**Objective** To explore how the human immunodeficiency virus (HIV) epidemic has affected the infant-feeding experiences of HIV-positive mothers in South Africa.

**Methods** This was a qualitative interview study within a prospective cohort study. We purposively selected a subsample of 40 women from a larger cohort of 650 HIV-positive mothers for in-depth interviews.

**Findings** The HIV epidemic has changed the context in which infant-feeding choices are made and implemented. HIV-positive mothers in this study — who were predominantly young, single and unemployed — were struggling to protect their decision-making autonomy. Uncertainty about the safety of breastfeeding has increased the power and influence of health workers, who now act as gatekeepers to not only this new knowledge but also to essential resources such as formula milk. Fear of disclosure of HIV status and stigma has also weakened the ability of mothers to resist entrenched family and community norms that encourage early introduction of fluids and foods and that question non-breastfeeding. Women who chose to exclusively formula feed had difficulties accessing formula milk because of inflexible policies and a lack of supplies at clinics. Limited postpartum support led to social isolation and mothers doubting their ability to care for their children.

**Conclusion** The infant-feeding experiences of HIV-positive mothers have serious implications for the operational effectiveness of programmes that aim to prevent HIV transmission from mother to child. A better understanding of how HIV is changing infant-feeding practices can inform the development of interventions to improve infant-feeding counselling and postpartum support.

**Keywords** Infant food; Breast feeding; HIV infections/transmission; HIV infections/prevention and control; Disease transmission, Vertical/prevention and control; Cohort studies; Africa South of the Sahara (source: MeSH, NLM).

**Mots clés** Aliments pour nourrisson; Allaitement au sein; Infection à VIH/transmission; Infection à VIH/prévention et contrôle; Transmission verticale maladie/prévention et contrôle; Étude cohorte; Afrique subsaharienne (source: MeSH, INSERM).

**Palabras clave** Alimentos infantiles; Lactancia materna; Infecciones por VIH/transmisión; Infecciones por VIH/prévention y control; Transmisión vertical de enfermedad/prevención y control; Estudios de cohortes; África del Sur del Sahara (fuente: DeCS, BIREME).

However, the HIV epidemic has significantly altered the context within which women make decisions about how they will feed their infants. In the South African PMTCT programme, women are counselled to choose either exclusive breastfeeding with early weaning at 4–6 months or exclusive formula feeding with free infant formula provided until 6 months.

The effectiveness of PMTCT and child survival programmes could be seriously compromised unless there is careful study of the infant-feeding experiences of HIV-positive women. Our research sought to explore how HIV has changed the context within which infant-feeding decisions are made and implemented within a cohort of HIV-positive women in three diverse settings in South Africa.

Methods

We conducted qualitative interviews with a subsample of participants from a prospective cohort study.

Study setting

A prospective cohort study of 650 HIV-positive mother–child pairs with follow-up from birth to 9 months is being conducted to assess the effectiveness of the national PMTCT programme. The study is being done in three PMTCT pilot sites in South Africa selected to represent the diverse types of communities in South Africa. They are: Paarl (PA), a peri-urban farming area in the Western Cape; Rietvlei (RV), a rural district in the Eastern Cape; and Umlazi (UM), a peri-urban township in KwaZulu-Natal.

The protocol for the South African national PMTCT programme includes voluntary HIV counselling and testing during antenatal care, infant-feeding counselling, single-dose nevirapine for mother and infant, free formula milk for mothers who opt not to breastfeed for a period of 6 months, and infant HIV testing at 12 months with a rapid antibody test. 5

Antenatal infant-feeding counselling involves mothers being offered the option of exclusive breastfeeding with rapid weaning at 4–6 months or exclusive formula feeding with free formula provided by local clinics until 6 months postpartum. The quality and intensity of infant-feeding counselling — and hence mothers’ infant-feeding choices — differs greatly between these three sites and is influenced by staff training, availability of lay counsellors and individual facility preferences. 6 The proportion of HIV-positive mothers choosing exclusive breastfeeding is 30%, 31% and 64% in Paarl, Rietvlei and Umlazi, respectively. The remaining mothers choose exclusive formula feeding. 7

There is no formal infant-feeding counselling given to women postnatally, but the national PMTCT protocol states that during routine clinic visits, mothers should be encouraged to practise their chosen feeding option exclusively. 5

Sample

We purposively selected HIV-positive mothers from the larger cohort who had achieved some early success in practising either exclusive breastfeeding or exclusive formula feeding. Recruitment continued until we determined that theoretical saturation had occurred — i.e. that no new information was emerging from the interviews. Field staff contacted mothers and invited them to participate in an in-depth interview about infant feeding. Following an explanation about the purpose of the interview, we sought verbal consent from the women to participate in the study. All people approached for interviews agreed to participate. Forty mothers were interviewed; 15 each in Rietvlei and Umlazi and 10 in Paarl.

