationship with so were able to buy pure goat's milk. A major problem with sourcing milk from animals is that they do not produce milk all year round. This is not a problem if you want cow's milk as it is widely available in the market, but goat's milk is not commonly sold. One mother bought goat's milk from a neighbour with four goats so at least one goat was lactating at one time, but the other mother sourced milk from a neighbour with a single goat, so when the goat was not lactating she was forced to buy cow's milk instead.



The TASO jerry can (in the middle) to be used with waterguard water purifier. The TASO members are all given one.

Safe:

Replacement foods are correctly and hygienically stored and prepared in nutritionally adequate quantities, and are fed with clean hands using clean utensils, preferably with cups.

MoH (2006b, 2006c) state that cow's milk must be prepared using set quantities of milk, water and sugar, and must be made fresh each time, unless there is a refrigerator. Throughout the research, discussions on the methods of preparations were always

interesting and very confusing as everyone, antenatal staff, TASO counsellors, elder female relatives and HIV-positive mothers, all had different opinions. Dr Siraje, the nutritionist, and Gerard Ochieng, medical trainer and TASO counsellor at TASO, were both alarmed by the high quantities of sugar being given to some infants and suggested that this can contribute to the onset of Type 2 diabetes in later life. Water is usually fetched from a protected water source, either a borehole or a tap, and treated with Waterguard, a liquid sodium hypochlorite solution that purifies water, which TASO supplies to all clients free of charge. The water is also boiled during the preparation stage. The MoH (2006b) guide recommends that water from boreholes and taps is not suitable for use in replacement feeding options, but it does not state if it is safe to use with treatments and sufficient boiling. MoH (2006b, 2006c) state that if there is not a refrigerator then the excess food should not be given to the infant at the next feed but either thrown away or given to a sibling. None of the mothers spoken to had access to electricity or a refrigerator. They did not have time to, or could afford to, light a fire or charcoal stove every time the infant needed feeding so they either stored the food in a saucepan covered with a lid, or more commonly, in a thermos flask. The majority of mothers did use cups to feed their infants, as recommended, and many used spoons as well, but there were a few mothers who still used bottles which posed a high risk of bacterial infection if not sterilised properly. The cups, bottles and spoons were washed using cold water and soap by adults and children so it is hard to tell how effectively they are being cleaned. In some cases they were being sterilised by being put into boiling water.

This section has illustrated the alarming reality of IYCF in Mbale region. HIV-positive mothers are receiving often conflicting advice without sufficient support from family and friends or follow-up support from clinics. They are led to believe that breastfeeding is not the best option and feel guilty and ashamed for doing so. Instead mothers are opting for replacement feeding options that are rarely, if ever truly, AFASS and so mothers are leaving their infants at risk of malnutrition, diarrhoea and pneumonia. The next section will analyse how goat's milk is viewed in Mbale region and discuss people's experiences of using it to see if it is a culturally and economically viable option.

6. Is goat's milk a culturally and economically viable option?

Discussions throughout the research revealed that there are no cultural barriers in the Mbale region to using goat's milk, but goat's milk is viewed very differently to cow's milk. The majority of people keep local goats but the milk is not regularly consumed by humans because the local goats only produce enough milk for their own kids.

The majority of the people had never tasted goat's milk, or had tasted it when they were very young, but they all knew that it is thicker than cow's milk and more nutritious. During focus group discussions, the mothers who had first hand experience of drinking and preparing goat's milk, were able to explain its excellent benefits and methods of preparation. There were cases where mothers had been given goat's milk as a child and she had grown fat and healthy, and there were the two mothers who are currently using goat's milk for their own infants and children who praised goat's milk.

'Goat's milk is nicer and more nutritious than cow's milk. After taking goat's milk you feel stronger and more energetic.'

Mother from Bukedea Focus Group

'I have used goat's milk and it's heavy, it tastes good, it's different to cow's milk.'

Case Study mother from Bududa

Similarly to the preparation of cow's milk, there was a great debate about the correct way to prepare goat's milk and no one could agree on a standard method. TASO and antenatal clinic staff were not confident in discussing goat's milk because it had not been included in the MoH guidance books:

'(t)here is no information on goat's milk so we don't teach it.'

Gerard Ochieng from TASO Mbale

The staff were all aware of the benefits of goat's milk, but like the mothers, they also felt that it was not commonly consumed because the local goats do not produce enough milk. They felt that if mothers had access to it then they would appreciate training so they could encourage mothers to use it. It was only Dr Siraje and Ziporah Wamoto, the community nurse and midwife for TASO and Bukigai Health Centre, Bududa District, who knew that goat's milk could be used as a replacement feeding option. Dr Siraje knew that goat's milk

could be prepared in exactly the same manner as cow's milk as it comes under the wider title of 'animal milk' as defined by WHO, UNAIDS and UNFPA (2003). This means for:

- an infant 0-2 months old using 1 cup of goat's milk, ½ cup water, 10 per cent sugar; and,
- an infant 2-24 months old using pure goat's milk with multivitamin syrup.

However, Ziporah Wamoto suggested different concentrations:

- for an infant 0-3 months old using 1 cup goat's milk, 1 cup water, ¼ tablespoon of sugar;
- for an infant 3-6 months old using 1 cup goat's milk, ½ cup water, ¼ tablespoon of sugar; and,
- for an infant 6-24 months old using 1 cup goat's milk, ¼ cup water, ¼ tablespoon of sugar.

