



Infant Feeding Options for Mothers with HIV —using women's insights to guide policies

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The objective of this paper is to discuss the difficult and controversial topic of mother-to-child transmission of HIV through breastfeeding. Based in part on a small study conducted in the Kiambu district of Kenya last year, women's ideas, opinions, feelings and preferences regarding infant feeding options for mothers with HIV are presented. The importance of dialogue with mothers in the selection of a feeding choice is discussed and specific ways in which women's views can be used to guide policies on HIV and infant feeding are suggested.

Mother-to-child transmission of HIV^a: importance of the problem

An estimated 590,000 infants acquired HIV-1 from their mothers in 1998; 90% were in Sub-Saharan Africa. About two-thirds were infected during pregnancy or at delivery and the other one-third through breastfeeding¹. Although breastfeeding accounts for only part of mother-to-child transmission of HIV, in countries where both fertility and rates of HIV infection among pregnant women are high, the issue of HIV transmission through breastfeeding is of public health importance². There is a pressing need for countries to develop sound policies on HIV and infant feeding³.

a. In this paper, Human Immunodeficiency Virus (HIV) means HIV-1. Cases of mother-to-child transmission of HIV-2 are very rare.

Infant feeding options for mothers with HIV: the dilemma

Breastfeeding significantly improves child survival by protecting against diarrhoeal diseases, pneumonia and other potentially fatal infections, while it enhances quality of life through its nutritional, psychosocial and many other benefits. As a result, not breastfeeding presents substantial disadvantages and risks to both children and mothers³. Balancing the risks of not breastfeeding, such as increased child morbidity and mortality, versus the risk of HIV transmission through breastfeeding, presents a serious dilemma particularly for mothers in poorer countries, and also for policy makers and health workers⁴.

For poor women living in developing countries the choice not to breastfeed is much more problematic than for affluent women in northern countries⁴. Poor women have inadequate access to resources, including resources necessary to obtain sufficient breast milk substitutes, as well as equipment, fuel and potable water to prepare it safely⁴. If tests were used that showed a mother had infected her infant with HIV in utero or intra partum, then the mother would be advised to breastfeed her infant.

Mothers' rights

Guidelines prepared jointly by UNAIDS and two of its co-sponsors (UNICEF and WHO) in 1998² recommend that breastfeeding should continue to be protected, promoted and supported among HIV-negative mothers and among mothers of unknown HIV status. The guidelines promote fully informed and free choice of infant feeding

methods for HIV-positive mothers. Counseling HIV-infected mothers should include the best available information on the benefits of breastfeeding, on the risk of HIV transmission through breastfeeding and on the risks and possible advantages of alternative methods of infant feeding. The consequence of these recommendations is as follows: compared to HIV-negative mothers for whom the decision to breastfeed is supported by international and national recommendations as well as long-standing cultural practices, mothers with HIV are expected to assume increasing responsibility for infant feeding decisions⁵.

Most previous discussions have focused on weighing competing risks of HIV transmission through breastfeeding against risks of increased child morbidity and mortality associated with not breastfeeding⁶. The opinions of women themselves regarding infant feeding options in the face of HIV have not been reflected in these discussions^{6,7}. As well, relatively little attention has been directed to the problem of preparing mothers to play a more active role in infant feeding decision making.

Challenges for the informed approach

By far the majority of pregnant women are not being tested for HIV, so their status is unknown both to themselves and the health worker⁸. Even where women do get tested, some studies, particularly in Sub-Saharan Africa, indicate that health care providers do not have accurate information to share with HIV-positive mothers^{6,9,10} and may convey a lesser risk for formula feeding than for breastfeeding^{6,9}. The importance of accurate information is illustrated in a study in KwaZulu Natal, South Africa¹¹. In this study, a woman was reported to have said:

I was never told anything about HIV and breastfeeding. I breastfed my baby for 11 months. If I knew anything, I would not have fed him poison, and maybe my baby would have lived a longer time....

According to the authors, because of lack of adequate information, this woman was assuming that her child was necessarily infected through breastfeeding, whereas the child could have been infected in utero or intra-partum.