Interviews were carried out between February and June 2004.

In order to enrich and validate data from individual interviews, one focus-group discussion was held in each of the sites with 8–10 local community health workers. These workers make regular visits to mothers in the larger cohort study to record feeding practices.

Data collection and analysis

Most of the interviews took place in the mothers’ homes and were conducted by a local trained qualitative interviewer in the preferred language of the mother. Because our participants were already enrolled in the larger cohort, they were accustomed to visits from field researchers at home, and therefore many women preferred the interviews to be done at home. Some participants requested to be interviewed in the study office if they had not disclosed their HIV status to family members or if there was no private space for the interview in the home.

We used a semi-structured interview guide with open-ended questions to explore experiences of the PMTCT programme, infant-feeding decision-making, and experiences of early infant-feeding practices. Focus-group discussions took place in the offices of community organizations. A focus-group-discussion guide was used to explore normative infant-feeding preferences.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Qualitative sub-sample (n = 40)</th>
<th>Epidemiological cohort (n = 650)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age of mother (standard deviation)</td>
<td>24 (4.75)</td>
<td>25 (5.22)</td>
</tr>
<tr>
<td>Mean age of infant at time of interview (standard deviation)</td>
<td>8 months (4.41)</td>
<td>Followed from 0–9 months</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–7 years</td>
<td>5 (12%)</td>
<td>124 (19%)</td>
</tr>
<tr>
<td>8–11 years</td>
<td>25 (63%)</td>
<td>363 (57%)</td>
</tr>
<tr>
<td>12 or more years</td>
<td>10 (25%)</td>
<td>153 (24%)</td>
</tr>
<tr>
<td>Marital status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single — never married</td>
<td>25 (63%)</td>
<td>443 (68%)</td>
</tr>
<tr>
<td>Married</td>
<td>8 (20%)</td>
<td>120 (19%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>0</td>
<td>5 (0.7%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>1 (2%)</td>
<td>10 (1.5%)</td>
</tr>
<tr>
<td>Co-habiting</td>
<td>6 (15%)</td>
<td>68 (11%)</td>
</tr>
<tr>
<td>Mother’s main activity during the day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housework/unemployed</td>
<td>35 (87%)</td>
<td>531 (83%)</td>
</tr>
<tr>
<td>Student</td>
<td>3 (8%)</td>
<td>30 (4%)</td>
</tr>
<tr>
<td>Formal employment</td>
<td>2 (5%)</td>
<td>29 (6%)</td>
</tr>
<tr>
<td>Informal employment/part-time</td>
<td>0</td>
<td>46 (7%)</td>
</tr>
<tr>
<td>Disclosure of HIV status</td>
<td>21 (53%)</td>
<td>172 (26%)</td>
</tr>
</tbody>
</table>

Table 1. Characteristics of HIV-positive mothers in the qualitative sub-sample and the epidemiological cohort
feeding practices and community perceptions about PMTCT. The researchers consulted existing guides and tools on infant feeding in the development of the individual and focus-group guides. All interviews and focus group discussions were audiotaped and transcribed verbatim. To maintain participants’ confidentiality, transcripts of interviews were labelled only by a participant or focus-group code. We used an interpretive approach to analyse data, identifying key categories and recurrent themes within the transcripts. Sections of text were marked manually and linked to sections of text from other interviews that covered similar issues or experiences. Data analysis continued until no new themes or ideas were emerging. We read all of the transcripts independently and jointly reviewed emerging themes to reach consensus on the interpretation of the data.

**Results**

All the mothers interviewed had attended antenatal appointments, were HIV-positive and had participated in the PMTCT programme. Mean age was 24 years (range 18–38 years); 25 women were breastfeeding and 15 were formula feeding. Mean age of infants at the time of the interviews was 8 months (range 4–18 months) and 21 (53%) of participants were primiparous. General characteristics of the mothers we interviewed were similar to those noted for the larger cohort from which they were selected, with most mothers unemployed and single (Table 1).

Although we sampled mothers for interviews based on their reported optimum (i.e. exclusive) early feeding practices, during the in-depth interviews it emerged that most mothers were only able to maintain exclusive feeding practices for a short period of time because of various community and health-system constraints. We present five key themes that characterized the infant-feeding experiences of mothers with HIV, in particular the challenges to exclusive infant feeding: protecting the child, the influence of health workers and significant others, hiding the truth, realities of free formula milk, and self-efficacy.