Every single mother was willing to try goat's milk and they were all eager to find out how they could access it. However, it is not possible to buy goat's milk in markets at present because insufficient amounts are produced. The researchers found cases where people had received exotic/hybrid goats from Heifer International, Send A Cow, as well as FARM-Africa, which produced a higher yield of milk compared to the local goats. There were also cases where people were feeding local goats with the right quantity and quality of fodder which resulted in increased milk yields. These people usually sold the excess milk to neighbours.

The price of goat's milk is slightly higher than cow's milk, 1 cup/0.5 litres goat's milk costs around 400-500, with a maximum of 750Ush, compared to cow's milk that costs 250Ush or 300Ush per 0.5 litre/1 cup. The reason for the slightly higher value of goat's milk was due to its scarcity and its thickness and nutritional value compared to cow's milk. Mothers indicated they were willing to pay a little higher for this high quality and additional benefits. For those mothers with access to goat's milk already, they made it a priority to be able to buy it.

Access to goat's milk is a major constraint, due to the lack of high milk yielding goats in the area. Organisations, such as FARM-Africa, Heifer International and Send A Cow, have the potential to increase access throughout the region, both directly and indirectly. For example, only a limited number of people are directly involved with FARM-Africa's Dairy Goat and Animal Health project but many more benefit indirectly. In the long term it would be most beneficial for HIV-positive mothers to be direct beneficiaries of these projects.

Alternatively, projects could promote access to buck stations for HIV-positive mothers where they are able to take their local female goat for servicing at a buck station. The

offspring would have a higher milk yield than the local goats, amongst other benefits. HIV-positive mothers would then have a more sustainable source of goat's milk. Similarly, project beneficiaries could target this new market and sell their goat's milk directly to HIV-positive mothers and this could cover periods where their own goats are not lactating. Mothers are already spending money on cow's milk so there is cash available to buy it but it would be preferable to have a trustworthy source of high quality milk, from their own goats and/or a constant supply from goats in the local area.

7. Examining goat's milk and Mother-To-Child Transmission:

Options for action

In conclusion, we have examined how wide the gap between policy and practice in PMTCT really is. HIV-positive mothers have limited sources of information on infant feeding and they often receive conflicting advice. Their support networks are also limited, although the TASO Mama Club is a promising example of how mothers can be offered the support they require. These mothers are so frightened of passing on the virus to their infants that they would, and clearly are doing anything they can instead. The replacement feeding options being adopted are rarely, if ever truly AFASS, and so tragically mothers are leaving their infants at risk of malnutrition, diarrhoea and pneumonia.

FARM-Africa calls upon the MoH and its stakeholders, including the Ministry of Agriculture, Animal Industry and Fisheries, to reduce the gap between policy and practice and reduce the devastating impacts of MTCT of HIV and poor IYCF in Uganda. It is encouraging that the MoH and UNICEF are developing new policies and strategies to develop the PMTCT programme but it will take a considerable amount of time, resources and effort to be published and then filter down to the grassroots level. Discussions with UNICEF revealed that goat's milk still does not play a role in the MoH's PMTCT policy which is perhaps due to the wide recognition of its potential nutritional benefits in the post exclusive breastfeeding period and its recognition by UNICEF, UNAIDS, WHO and UNFPA (2003).

In the Mbale region of Uganda, goat's milk is culturally acceptable and is in demand for its excellent nutritional benefits compared to cow's milk, with some mothers already using it. However, issues regarding access to goat's milk, correct preparation methods and a lack of education for MoH and TASO clinic staff have been highlighted and suggestions on how FARM-Africa and other NGOs can help directly and indirectly to overcome access issues have been discussed.

Issues of correct preparation methods and developing MoH education manuals would require a lead from the MoH itself and UNICEF. Thankfully, discussions with both of them revealed they would welcome the possibility of working with FARM-Africa and further exploring the potential that goat's milk has to play in PMTCT as an acceptable, feasible, affordable, sustainable and safe feeding option.

Therefore, we suggest further clinical research, with appropriate ethical licences, to assess the effects of using goat's milk once exclusive breastfeeding has stopped being practised, involving MoH, UNICEF and TASO. This would involve recording the quantity, quality and preparation methods of the goat's milk being used and assessing the general health condition and weight of the infants being fed the goat's milk. This would be documented over at least a 12-month period, and assessed against WHO and MoH guidelines on recommended child growth rates. If the clinical research successfully shows that infants fed with goat's milk can grow up healthily, then FARM-Africa would call for MoH and UNICEF to develop IYCF counselling guidance notes to include the use of goat's milk, and offer recommendations.

It is neither viable nor ethical for an NGO such as FARM-Africa to promote goat's milk for infants under six months old. We must adhere to international and national policies on the promotion, protection and support of breastfeeding including the International Code of Marketing of Breast Milk Substitutes, The Innocenti Declaration and the Baby Friendly Hospital Initiative (WHO, 2004). In the interim, FARM-Africa could collaborate with MoH, TASO and Dr Siraje at Mbale hospital, and adopt the current guidelines for goat's milk preparation recommended by UNICEF, UNAIDS, WHO and UNFPA (2003), including the promotion of folic acid. This partnership could develop a plan which would enable FARM-Africa and TASO to encourage project beneficiaries, who are HIV-positive mothers, to use goat's milk as a replacement feeding option once a mother has stopped practising exclusive breastfeeding.

In conclusion, this research has shown that goat's milk can make a viable contribution in the challenge to prevent Mother-To-Child Transmission of HIV in the Mbale region but the full extent to which it can be used as an acceptable, feasible, affordable, sustainable and safe replacement feeding option in Uganda is still yet to be realised.

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