Considering the complexity of information to be imparted, informed decision-making also faces educational challenges related to common misperceptions regarding HIV/AIDS and mother-to-child transmission of HIV¹². The widespread belief that all babies of HIV-positive

mothers will be born infected which is documented in various studies^{6,9,10,12,13,14} would need to be countered with accurate information on the rate of mother-to-child-transmission and current understanding of the risk of transmission through different routes.

In some communities, a woman's authority to make infant feeding decisions may receive scant respect^{6,7}. For example, in Zimbabwe, decisions about infant feeding are made by the infant's father, the woman's mother-in-law and often the woman's own mother¹⁵. In other countries, some studies suggest that many women refuse to question their health care providers about decisions, partly because they trust them since they possess requisite knowledge^{12,16} and partly because of paternalistic attitudes held by many health care providers.

Early detection of HIV is also needed to enable mothers to recognize their role in infant feeding decision-making¹⁶. Women should receive the information as early as possible, either prior to conception or during prenatal care, to allow sufficient time for reflection¹⁶. The importance of early detection in influencing infant feeding choice is evident in Cape Town⁶. Seventy-three out of 88 HIV-positive mothers interviewed were not aware of their HIV status at the time of their child's birth and only discovered it when their child, or they themselves, became ill. According to the authors, women who knew their HIV status at the time of their child's birth were more likely than others to abstain from any breastfeeding.

Since women are expected to assume responsibility for infant feeding decisions, and also to bear the consequences of whatever method they choose, they should be allowed to voice personal values and preferences related to the options, and make informed choices under conditions of uncertainty about possible outcomes¹⁷. According to Bassett, by learning from those who must make decisions and live with these hard choices, public health workers will be in a better position to offer advice⁷.

There have been relatively few reports, and even fewer published studies, on women's views of infant feeding options, including exclusive breastfeeding, animal milks, wet nursing, heat treating expressed breast milk and others. There is a paucity of data on the perceptions of mothers as decision-makers in guiding policies and counselors' advice. Little attention has been directed to the views of ordinary women in the community, the views of the decision-makers themselves.

Knowledge about women's ideas, opin-

ions, feelings and experiences suggests specific ways in which health care providers can facilitate informed decision-making¹⁸. Providing information about infant feeding options needs to be individualized. This information must be unbiased and accurate to help women make a decision that is in keeping with their personal values and beliefs¹⁸. Truly informed decision-making can only take place when the mother is given both the fullest possible information from which to draw her conclusions, and appropriate, culturally-located support for the course of action she chooses.

Mothers' views of infant feeding options in the Kiambu district of Kenya

Mothers' views on infant feeding options were investigated in one Kenyan community. Mothers were asked what alternative they would choose if they hypothetically tested positive for HIV. A set of infant feeding options was presented to them. These included: expressed and heat-treated breast milk, milk banks, goat's milk, wet nursing, infant formula and cow's milk. Women were requested to give their opinion on all of the options presented.

Site, sample selection and access to sample

Mothers of unknown HIV status attending Nazareth hospital in the Kiambu district of Kenya between June and August 2000 were invited to participate in the study. The criterion for eligibility was to have an infant less than 2 years old. A clear verbal description of the research, its aims and methods, was given to each woman in the local languages (English, Kiswahili or Kikuyu). Only those mothers who gave informed consent were interviewed. Interviews were tape-recorded and transcribed verbatim where consent was given.

Measuring instrument

Since little empirical research exists in this area, a qualitative inquiry seemed to be the most reasonable approach for answering the research question¹⁹. In the first phase of this study, in-depth interviews were carried out with the mothers. Using themes emerging from these in-depth interviews, a semi-structured questionnaire was designed in the second phase. This instrument provided a basic framework for common areas of

beliefs associated infant feeding options in the face of HIV while allowing individual respondents to explore and define particularly relevant issues²⁰. Interviews ranged from 30 minutes to one hour in length.

