

Sociocultural influences on infant feeding decisions among HIV-infected women in rural Kwa-Zulu Natal, South Africa

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Abstract

The promotion of exclusive breastfeeding for 6 months, followed by rapid transition to alternative food sources may be an important public health approach to the reduction of mother-to-child transmission of HIV through breastmilk. The basic ethical principle of 'informed choice' requires that HIV positive women are provided with adequate information about their options. However, information is only one factor that affects their decisions. The objective of this ethnographic study was to identify sociocultural influences on infant feeding decisions in the context of a large cohort study designed to assess the impact of a breastfeeding counselling and support strategy to promote exclusive breastfeeding on postnatal transmission of HIV in African women. Following an initial period of exploratory interviewing, ethnographic techniques were used to interview 22 HIV positive women about their views on infant feeding and health. Interviews were tape-recorded, transcribed and analysed with a text analysis program. Five themes of influences on feeding decisions emerged: (1) social stigma of HIV infection; (2) maternal age and family influences on feeding practices; (3) economic circumstances; (4) beliefs about HIV transmission through breastmilk; and (5) beliefs about the quality of breastmilk compared to formula. The study highlights the role of cultural, social, economic and psychological factors that affect HIV positive women's infant feeding decisions and behaviour.

Keywords: family influences, stigma, economic constraints, beliefs, ethnography.

Introduction

Breastfeeding significantly improves child survival by protecting against diarrhoeal diseases, pneumonia and other potentially fatal infections, while also

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enhancing quality of life through its nutritional, psychosocial and other benefits. The discovery that HIV can be transmitted through breastmilk has precipitated a public health dilemma, particularly in countries where HIV affects significant proportions of the population and where breastfeeding is the cultural norm (DeKock *et al.*, 2000). However, the finding that exclusive breastfeeding (see Table 1 for definitions of

Table 1. Definitions of feeding (World Health Organization).

Breastfeeding pattern	Definition
Exclusive breastfeeding	Giving the infant no other food or drink, not even water, apart from breastmilk (including expressed breastmilk), with the exception of drops or syrups consisting of vitamins, mineral supplements or prescribed medicines
Mixed feeding*	Giving a baby some breastmilk and also any other fluid or feeds, even a teaspoon of water
Replacement feeding	The process of feeding a child who is not receiving breastmilk with a diet that provides all the nutrients the child needs, until the child is fully fed on family foods
Complementary feeding	Giving other foods (called complementary foods) in addition to breastmilk

*This definition is not included in the WHO statement, but has come into common usage in HIV transmission research.

infant feeding terms) may be as effective as replacement feeding in reducing mother-to-child transmission (MTCT) of the disease (Coutsoudis *et al.*, 1999) raises new hopes that MTCT can be reduced in conditions where safe and nutritionally adequate replacement feeding is difficult to achieve.

In the present situation of incomplete knowledge about the safety of exclusive breastfeeding and solid knowledge about the risks of replacement feeding in environments with poor sanitation and economic constraints, HIV positive women face difficult choices about how to feed their infants (Latham & Preble, 2000). The basic principle of 'informed choice' requires that HIV positive women are provided with adequate information about their options (United Nations, 1990). In line with this principle, guidelines prepared jointly by UNAIDS and two of its partner agencies (UNICEF and WHO) promote fully informed and free choice of infant feeding methods for HIV positive mothers (UNAIDS, 1998). Counselling HIV-infected women 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.

However, information is only one factor influencing women's decisions. In principle, informed decision-making can only take place when women are provided with individualized, unbiased and accurate information about infant feeding options, and when this information is presented in a way that is compatible with women's belief structures (Thairu, 2001). The context within which information is made available is also critical, and, in reality, the constraints may be so great that women cannot make an informed choice. Under these circumstances it is even more important to provide culturally compatible support for the decision-making process, which requires attention to the decision makers themselves and their social context.

The objective of this ethnographic study was to investigate sociocultural influences on infant feeding decisions in a sample of HIV positive women who had been given counselling about infant feeding and HIV. The investigation was embedded within an ongoing study designed to examine the postnatal transmission of HIV in a cohort of women who choose to exclusively breastfeed (Africa Centre for Health and Population Studies, 2001). Women attending prenatal care are provided with free HIV counselling, testing and provision of nevirapine if they are positive. Both infected and uninfected women are invited to join the study.

