Effect of a mother-to-child HIV prevention programme on infant feeding and caring practices in South Africa

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Objectives. To conduct a rapid assessment of the impact of the Khayelitsha Prevention of Mother-to-Child Transmission (MTCT) programme on infant care practices among programme participants and the local population.

Study design. Cross-sectional survey and qualitative in-depth interviews.

Setting. Khayelitsha, a large formal and informal settlement of about 300 000 people on the outskirts of Cape Town. At the time of the study the HIV seroprevalence rate among antenatal women was about 15% and the MTCT programme had enrolled nearly 800 infected women.

Subjects. Seventy randomly selected caregivers with young children in the survey; in-depth structured interviews with 11 nutrition counsellors and 11 mothers enrolled in the programme.

Results. Caregivers have good knowledge of the spread and prevention of HIV. A majority knew that breast-feeding can transmit HIV but 90% stated that this did not affect their feeding decisions. Over 80% had stopped exclusively breast-feeding by the time their infants were 3 months of age. All of the respondents felt that being diagnosed HIV-positive would result in serious social and domestic consequences. None of the health workers could correctly estimate the risk of spreading HIV through breast-feeding and many reported feeling confused about what they should counsel mothers. All the mothers on the programme reported exclusive formula-feeding. Some had serious problems with preparation and feeding of formula milk. Nearly all reported running out of feeds before being able

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to fetch new supplies. None reported any negative social effects of not breast-feeding. Most of the mothers endorsed the programme and felt that it had given them strength to face up to and plan for the consequences of their diagnosis.

Conclusion. This rapid appraisal of the infant feeding and care component of the MTCT programme has raised a number of important challenges which health managers and policymakers need to address. Similar assessments in the new pilot sites will be important.

S Afr Med J 2002; 92: 298-302.

South Africa has one of the fastest growing HIV epidemics in the world. According to the national HIV survey of women attending antenatal clinics of public health services in South Africa, the prevalence of HIV infection among women under 20 years of age is estimated to have nearly tripled from 6.5% in 1994 to 19% in 1999.[1]

An important mode of transmission of HIV is from mother to the child *in utero*, intrapartum or postpartum. It has been estimated that between 30% and 40% of children of HIV-positive mothers will become infected with HIV. The evidence that breast-feeding transmits HIV is based on the detection of HIV in the breast-milk,[2] cases of transmission through wet nursing[3] and comparison of mother-to-child transmission (MTCT) rates between formula-fed and breast-fed infants.[4,5] The risk of HIV transmission through breast-feeding varies depending on duration, pattern of breast-feeding, and maternal health. Recent estimates suggest that where breast-feeding is continued into the second year of life, postnatal HIV transmission through breast-feeding occurs in 10 - 20% of infants.[6] The prognosis for HIV-positive children is very poor in resource-constrained settings; they are prone to increased rates of infection, hospitalisation and premature death.

On the other hand, breast-feeding has long been recognised as central to the health and wellbeing of children, especially in developing countries. These advantages are still present even in middle-income countries such as Brazil.[7] Breast-feeding also has important health, psychological and economic benefits to the mothers. Knowledge that breast-feeding can transmit HIV makes the decision about whether to breast-feed or not a potentially very difficult one for HIV-infected women.

All the major agencies involved in HIV and child health have agreed on the concept of informed choice — that it remains the mother's right to choose the most appropriate method of feeding her child no matter what her HIV status. However, the application of this right depends on decision-makers, primarily mothers, being aware of the risks and benefits of different feeding options. For women who choose not to breast-feed, continuous access to appropriate feeding alternatives (known as replacement feeding) and information on how replacement feeding can be practised safely are also required.

Prevention of MTCT through the use of antiretrovirals is being very strongly promoted as a feasible and cost-effective intervention for prevention of HIV infection.[8] Short-course antiretroviral prophylaxis may reduce late-pregnancy, intrapartum, and early postnatal transmission from 40 - 50% to 7 - 14%.[9] The challenge of providing sound and consistent breast-feeding advice for HIV-positive mothers will become increasingly important as MTCT prevention programmes become established in South Africa. Health professionals will have to assess the impact of advice about not breast-feeding, not just on HIV-positive mothers but also the spillover effects on uninfected caregivers, and the constraints HIV-positive mothers face in feeding and caring for their infants.