Data analysis

Data were first displayed in a conceptually ordered matrix in which several research questions were clustered together so that meaning could be generated more easily²¹. This matrix allowed comparison between respondents and lent itself easily to cross-case analysis.

Once the sample of texts were established, data were carefully reviewed line by line, typically within a paragraph, while looking for processes, actions, assumptions and consequences²¹. Beside the paragraph, labels were generated. These labels represented key concepts contained in the paragraph and were phrased in the person's own words, such as *the virus can't die* and *babies should only drink their own mother's milk*. Using this "grounded" approach to coding allowed the researchers to be more open-minded and more context-sensitive compared to using pre-fabricated codes²¹.

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Findings

The data presented in this paper are drawn from 75 face-to-face interviews with mothers about infant feeding options the mothers would consider if they hypothetically tested positive for HIV. The respondents ranged in age from 15-39 years and their HIV-status was unknown to the interviewers. Where appropriate, the respondent's own words have been used to illustrate some interpretative points.

Level of education

As previously mentioned, these women had a moderate level of education. One woman never attended school, 34% of the women had some primary school education, 39% had some high school education, 23% some college education and one woman had university education. Having some college education was interpreted as having undergone some formal training after high school. For instance, tailoring and secretarial training, which typically takes less than two years to complete in Kenya, was included in this category.

To breastfeed or not to breastfeed?

In this study, women seemed undecided about whether they would breastfeed if they tested positive for HIV. Some of the women (55%) stated that they would breastfeed as usual. Among them, some 50% expressed their strong belief that, because their babies would necessarily be HIV-positive even before being tested, breastfeeding could not possibly pose a risk for infection. However, some women (45%) reported they would stop breastfeeding if they tested positive for HIV. One of the respondents said:

The viruses are not so strong in the baby's body, they will get finished with time, if I continue breastfeeding, the viruses will continue getting into the baby's body and the baby will eventually die.

Exclusive breastfeeding

Although 98% of the women in the sample breastfed^b, none of them had exclusively breastfed^c for more than a few weeks, and all infants had been fed water and cow's milk before two months of age. Only 34% of the women stated that they were willing to breastfeed exclusively for three months if they tested positive for HIV. Those who would not choose to breastfeed, gave reasons including the following:

- *Water is necessary to prevent stomach problems*
- *If I don't [give him water] he will get hard stool*
- *I must give him other things to help him grow*
- *I have to give him water to dilute the milk in his stomach and help in digestion*

Stigmatization if women do not breastfeed

One of the respondents interviewed alluded to the issue of stigmatization. She cited the example of her HIV-positive friend who was advised by doctors not to breastfeed, and who told people why she was not breastfeeding. According to the respondent, people were very understanding and did not stigmatize the HIV-positive woman. This respondent narrated:

[I know this HIV positive woman who was advised by the doctors not to breastfeed. This woman told people why she was not breastfeeding her child. In such a case everybody...would understand. But in a case where [a mother] decides just like that not to breastfeed her child, I don't know whether one should not be taken to the police ... of course people may think that the mother is one of these arrogant mothers.

Heat treating expressed breast milk

Only 9% of the respondents would choose to heat-treat expressed breast milk. Some 23% expressed their disbelief that heat treatment could inactivate the virus. One respondent said:

Me, what I believe is that a virus is very strong, I know that they cannot even die through boiling.

Some women, (34%) thought that human milk cannot be boiled *like cow's milk* while others (43%) expressed concerns including *disgusting* and *unhygienic practice*.

Milk banks

Regarding the use of banked milk, only 12% of the women interviewed would consider this option. Reasons against milk banks included *not done in our culture* (62%), *not hygienic* (19%) and *fear of disease transmission* (14%). Regarding culture, one of the respondents noted:

Some people believe in culture, they say, oh, my kid cannot be given milk that belongs to someone else, oh, my kid when she is given such milk [she] will die.

Wet nursing

As with the above infant feeding options, women had strong views about the acceptability of wet nursing. Only 35% would have their infants wet nursed if they tested positive for HIV. Reasons against wet nursing included the belief that *babies should only drink their own mother's milk!* (51%), *fear of disease transmission* (26%) and *not done in our culture* (21%).