Background

The large cohort study is being conducted in rural Kwa-Zulu Natal, South Africa, where the prevalence of HIV infection among pregnant women is close to 40%. The area has a population of about 220 000 that is entirely Zulu speaking. The economy is mainly agricultural, with gum trees and sugar cane being the main cash crops. Most people in the district derive their income by working on plantations. However, these sources of formal employment are limited, and there is a high level of unemployment – over 59% of the population in the 15–64-year-old age group is unemployed, which is almost double the national average of 34% (Curtis *et al.*, 2002). There is one government hospital in the northern part of the

region, 14 fixed government clinics and two mobile clinic services that provide health care in the more rural areas. In 2001, over 95% of the public health care workers were nurses. There were six full-time doctors and 349 registered traditional healers, as well as an unknown number of unregistered traditional healers (unpublished).

Drawing on a small sample of mothers enrolled in the larger cohort study, this study explores the role of cultural, social, economic and psychological factors in women's decisions about infant feeding and their subsequent practices. To appreciate the significance of this focus, it is important to know that the cultural pattern in the study region is one in which mixed feeding is the norm, but exclusive breastfeeding is not (Bland *et al.*, 2002). Infants are given breastmilk substitutes when their mothers are away from home and they are left with other caregivers (Bland *et al.*, 2002). Typically infants receive semisolid foods before the recommended time for introducing complementary feeds (i.e. 6 months of age). Giving foods, teas and other liquids is motivated by well-established beliefs about how infants should be fed.

Previously, in this area, only a very small minority of infants exclusively received breastmilk or formula milk in early infancy (Bland *et al.*, 2002). Customarily, the baby is put to the breast within a short time after delivery, and during the subsequent weeks the breast is used as a comforter/pacifier even when the infant is predominantly replacement fed. Thus, the success of the ongoing cohort study in reducing HIV transmission through breastmilk depends on its ability to change strongly held cultural practices and beliefs.

Methods

The ethnographic study was conducted in the period June–August 2002. Informed consent was obtained from all the individuals who participated in the study, and approval was obtained from the research ethics committees of both the University of Natal and Cornell University. To prepare a set of guiding questions for interviews with the mothers, the results of which are presented in this paper, the principal investigator (L.N.T.) and her research assistant (N.N.), first

carried out in-depth exploratory interviews with counsellors and nurses working for the Africa Center project; observed routine, individual counselling sessions in women's homes; and attended five routine, group counselling sessions held in participating clinics.

The exploratory interviews were very open-ended discussions in which respondents were encouraged to talk about their experiences, and questions took the form of probing for detail, with encouragement such as 'Can you tell me more about that?', 'Could you give me an example of ___?', 'What did you feel when that happened?'. By the end of this first round of interviews, a number of issues or factors that appeared to be related to feeding choice were identified.

We then created a set of cards to use in interviews with a small sample of mothers enrolled in the cohort study. Each card contained a word or phrase, written in Zulu, that was used as the stimulus to discuss a specific issue or factor that we felt was relevant for women's decision-making. The content of the cards was as follows: (1) work; (2) school; (3) what you know about HIV; (4) your health; (5) your baby's health; (6) people living with you; (7) hospital's view of breastfeeding; (8) how your counsellors advise you to feed your child; (9) your partner's knowledge of HIV; (10) your family's knowledge of HIV; (11) your friends; (12) what you believe about formula feeding; (13) what you believe about breastfeeding; (14) cost of formula feeding; (15) what you fed the children you already have.

There are six clinics participating in the larger cohort study; women in the cohort are assigned to a clinic based on their place of residence. Two clinics were chosen for the interviews: one because it was the most rural of the six, the other because it was the most urban. As of June 2002, there were 205 HIV positive women enrolled in the cohort study. From this cohort, women who had already delivered were asked if they would be willing to be interviewed when they came to the two clinics for routine postnatal visits. None of the women we approached refused to participate.

In this way, we recruited a sample of 22 women for the semi-structured, ethnographic interviews. These women constitute a convenience sample in the full sense of the word because they were women who

happened to attend the clinics on the days during which we were interviewing.

In interviews with the mothers, we would shuffle the cards we had previously developed, show them, one by one, to the respondent and ask: 'how did [concept written on the card] influence your choice of infant feeding?' For example, 'how did your friends influence your choice of infant feeding?'. As some of the women did not read comfortably, the word or phrase on the card was always read to them. The advantage of the cards as an interview tool was that women found it fun. The technique helped to make them feel comfortable talking about sensitive topics.