The Western Cape Department of Health has established one of the first pilot MTCT programmes administered by health authorities in Africa. The objectives of this study were to conduct a rapid assessment of the impact of the MTCT programme on infant care practices among programme participants and the local population.

METHODS

This study was carried out in Khayelitsha, a large formal and informal settlement of about 300 000 people on the outskirts of Cape Town. At the time of the study the HIV seroprevalence rate among antenatal women was about 15%, and the MTCT programme had enrolled nearly 800 infected women. The programme recommends that HIV-positive mothers avoid breast-feeding, and it provides free formula milk to participants.

The study employed a combination of qualitative and survey research methods. Permission to conduct the study was obtained from the MTCT programme organising committee and the Research Ethics Committee of the University of the Western Cape. Permission to interview the HIV-positive mothers was negotiated through one of the participating health clinics and a local non-governmental organisation (NGO) that provides additional support to the HIV-positive women. All participants gave verbal consent to be interviewed. The research methods and sample included:

1. A structured questionnaire administered to 70 caregivers of young children who were randomly selected from all the clinics participating in the MTCT programme. The topics covered in these interviews included general awareness of HIV, MTCT and breast-feeding-related HIV transmission issues, impact of knowledge of the HIV epidemic on current breast-feeding and complementary feeding practices, perceptions in the community about women who do not breast-feed, and options on the feasibility and appropriateness of current infant feeding guidelines developed by the province.

2. Semi-structured interviews were conducted with 11 health providers who were identified as the main nutrition counsellors of mothers on the MTCT programme. Those interviewed were professional nurses (7), staff nurses (2), and lay (non-professionally trained) counsellors (2). The topics covered in these interviews were the same as those covered in the structured interviews with caregivers. In addition, health providers were asked about their case management procedures, and infant feeding education and counselling practices.

3. Semi-structured interviews were held with 11 HIV-positive mothers. Seven of these women had participated in the MTCT programme. The remainder did not receive zidovudine (AZT) during their pregnancy or delivery but were receiving infant formula supplements. The topics covered in these interviews included an infant feeding history for the reference infant, use of infant formula and milk (and observation of preparation), experience making feeding decisions in light of their known HIV status, opinions about exclusive breast-feeding and early weaning practices, and experience participating in the MTCT programme.

Three local dieticians working for the province and a study researcher were trained to use the various data collection tools. Interview findings were reviewed daily by the principal investigators. All semi-structured interviews were tape-recorded in local languages, transcribed verbatim, and translated into English. Interview texts were content analysed. Open coding[10] generated units of meaning, which were labelled and categorised.

RESULTS

Of the caregivers interviewed ($N = 70$), all bar one had heard of AIDS and 90% were able to mention at least one correct route of transmission. Unprotected sexual intercourse with someone who has the virus was the most common mode of transmission mentioned. HIV prevention strategies were also very well known, with nearly all respondents mentioning condom use.

Most caregivers (80%) believed that a baby can get HIV from an infected mother. Pregnancy was the most frequently mentioned route of MTCT (40%). Fewer (27%) mentioned breast-feeding as a route of transmission. Only a few caregivers (5 of 70, 7%) mentioned that transmission could occur during childbirth and delivery. When asked more explicitly whether they thought HIV could be transmitted from a mother to her baby through breast-feeding, a majority of caregivers (62%) answered in the affirmative. They reported hearing about HIV transmission through breast-feeding at the health centre, maternity unit, or on the radio. Nearly all (90%) said that they had not changed their feeding practices as a result of this knowledge.

When asked if they thought an HIV-positive mother should breast-feed, more than half (68%) said 'no'. Caregivers were also asked what proportion of HIV-infected mothers passed the virus to the babies through breast-feeding. About half of the caregivers (45%) did not know and one-third of caregivers (30%) thought that all HIV-positive mothers transmit the virus through breast-feeding. This finding is similar to responses given by the health workers. Three of the 11 health workers stated that all mothers will pass on the virus through breast-feeding, while 5 did not know and the other 3 thought it was about one-half.

Other milks and liquids are introduced early to babies in this population. Half of the caregivers (52%) reported that they had introduced other milks before 1 month, and most (82%) reported that they had stopped breast-feeding exclusively before their infants were 3 months of age. Reasons for stopping exclusive breast-feeding mainly involved a perception that the baby was no longer content with breast-feeding (or breast-milk alone), or because the baby rejected the breast or cried after feeding. Many caregivers (80%) reported knowing a mother who did not breast-feed her young baby at all. About one-third of these caregivers said they thought these mothers did not breast-feed because they were HIV-positive.