Infant formula

Fifty-six percent of the women would consider infant formula. Some women perceived its composition as being close to that of breast milk. Among women who would not consider this option, 65% expressed fear that this milk would have passed its expiry date in the local shops and 20% strongly believed that infant formula *contains things that are not good*. One of the respondents ex-

b. The definition of breastfeeding was open to the respondent's interpretation; thus, breastfeeding included both exclusive and mixed feeding.

c. Exclusive breastfeeding is defined as not giving any other foods or liquids to the baby except breastmilk and medication.

plained:

You know cow's milk is being milked there and then. You can see it is fresh. Tinned milk [infant formula] may have stayed in the shop for long. You can sometimes buy and when you give the baby it might not be good for her.

Goat's milk

Only 23% of the respondents would opt for goat's milk. Women were generally unfamiliar with this option. Some 42% of women said they had never heard of goats being milked. One respondent asked:

Are goats milked? Do they have milk?
[laughter]

Some women (31%) were concerned about the thickness of the milk, which would cause constipation, while others (23%) thought that because *even adults don't* infants should not be fed goat's milk.

Cow's milk

Some 87% of the women stated that they would use cow's milk without being prompted. Reasons included its wide availability and the belief that it is "fresh" relative to infant formula. However, women did not seem to know how to modify cow's milk to be nutritionally adequate. Regarding dilution, 64% thought that, for cow's milk to be nutritionally adequate for any two-week old infant, the volume of milk should be more than that of water, 18% thought that water should be more than milk, and another 18% that both volumes should be equal. Regarding supplementation, only ten percent of the women would add glucose, salt or sugar to the milk; none of the women would include a micronutrient supplement.

Discussion

In this setting, the majority of women thought that cow's milk was the most acceptable alternative. In Kiambu district, cow's milk is sold in local shops and kiosks, and is relatively cheap. A price comparison showed that the cost of cow's milk is 12% that of infant formula in the local shops (\$28 versus \$232 for six months' supply for an infant).

However, according to Yeung and co-workers, the use of unmodified cow's milk for

infant feeding is not ideal and may present additional challenges, especially if it is used to replace either breast milk or formula in the first six months of life²². This is because unmodified cow's milk may lead to iron deficiency anemia²³ and, due to its high protein content relative to breast milk, cause constipation in young infants²⁴. Modifying cow's milk to make it nutritionally adequate for young infants requires dilution as well as supplementation with iron and other micronutrients².

This study indicates that women do have strongly held views and opinions about the acceptability of infant feeding options in the context of HIV infection. However, it is important to recognize that a group of mainly Kikuyu women from Nazareth hospital is probably not representative of all African, Kenyan or Kikuyu women. These women were peri-urban. They were neither affluent, nor very poor. Most of them had some schooling and they had reasonable access to health care. Such characteristics may not be present in much of Africa. Hence, the conclusions of

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this research cannot be generalized to other women with different socio-economic status, access to health care and level of education may be different. The need for policies and

advice to be appropriate for cultural settings, geographic locations and levels of living cannot be overemphasized.

In addition, women in this study were asked a hypothetical question about infant feeding choices if they tested positive for HIV. One way to assess acceptability is to ask women what they think and what they would do, given a choice⁷. This hypothetical scenario is more successful at capturing negative responses. If women do not like something hypothetically, they will probably not use it in practice. However, experience suggests that the best way to assess what women will do is to offer them choices and see what they actually do. In actual decision-making, significant individuals such as husbands and mothers-in-law may influence women's infant feeding choices. The validity of answers to these hypothetical questions cannot be assumed.

Recommendations: using women's views to guide policies on HIV and infant feeding

For each mother to be able to make a truly informed choice in the face of this complex issue,

information developed from an understanding of mothers' perspectives is needed. Developing this "grassroots" knowledge is crucial because of the dramatic shift in the locus of decision-making for infant feeding that has occurred with HIV. For HIV-negative mothers, the decision to breast-feed is supported by international and national recommendations as well as long-standing cultural practices. However, according to international guidelines, for HIV-positive mothers the decision whether or not to breast-feed is to be made by each mother. This decision should be fully informed and of free choice.