As most women did not speak English, interviews were carried out with the help of a Zulu-speaking research assistant from Hlabisa (N.N.). All interviews were tape-recorded and transcribed using standards required for conversation analysis, which include notation of hesitations, pauses in conversation and laughter (Seale & Silverman, 1997). The text retrieval software (NUD*IST), was used to code the text (QSR, 2000). To start, any text concerning infant feeding was extracted, and coding was done at several levels, beginning with broad descriptive coding (e.g. 'formula'), followed by more refined coding as the text analysis progressed (e.g. 'no money to buy formula'). The next step in the analysis was to compare interview content across respondents. Although the coding system made it easy to compare responses to the specific cards, this analytic approach failed to capture the context of the statements, which were important for understanding their meaning. We therefore turned to a different type of analysis in which we searched for themes that appeared in more than one interview. For each theme, the context of the statement and characteristics of the respondent were noted in order to build a fuller description. The findings from the study are presented here in terms of these themes as they relate to the women's decision-making about how to feed their infants.

Results

The characteristics of the ethnographic sample are shown in Table 2 in comparison with the full cohort study. Compared to women in the larger cohort study,

Table 2. Characteristics of the full study cohort (as of June 2002) and the ethnographic study sample.

Characteristic	Full study cohort N = 205	Ethnographic study N = 22
Mean age (SD)	26.1 (8.5)	27.5 (6.6)
Median parity (range)	1 (0–8)	2 (1–6)*
Highest educational level achieved (%)		
None	15 (7)	Not asked
Some primary	99 (49)	
Some secondary	52 (25)	
Completed secondary	39 (19)	
Mother is main income provider (%)	20 (10)	6 (28)
Infant feeding choice		
Breastfeeding	187 (91)	17 (77)
Formula	18 (9)	5 (23)

*All 22 women had delivered; their infants were all under 6 months of age.

women in the ethnographic sample were more likely to be the main income providers (28% vs. 10%) and to have chosen formula feeding (23% vs. 18%).

Theme I: Social stigma of HIV infection

A pervasive theme identified in the interviews with the 22 women was the stigma associated with HIV and the relationship of choice of feeding mode to social disapprobation. In a community where breastfeeding is normative in the strongest sense of the word, choosing replacement feeding would have seemed abnormal, even prior to the advent of the HIV epidemic. Now there has been sufficient public discussion about transmission of the virus through breastmilk that choosing to bottle feed is tantamount to announcing that one is HIV positive.

Negative attitudes toward victims of the disease were a common theme in the interviews. For example, one woman described her family's (general) reaction to HIV positive people as follows:

I always hear when they talk about HIV positive people, they isolate them [...] as if, if you [have] the virus, you are [...] not behaving good. They don't know you can get the virus in whatever way.

¹Indicates that text has been modified to facilitate readability.

As a consequence of negative community attitudes, women face a very difficult decision about whether to disclose their HIV status when they learn they are infected. Most of the women we interviewed had decided not to disclose their status, even to their families. A woman who had chosen breastfeeding and kept her status confidential from her family noted: 'I don't see the reason for that, to tell them [I am HIV positive]? There is no need, there is nothing I need to discuss with them.'

The minority of women we interviewed who had decided to use replacement feeding discussed the relationship between their feeding choice and disclosure. One woman, who had negotiated formula feeding with her husband, and whose husband knew of her HIV-positive status, said:

What I am doing is none of their business, people talk, you know? If they see these cars [from the Africa Center] coming [for home visits] they start talking [saying] you know she is HIV positive, [they speak] of something they don't know, so you just need to [ignore] them.

For women who deliver their babies in local hospitals, the dilemma of disclosure in relation to feeding choice is immediate at the time of delivery. Most women perceived the hospital personnel as being supportive of breastfeeding (Table 3) and that not breastfeeding in hospital therefore required disclosure of their status. As one counsellor explained to the interviewer:

... hospitals [here are] baby friendly, they promote breastfeeding, so when [mothers] come to hospital [they] have to explain to the nurses why [they] are not breastfeeding, [so

Table 3. Women's perceptions about the mode of infant feeding promoted in local hospitals.

Perception	No. of mothers expressing this view (% in brackets)
'Hospitals encourage breastfeeding'	16 (73)
'They didn't tell us anything'	1 (4)
'They say it's your choice'	1 (4)
'They don't encourage breastfeeding'	1 (4)
Question not asked	2 (9)
Total	<i>N</i> = 22 (98*)

*Less than 100% because of rounding.

they think] think ah, rather than explaining [they are] HIV positive [...] let me breastfeed. [Mothers] don't want their status known to everybody, so generally that is the reason.