None of the HIV-positive mothers reported being discriminated against as a result of not breast-feeding their babies. Most HIV-positive mothers reported that they found it difficult to stop breast-feeding: 'It was difficult for me not to breast-feed because I didn't know how to explain to people — even my mum'.

Despite these difficulties all the HIV-positive mothers reported that they had never breast-fed their children as the risk of infecting the children with HIV outweighed their concerns about not breast-feeding. Partial breast-feeding (with breast-milk and infant formula milk) does not appear to be practised in this group of infected mothers. The suggestion of heating breast-milk or offering diluted cow's milk with additional multivitamins was rejected by all the mothers and caregivers.

The feeding advice given to mothers on the MTCT programme was extremely limited. Most mothers stated they had received feeding advice during HIV pre-test counselling (when the appropriate feeding options would not be known by the health providers). In all cases mothers said they had been informed about the risk of HIV transmission through breast-milk during pre-test counselling, and they had been told that they should stop breast-feeding (or not breast-feed at all) if they were found to be HIV-positive. No mothers reported being informed about the risks of not breast-feeding their babies.

Six of the 11 HIV-positive mothers reported that they had received some advice on how to prepare formula feed from health workers, although the information was very limited. For example, none of the mothers received any information on how

often to feed the formula, and none reported receiving advice on weaning (or replacement) foods. Sometimes this lack of information had potentially dangerous consequences: 'I only fed my child water in the first week, but when my child became ill, I started the formula feed. I never received any information. I was told by another mother at the clinic, while waiting at the waiting room, how to prepare the infant formula, but now I am reading the tin for instructions.'

Another problem that nearly all of the participants faced was running out of formula feed. All of the mothers denied diluting the mixture and instead reported that they bought more milk (4 mothers), gave sugar and water, or gave sweetened fruit drink (6 mothers) in between feeds. All the mothers stated that they only fed their children three to four times a day as another strategy to conserve the milk.

Health workers had limited knowledge about appropriate child-feeding practices. For example, only 1 was able to define the term 'exclusive breast-feeding' correctly, 1 had never heard of this term, and 6 gave incorrect definitions. When giving advice on insufficient breast-milk (a commonly reported problem by mothers), health workers' messages varied: 6 health workers mentioned the need to have a proper diet and increase fluid intake, 7 spoke of the use of yeast tablets, and 3 advised mothers to drink ginger beer. Only 2 mentioned the need to increase the frequency of breast-feeding.

All health workers reported telling HIV-positive mothers not to breast-feed, citing vertical transmission of the virus as the reason. They reported mixed feelings about this — 3 health workers said they did not have a problem with the recommendation for HIV-positive mothers, but the remaining 8 were 'uncomfortable', found it to be painful, or felt bad.

Disclosure of positive HIV status can be a very isolating experience in the community. According to the structured interviews, people don't want to have contact with those who are infected and they gossip and laugh at them. There was a feeling among the women that husbands or partners would reject them personally if they were HIV-positive. All but one of the HIV-positive women interviewed had disclosed to a partner or a family member that they were HIV-infected. Eight of the 11 women had disclosed their status to their partner (a husband or boyfriend), and in some cases a sister and/or a mother had also been told. In two cases the women's partners had left them. The rest of the women said they had received emotional and financial support from their partners and/or their families upon disclosure. However the women's partners were also tested in only 2 cases.

The majority of the mothers felt that being on the MTCT programme was a positive experience. While the provision of AZT and the supply of formula milk were mentioned by some as a positive aspect of the programme, the support that informants gained from meeting with one another was raised by all as a significant benefit. 'I like the programme because of the support I get — it is helpful meeting with other people and sharing similar experiences.' 'The programme is good — we get AZT, which might help the baby, and the support is good (sharing ideas and supporting each other) and the counselling helps you solve problems.'

The HIV-positive mothers all desired more information on infant care and how to maintain the health of their babies. Half of the mothers' responses suggested that they would like to be part of an income-generation project.

Discussion

This study highlighted a number of strengths and weaknesses of the present MTCT programme in Khayelitsha. Most of the mothers interviewed on the programme have benefited from facing up to their diagnosis. The clinic and NGO support groups have played a key role in this process. However this study has also highlighted some important issues that managers of MTCT programmes will need to face.