As recommendations for fully informed and free choices of infant feeding methods are made for HIV positive mothers, it is necessary to reflect on what fully informed decision-making really means. Compared to paternalistic decision-making where health care providers have the responsibility to make decisions, the medical literature indicates that there are two models for informed decision making. In the first model (shared informed decision) the health care provider helps the woman assess the impact of her choice with regards to her values and lifestyles. In this case, both the woman and the health care provider reach the decision and the option is consistent with the woman's values and preferences. In the second (purely informed decision), the health care provider also informs the mother about the options available to her. However, the mother alone is responsible for making the decision (assuming she is accurately informed), whatever choice she makes is the correct one, and she should not be persuaded to change her mind²⁵.

In the case of a mother who opts to use cow's milk in early infancy, according to the purely informed decision making model, if she is accurately informed, she should not be persuaded to change her mind. However, she should be taught how to modify cow's milk to make it nutritionally adequate and safe. According to the shared informed decision-making model, such a mother could be educated on how to modify cow's milk and supplement it with micronutrients; or she might be persuaded to choose another feeding option.

If services are to be shaped by women's views, methodologically sound ways of obtaining their views and encouraging them to come forward and present them are needed. It is not easy to get representative views, for all countries have their bias, and opinions change over time. In all cases however, providing women with accurate, high quality, up to date information is an important starting point²⁶.

Conclusions

At present, the proverbial black box exists between the policy of fully informed and free choice of infant feeding method, and women's actual infant feeding decisions. In this paper, some new approaches in facilitating fully informed and free choice of infant feeding method in the face of HIV have been suggested. As previously mentioned, many factors may influence women's infant feeding decisions, including values and preferences, significant others and the availability of resources.

This paper has discussed women's beliefs, values and feelings about different options, and how these may affect their infant feeding intentions. It is important to recognize that views may be much influenced by women's current knowledge regarding options discussed. For example, as discovered, if women do not know about goats being milked or even about milk banks, then these options will not be adequately considered. In addition, it is suggested that women may be educated to shift away from an option they chose. However, to modify women's beliefs, values or preferences, these have to be known in the first place, and this "grassroots" knowledge used to inform appropriate policies on HIV and infant feeding.

Since each mother will bear the consequences of whatever infant feeding option she chooses, it is important that information be developed from an in-depth understanding of the mother's own perspectives. The mother's values, preferences and feelings should be respected. Finally, her views, the views of the potential decision-maker herself, should be used to inform policies and programs on HIV and infant feeding.

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Discussion



Question from the audience This paper raises some controversial areas that will be discussed for the next few years. Firstly, within UNICEF, I have criticized the UNAIDS/UNICEF/WHO Guidelines because our own staff see only two options: breastfeeding and infant formula. In our pilot trials to prevent mother to child transmission, in all countries except Tanzania, UNICEF has actually convinced mothers to use infant formula. Those in the nutrition community, who really support exclusive breastfeeding, and the infant formula companies, have similar views on the range of options available to mothers: they see only two options. The infant formula companies write on the package labels “exclusive breastfeeding is best but if you can’t do that you should use formula.” Nutritionists tend also to see only exclusive breastfeeding as a choice and no other feeding method. Lucy Hair’s paper deals with all options available to mothers which opens up research and this is most welcome. Secondly, can mothers really make informed decisions? I believe that children have a right to be breastfed and mothers have an obligation to breastfeed. In addition, all the people around those mothers have an obligation to make it possible for mothers to breastfeed. If the mother does not breastfeed her baby, we should not blame the mother. We should look carefully at the environment in which she lives. How can we expect a poor mother, who lives in terrible conditions and who is HIV positive, to make informed decisions?