Asked why they do not want their status known, the counsellor replied: 'Around here it's still a stigma, HIV is still stigmatized [...] it hasn't got to the stage where it's accepted just like any other disease.'

Theme II: Age and family influences on feeding practices

Another theme which appeared in the interviews is the influence of other family members, particularly as it relates to exclusive breastfeeding. As one younger woman said:

[Older people] at home they wish to see the baby eating [...] they like to see the baby eating every time [...] they believe if the baby is crying [you should] give him something to eat.

An 18-year-old mother who had chosen breastfeeding reported:

At home they say breastmilk is not enough for the baby, they say I must give him other foods so that he can grow. They feel it's a burden [for] me to give only breastmilk.

The effect of social independence on the importance of family influences is apparent in the differences between older and younger respondents. Although about one-third of the sample was under 19 years of age, none of the women who decided to feed formula were under 19 years. With regard to her family, one 33-year-old woman who had chosen infant formula told the interviewer: 'What can [they tell me]? Only I am staying with my children.'

We also see the influence of age in the discussion about disclosure. Compared with older mothers, many of whom chose to discuss their HIV status to us even though we did not ask them for this information, younger mothers were less likely to tell us they were HIV positive. A counsellor summed up the situation for younger mothers as follows:

Teenagers most of the time they are not taking [HIV] seriously compared to [older women], [...] sometimes when they experience [...] difficulties it is hard to talk to their parents because they don't even want them to know that

they had [sex]. Teenagers most of the times deny [their results]; they become very happy when it's negative, forgetting the window period, so they are negative, but they could be positive.

Theme III: Economic circumstances

The role of economic circumstances in decision-making was a common theme in the interviews. As one woman who had chosen breastfeeding explained: 'I am not working, I don't even have the money to buy formula milk.' Another woman who had also chosen breastfeeding reported:

My husband is very happy if I give breastmilk to my baby [...] money to buy milk is a very great problem because he is not working, that's why he [prefers] that I give breastmilk to the baby.

Women who had chosen formula feeding also noted difficulties associated with their choice. One of these women complained:

The tins are very costly. At home we take 6 [tins] for a month, but it doesn't end. It doesn't end. Six, six, six, but they don't last for a month, when the month is [halfway through] we need to go and buy more. [At least] with breastmilk, you know you can take that money and buy other things.

Theme IV: Beliefs about HIV transmission through breastmilk

Statements that relate to transmitting infection through breastmilk occurred in many of the interviews (14 out of 22). Sometimes the statements were explicitly associated with fear of infecting the infant. Of the five HIV-infected women who chose to give their infants formula, four talked about their fear of transmitting the virus to their infants. As one of these mothers explained:

[at the clinic], when they [were] taking blood there is a disease they found in me so I decided I must formula feed my baby [...] the breastmilk I believe in it because it's the thing I am used to but ... [silence].

On the other hand, the potential for transmission was sometimes discussed without an explicit statement of fear as in the case of a woman who explained:

I must breastfeed my baby until she is 6 months old, not giving anything else, even formula milk. The reason is that if I mix feed my baby she will get this sickness I am having.

Another woman noted: 'Breastmilk is very good. But what is bad is that now I am sick, the baby is [being] breastfed by an unhealthy person.'

Theme V: Beliefs about the quality of breastmilk compared to infant formula

Statements about the positive qualities of breastmilk appeared in nearly all of the interviews, especially with women who had elected to breastfeed. Sixteen of the 17 women who had chosen breastfeeding mentioned that breastfeeding 'protects against diseases'. Often the value of breastfeeding was juxtaposed to formula, as in the following statement: 'The baby who is formula fed always gets sick.' The strength of the belief in the superiority of breastmilk over formula is so great that one of the women who had chosen infant formula felt obliged to counter the prevailing view, explaining: 'I have never seen any problem, the difference between formula feeding and breastfeeding? I don't see any problem.'

Discussion

The discovery that HIV could be transmitted through breastmilk has initiated a public health dilemma of major proportions. As this knowledge has been disseminated from the scientific and public health sectors to communities where HIV/AIDS has become a reality of daily life, it has also created powerful personal dilemmas for thousands of women. In this ethnographic investigation in one such community, we have a glimpse of the forces that influence HIV positive women as they attempt to make an informed choice about feeding their infants.