**Protecting the child: decision-making and mixed messages**

For breastfeeding and formula-feeding mothers the reasoning behind their infant-feeding choices was related to a desire to protect their child. For mothers who had chosen breastfeeding, the entrenched knowledge that “breast milk is best” often outweighed the perceived risk of HIV transmission through breast milk (Box 1). Mothers who chose to formula feed cited protecting their child from HIV infection as the strongest influence on their infant-feeding decision. However, fears of HIV transmission through breast milk often resulted from information that over-estimated this risk (Box 1).

In many instances mothers face an internal struggle between prevention of infant HIV infection and the desire to breastfeed. Community health workers described how HIV has created confusion about infant feeding because of mixed messages; there are posters promoting breast-feeding and others promoting formula feeding within the same clinic (Box 1).

**The influence of health workers and significant others on infant feeding**

Health workers seemed to have the greatest influence over mothers’ initial infant-feeding choices (Box 2). In developing countries and especially in public-health settings, the relationship between clients and health workers is one often based on power and hierarchy. However, the results of our interviews suggest that the uncertainty about the association between HIV and breastfeeding and the fact that health workers are now giving different infant feeding messages, has led to an increase in health-workers’ authority over infant feeding choices. Some mothers expressed feeling “forced” to choose a particular feeding option because of their HIV status.
Although health workers have an important influence on initial infant-feeding choices, this power diminishes in the postpartum period. For our participants, intentions to practise exclusive feeding methods were quickly affected by family members who encouraged early introduction of other liquids (Box 2).

Twenty women (80%) who had chosen exclusive breastfeeding had introduced other liquids within the first month because of pressures placed on them by family. The experiences of individual mothers were echoed by the community health workers who confirmed the authority that family members have over infant feeding practices (Box 2).

The influence of family members may be related to the extremely vulnerable situation of these women. Thirty (75%) of them lived with their mother, mother-in-law or grandmother. These participants were financially dependent on family members since partners or fathers of their children were largely absent.

Hiding the truth: effect of HIV status on communication

Being HIV-positive greatly affected participants’ communications with their families and friends about infant feeding, largely because of the need to hide their HIV status. Half the participants, mostly those choosing to formula feed, had disclosed their HIV status to someone. Usually, this person was the father of the child, who in most cases was not living with the woman. To maintain the confidentiality of their HIV status at home, communication with family members revolved around hidden truths and excuses for certain non-normative feeding practices such as formula feeding or early cessation of breastfeeding (Box 3). These mothers faced many questions from family and neighbours and had to develop plausible explanations for their actions. Community health workers described the great lengths to which mothers go to avoid disclosure of their HIV status because of the link in some communities between free formula and HIV (Box 3).

"When the milk finishes ...": realities of free formula milk

Mothers who chose to formula feed faced a constant struggle to access formula supplies because of their dependency on health workers to obtain milk for their infants. Of the 15 mothers who chose to formula feed, 12 had run out of formula milk at least once and some were afraid to go to the clinic to fetch more supplies before the scheduled date on their clinic card (Box 4). These stories show the power dynamics in the relationship between health workers and clients. At health facilities mothers are only given supplies on a specified date, irrespective of whether the supplies have run out early. Mothers with scarce resources for sustaining formula feeding expressed despair at having nothing to feed their children when the supplies end early or the clinic stock runs out (Box 4). Community health workers confirmed this situation, reporting that they had encountered mothers with no formula supplies during their home visits.

Self-efficacy

For many of the mothers in our study, being HIV-positive led to feelings of social isolation, despair and powerlessness. Within a context of high levels of stigma toward people with HIV, especially mothers accessing free formula milk, sometimes the only option is to hide away rather than face ridicule and scorn (Box 5). We noted low levels of self-efficacy in this cohort with many mothers doubting their ability to carry out certain feeding practices — particularly exclusive breastfeeding — and lowered beliefs in their own ability to care for their children (Box 5).

Discussion

The HIV-positive mothers in this study were struggling with a recent HIV diagnosis, uncertainty about how to care for their child, and fear about disclosure of their status. Other researchers have also reported low levels of disclosure in mothers diagnosed with HIV during antenatal care. This lack of disclosure makes adherence to drug regimens or infant-feeding guidelines difficult. For example, even in a well resourced setting such as Botswana, only 40% of HIV-positive women who started a short course of zidovudine completed their treatment. In Zambia more than a quarter of women (26%) were not adherent to the even simpler single-dose nevirapine regimen.

The HIV epidemic seems to have changed the context in which women make choices about feeding their infants. There is already a very hierarchical relationship between health workers and women, indeed the only verb in Zulu to describe interactions with a health worker is translated as “to tell”. Uncertainties about the risk of HIV transmission through breastfeeding and control of the provision of formula feeds further accentuate this power divide. Many women felt confused and unsure about the best infant-feeding choice and, therefore, chose whatever they were told would provide the best protection for their child.