Despite the high awareness of the presence of HIV/AIDS in the community, it is still associated with stigmatisation and fear among community members. In contrast, many of the HIV-positive mothers reported that they had managed to cope quite well with disclosure. It is unclear from this study to what degree the high awareness about HIV/AIDS is as a result of the MTCT programme in the community, but the wider availability and encouragement to get tested could further help to destigmatise the disease.

Another strategy could be to highlight positive examples of mothers who are coping with their diagnosis and making informed decisions about their own and their children's future. This could reduce the sense of fatalism about the disease.

Among both health workers and caregivers there is widespread misunderstanding about the risk of spreading HIV through breast-feeding. This is a common finding in many MTCT programmes.[11] All the HIV-positive mothers were struggling financially and there were a number of examples of over-diluted formula milk or insufficient amounts being given to non-breast-fed babies to save expense. Some women also reported the psychological and social costs of not being able to breast-feed. In both Cape Town and Soweto many HIV-positive women have consciously chosen to continue breast-feeding, either because of the health benefits or because of the fear of stigmatisation from not breast-feeding.[12,13] In this study all the women chose not to breast-feed, although it is possible that some of them might have chosen to breast-feed if they had been presented with all the information. The consequences of not breast-feeding in more deprived areas will probably be much more serious. There is an urgent need for straightforward and accurate information about MTCT of HIV, including the risks during pregnancy, childbirth and breast-feeding in this and other populations where MTCT

programmes are to be implemented. Information should be given to women and their partners/family members. Health workers also need information about the probable risks of not breast-feeding in different settings so that they can fully inform mothers.

Currently, mothers who do not breast-feed do not appear to be stigmatised (or assumed to be infected with HIV). However, this may change as awareness of the association between HIV and breast-feeding increases. To date, MTCT programmes have not yet reported the possible 'spillover' effects of advising HIV-positive mothers not to breast-feed adversely affecting feeding practices among HIV-negative women and women of unknown status in the general population — this should be monitored in the future (UNICEF/UNAIDS/WHO/UNFPA, African regional meeting on pilot project for the prevention of mother-to-child transmission of HIV, Gaborone, Botswana, 27 - 31 March 2000).

In keeping with the recent Demographic and Health Survey,[14] this study found a wide range of suboptimal early feeding practices in the general population, and very limited advice, skills and support being given by health providers on infant feeding issues. Exclusive breast-feeding is very rarely practised. Feeding formula milk is becoming the norm, even though many caregivers admitted that they could not afford to purchase the necessary amounts. In addition, the health providers themselves often recommend early supplementation with formula or solid foods. The Nutrition Directorate should plan and implement a large-scale communications strategy that emphasises appropriate breast-feeding, and complementary feeding practices for HIV-negative women, and women of unknown HIV status, as well as recommendations for safe feeding by HIV-infected women (this being conducted in collaboration with the MTCT programme). The strategy must include messages on the benefits of and correct ways to practise exclusive breast-feeding.

This study suggests that formula-feeding is the optimal alternative to breast-feeding. Heat treatment of breast-milk and breast-milk banks were uniformly rejected. Even though cow's milk is widely consumed the expense and poor availability of vitamin supplements make this option less desirable.

As only 11 mothers in the programme were interviewed it is important not to generalise these results to all participants. However, findings from this group of participants were triangulated with findings from the other interviews and the literature. Furthermore, even the finding of a handful of participants who have been confused and who have struggled to cope with infant feeding is important.

The efficacy of MTCT programmes has been well established in many research settings. This study, however, has highlighted important issues that could undermine the effectiveness of such programmes. It is quite clear that MTCT programmes require primary health care services that are sufficiently developed to provide good quality counselling and testing, follow-up, and support. The findings from this study should not be used to prevent the expansion of the MTCT programme, which was gratefully received by the HIV-positive mothers. The challenge today is to use the opportunity of preventing MTCT of HIV to assess and improve services for all members of the community. In this instance the introduction of the MTCT programme has led to the development of several easy-to-use assessment tools, which, it is hoped, will lead to the improvement of maternal and child health services for all users.

We acknowledge the support of the health authorities in advising the team on the study design, collection and analysis of data.

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Accepted 24 September 2001.