The sociocultural context in which women in rural Kwa-Zulu Natal make their decisions is one in which breastfeeding is highly valued. As in many areas of sub-Saharan Africa, breastfeeding here is culturally

normative, and there is no evidence in this study to suggest that this fundamental health practice is being eroded. The women we interviewed know that breastmilk has the potential to infect their child with HIV, but a dominant theme in the women's discussions was that breastmilk protects children and is superior to formula. This is a reassuring finding. The in-depth, nondirective nature of the interview techniques that were used to obtain the data provides some confidence that the views the women were expressing reflected their beliefs. However, one must be very cautious in generalizing from a small opportunistic sample to the larger community from which the sample was drawn.

A striking finding in the study is the role of social stigma in affecting women's decisions. This appears to be particularly acute for young women. This is consistent with other reports from South Africa, which suggest that young people have a harder time accepting their status and are more likely to be in denial for a longer time compared to older adults (Campbell & MacPhail, 2002; Eaton *et al.*, 2003). When this situation is considered in light of the fact that in South Africa over 35% of women under 20 years are pregnant or have a child, and over 21% of adolescents are infected with HIV (Jewkes *et al.*, 2001), it is important to highlight the need for health care providers to be particularly attentive to the needs of young people.

The importance of hospital breastfeeding policy and attitudes of health personnel in affecting breastfeeding practices has been repeatedly documented (Knodel *et al.*, 1990; Williamson, 1990; Weng *et al.*, 2003). The effect of pro-breastfeeding policies in situations of endemic HIV infection and high level of social stigma associated with the disease has not been adequately appreciated. In reality, the Baby Friendly Hospital Initiative does not preclude the use of replacement feeding in situations that are medically indicated (WHO/UNICEF, 1989). However, mothers need privacy and support for replacement feeding, on one hand to allow them to keep their HIV status confidential and on the other to prevent erosion of the breastfeeding policy of the hospital.

The difficulty of practising exclusive breastfeeding in social conditions where family members do not understand its value is by no means limited to the

situation of HIV positive women, and is likely to be most acute for young women. Adolescent mothers frequently noted that they received advice from their families to practice mixed feeding. Although there is a paucity of data on how adolescent mothers in sub-Saharan Africa negotiate conflicting advice from their families and health care providers, it is likely that, as with adolescents everywhere, they may hesitate to contradict families' opinions regarding infant feeding, especially if they are financially and emotionally dependent upon them. As described by Bentley *et al.* (1999), adolescents may also be inexperienced and insecure about their own beliefs and logically turn to their families, particularly their mothers and grandmothers, for parenting help. Even when adolescent mothers express disagreement, families may insist on their own decisions or, less frequently, implement their preferred feeding practices without the mother's consent. Accommodating the family's wishes may be an adaptive coping strategy as adolescent mothers struggle with the enormous challenge of parenting in the midst of their own development.

Finally, we note the results concerning the effects of poverty in constraining women's decisions about how to feed their infants. Historically, under the apartheid regime, black South Africans were deliberately excluded from access to land, capital, employment and education (Francis, 2002). In present-day South Africa, the most pressing need for large numbers of blacks is obtaining employment. The recurrent theme in the interviews that formula feeding was not a viable option highlights the need to include the larger context of political and economic influences on individuals and their families in relation to the concept of 'informed consent'. In the long term, efforts to reduce the high levels of poverty and unemployment among black South Africans may improve women's confidence and ability to direct their lives and take control of their health and that of their loved ones in ways that are consistent with their hopes and aspirations (Campbell & MacPhail, 2002).

Programmes to prevent MTCT in the Southern African region, and in other areas of high HIV infection, are struggling to support reproductively active women cope with their disease. Health staff and trained counsellors are under severe time constraints

to explain complex concepts such as relative risks and personal risk assessments. There is a danger that in this difficult environment, primary health practitioners advise mothers according to formal guidelines without being adequately aware of the mothers' preferences, skills and home circumstances. Health care programmes and providers need to better understand mothers' social circumstances, their beliefs, motivations and behaviours, and be better prepared to intervene in ways that permit mothers to 'hear' and respond. For example, because teenage mothers may have a harder time dealing with HIV positive status, they may encounter more difficulties in safely implementing their chosen method of infant feeding compared to adult mothers.

We suspect that the themes that emerged from the ethnographic study in Kwa-Zulu Natal may be important in other areas of the world where women have to make difficult choices in constrained circumstances. Apart from the specific thematic content, we have also sought to illustrate the importance of attention to the sociocultural context of MTCT interventions. Efforts to modify infant feeding practices must do more than increase women's knowledge about current recommendations. By examining the context within which feeding decisions are made, a better understanding of the multiple influences on feeding practices can be established. This is a necessary step toward the development of more effective programmes to address the special needs of women and children in populations where HIV is an issue of public health importance.

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