High quality training for counsellors that address attitudes and interpersonal...
relations can lead to greater support for women, increased disclosure rates and greater confidence for mothers in their ability to carry out infant feeding decisions. 16 More discussion and openness about HIV status within households might also start to shape community norms of infant feeding, which would create an easier environment for HIV-positive women to carry out their infant feeding choices.

Poor quality counselling, however, can have deleterious effects for mothers. For example, the spillover of less-than-optimum infant feeding practices in women who are not HIV-positive. 15 One aspect of the spillover effects of PMTCT programmes that has received little investigation is that women seek — and often receive suggestions from health workers about — ways to explain their deviant infant feeding behaviours in order to avoid the risk of stigma associated with HIV. These falsifications may serve to strengthen already existing myths that “insufficient milk” or “bad milk” are both real and common phenomena. Poor relationships between clients and health workers can also lead to fears in women that could influence their future health-seeking behaviour. 16 Indeed, we noted evidence for this effect in our own study in that women expressed fears about obtaining formula supplies from health workers.

The experiences of mothers in this study highlight that even within a fairly well-resourced setting such as South Africa, the sustainability of free formula-milk is problematic. Nearly South Africa, the sustainability of free formula-milk is problematic. Nearly 60% of the women in this study reported periods when no formula was available. Little has been written in the guidelines about what HIV-positive mothers who have chosen to formula feed can feed their infants when they do not have access to formula milk. Likewise, not much is known about the health outcomes of being without formula for varying lengths of time.

A key finding from this study is the isolation felt by HIV-positive mothers and the limited postpartum support available to them. To begin to change community norms and beliefs about infant feeding, support needs to be provided at the community level. Community peer support has been shown to increase exclusive breastfeeding rates within the general population. 7,8,9 However, these studies were not done in an African setting or in communities with a high prevalence of HIV. Studies of this nature are needed to determine the effect of community peer support for HIV-positive mothers on infant-feeding practices, disclosure of HIV status, and self-efficacy.

Generalizability of findings
We used purposive sampling to recruit HIV-positive mothers who had specific feeding practices from a larger MTCT cohort study. Therefore, our findings may not be generalizable to wider populations of HIV-positive mothers. However, we chose women who had intended and had initially been successful at practicing either exclusive formula feeding or exclusive breastfeeding. Although most participants ended up practising mixed feeding, these women probably represent the best-case scenarios in contexts where mixed feeding is the cultural norm.

Our sample size, typical of qualitative research, was small, and the accounts presented here do not reflect the experiences of all HIV-positive mothers. Because of the nature of purposive sampling, these mothers may have been more open to sharing their experiences than other HIV-positive mothers. However, we recruited women from three diverse geographic regions with similar sociodemographic variables to those in the larger cohort. We feel, therefore, that our findings could be generalizable to HIV-positive women living in these three types of settings.

Conclusion
Our findings provide some insight into the challenges facing HIV-positive mothers who have chosen to formula feed their infants. Most of the mothers who are formula feeding face the problem of not getting stock and they don’t even have money to buy on their own so during those days when they don’t have formula they decide to give juices and sugar water.” (FG-UM)
Effets de l’épidémie d’infection par le VIH sur l’allaitement des nourrissons en Afrique du Sud : « lorsqu’ils me voient arriver avec les boîtes, ils se moquent de moi »


Méthodes L’article porte sur une étude qualitative par entretiens, réalisée dans le cadre d’une étude prospective de cohorte. Un sous-échantillon de 40 femmes a été sélectionné à dessein à partir d’une cohorte plus importante de 650 mères séropositives, en vue de les soumettre à des entretiens approfondis.

Résultats L’épidémie d’infection par le VIH a modifié le contexte dans lequel s’opèrent le choix et la mise en œuvre du mode d’allaitement des nourrissons. Les mères séropositives prises en compte dans cette étude, - qui étaient en majorité jeunes, seules et sans emploi - s’efforçaient de protéger leur indépendance décisionnelle. Les incertitudes quant à l’absence de risque de l’allaitement au sein ont donné plus de pouvoir et d’influence au personnel soignant, qui non seulement détient les connaissances à ce sujet, mais aussi l’accès aux ressources essentielles comme le lait artificiel. La crainte d’une révélation de leur statut à l’égard du VIH et de la stigmatisation associée affaiblit la capacité des mères à résister aux normes familiales et communautaires très arrêtées, qui encouragent l’introduction précoce de liquides et d’aliments et qui remettent en question l’allaitement artificiel dès la naissance. Les femmes qui choisissent de nourrir leur enfant avec du lait artificiel uniquement rencontrent des difficultés pour se procurer ce lait en raison de l’inflexibilité des politiques et de l’approvisionnement insuffisant des dispensaires. Le faible soutien apporté aux mères post-partum conduit à leur isolement social et les fait douter de leur capacité à s’occuper de leurs enfants.


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**References**