Lucy Thairu To discuss whether informed choice is possible or even relevant in Sub-Saharan Africa, it is important to first look at its origins. In Europe and in the United States, informed decision-making has its origins in consumer science and in product development where people are given all available information regarding different choices before they make a decision. Another origin is the feminist movement where informed decision-making counters the paternalistic model in which doctors make decisions for women. Here, the informed decision-making model empowers women to make their own decisions.

Question from the audience We, the UN agencies, have been promoting alternatives to exclusive breastfeeding and not only formula. This is part of the UNAIDS/UNICEF/WHO Guidelines. Concerning the field questionnaire, have these mothers been supported in the past in their efforts to exclusively breastfeed? There is evidence from randomized controlled trials in different settings (including poor and middle income communities in Sri Lanka, Mexico, Brazil and Bangladesh) showing that it is possible to increase the rates of exclusive breastfeeding with counselling. There is a training course on breastfeeding counselling and there is a tool on HIV and infant feeding counselling. These tools deal with informed choice.

Lucy Thairu The issue of exclusive breastfeeding is important. Some mothers in the survey felt there was a need to dilute their breast milk with water so their infants would not get constipated. They said the same thing about cow’s milk. If exclusive breastfeeding is to be promoted effectively we need to find out what mothers are thinking about exclusive breast feeding and then make policies and programmes that are coherent with their views. Women’s views on exclusive breastfeeding have been studied extensively in both Sub-Saharan Africa and Latin America. We need to put these findings to good use, and meet mothers half way.

Comment from the audience UNICEF and the infant formula companies may promote only two options, but nutritionists in countries in this region have a broader perspective. In Zimbabwe our guidelines for the prevention of HIV transmission describe all the alternatives. Sometimes we find that the international agencies do not want to listen to us.

Question from the audience What about adding micronutrients to cow’s milk? As in Kenya, mothers in Tanzania feel the need to add water to cow’s milk. Why not provide a supplement to the infant via cow’s milk?

Lucy Thairu Women in my study were unsure about how they should modify cow's milk. When I asked them what volume of water should be added to cow's milk, 64% said that water should be more than cow's milk, 18% indicated that water should be less than cow's milk, while 18% of them said half and half. None of the women said anything about addition of micronutrients but they often added sugar to the cow's milk. Therefore, if mothers with HIV choose to use cow's milk, they would need information on how to modify cow's milk to make it nutritionally adequate.

Minister Dlamini In Africa, we need more local studies like this to document nutrition-relevant behaviours so that programmes are not designed in a vacuum. Concerning informed choice and decision-making, HIV has brought many difficulties for service providers whether it is in a hospital setting or society at large. Even in the simplest society where illiteracy is prevalent, illiteracy must not be mistaken for stupidity. When people are literate or semi-literate, it makes our job much easier. We owe it to all individuals to supply them with the information they need to know so that they can decide what is best for them. I don't agree that we should use one standard in the West and another in Africa. This is immoral and unethical. The challenge for us is to communicate simply and clearly in everyday vernacular. Let us tell them what is available and let them decide.

Question from the audience In terms of how to treat mothers in their decision-making, are we promoting the idea of shared information? And does not shared information compromise and commit the service provider in that decision making process?

Lucy Thairu The data collected in this study was not on shared, informed decision-making. This study was about what women's feelings and perspectives are about different infant feeding options. More research is needed in terms of shared, informed decision-making that would investigate in particular interactions between HIV-positive women and their health care providers.

Comment from the audience In our work we found very similar results about what women would do should they find that they were HIV positive. We have followed up the women who tested HIV positive. Most often these women really don't have much choice. Even if they say they would make a particular choice (should they test positive) in the absence of providing alternatives to these women, 95% choose to breastfeed.

Comment from the audience The recent technical consultations^a set up to review issues surrounding mother to child transmission have recommended possible alternatives to breastfeeding, but workers in the field ask "Where do we start?" This field study provides findings that can influence policy because it starts with what mothers already know about and can build upon.

^a Editor's Note: These consultations include the WHO Technical Consultation on Infant and Young Child Feeding held in Geneva, March 13-17, 2000, and the WHO Technical Consultation on Mother-to-child Transmission of HIV, held in Geneva, October 11-13, 2000.