

## Research

# Effect of the HIV epidemic on infant feeding in South Africa: "When they see me coming with the tins they laugh at me"

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**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; Etude cohorte; Afrique subsaharienne (*source: MeSH, INSERM*).

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

## Arabic

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Voir page 95 le résumé en français. En la página 95 figura un resumen en español.

## Introduction

Most women in sub-Saharan Africa have their human immunodeficiency virus (HIV) status diagnosed during pregnancy because of testing available through programmes for the prevention of mother-to-child transmission (PMTCT) of HIV. A diagnosis of HIV during pregnancy necessitates complex decision-making about participation in PMTCT programmes and infant feeding

methods. Patients usually make these decisions alone, as disclosure rates remain very low in sub-Saharan Africa.<sup>1</sup>

Adherence to a chosen infant feeding method is especially challenging for women with HIV. Avoidance of any breastfeeding eliminates the risk of postnatal mother-to-child transmission of HIV. But for many women in poor settings, complete avoidance of breastfeeding is either not possible, or is not the most favourable option. Recent evidence

suggests that exclusive breastfeeding has a lower risk of mother-to-child transmission of HIV than does mixed breastfeeding (i.e. when other liquids or solids are given).<sup>2, 3</sup> However, neither exclusive breastfeeding nor exclusive non-breastfeeding are the cultural norms in most African settings. Mixed breastfeeding is the predominant method of infant feeding.<sup>4</sup> Interventions to optimize infant feeding are more critical than ever for improving child survival.

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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.<sup>5</sup>

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.<sup>6</sup> 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.<sup>7</sup>

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.<sup>5</sup>

### 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-

Table 1. Characteristics of HIV-positive mothers in the qualitative sub-sample and the epidemiological cohort

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

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.<sup>8</sup>

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.<sup>9</sup> 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 prac-

### Box 1. Protecting the child

"... at the clinic they told us that it is important to breastfeed the babies because the babies grow well with breast milk. They said everybody must breastfeed because breast milk has nutrients and it is the one that the baby is supposed to be fed on." (UM-391, mother aged 23 years, infant aged 6 months, breastfed.)

"I thought that he would get the virus if I breastfeed him so I decided to bottle feed him." (RV-214, mother aged 19 years, infant aged 5 months, formula fed.)

"... what made my child to feed on this tin is my health condition. That is what is most important." (RV-202, Mother aged 27 years, infant aged 5 months, formula fed.)

"... at the hospital there are those posters that are promoting breastfeeding, have you seen the one promoting bottle feeding, they are written on a small paper around the corner. The very same baby that was supposed to have breast milk now they say she must be bottle fed so I think they must work hand in hand." (FG-UM)

tics 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 breastfeeding 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.<sup>10</sup> 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.

### Box 2. Influence of health workers and significant others

"I didn't want to give the baby the tin but I was forced to do so. If there was nothing that I had heard I would have given him breast milk." (RV-203, mother aged 22 years, infant aged 5 months, formula fed.)

"... the counselling changed me because I had planned that I would breastfeed him until he is 3 years then I got this advice from the hospital and it changed my mind." (RV-125, mother aged 18 years, infant aged 11 months, breastfed and abruptly weaned at 12 weeks.)

"... when I got home my sister said the baby must drink starch water, the thing with salt and sugar." (UM-408, mother aged 29 years, infant aged 4 months, breastfed.)

"My child was breastfed because I couldn't give him the bottle because my mother didn't agree. She said she doesn't want a child being bottle fed." (RV-178, mother aged 22 years, infant aged 9 months, breastfed.)

"The family will offer to buy her formula when she has chosen to breastfeed, they will tell her that breast milk is not enough for the baby, she must also mix it with formula feeding, and she can't deny that because she hasn't told them why she chose to exclusively breastfeed her baby so she will just mix feed." (FG-UM)

**Box 3. Hiding the truth**

"Here at home they were complaining but I told them I'm stopping. They were asking why am I stopping to give the baby the breast so early. I told them that it was enough." (RV-102, mother aged 24 years, infant aged 14 months, breastfed.)

"... my mother asked me why I did not breastfeed. I told her that they said I mustn't breastfeed because they said I have a problem in my breast." (PA-018, mother aged 22 years, infant aged 17 months, formula fed.)

"... the neighbours ask why am I not breastfeeding the baby. I then tell them the problem that I had that the baby did not want to breastfeed." (UM-400, mother aged 27 years, infant aged 5 months, formula fed.)

"They are asked in the community as to how come they do not breastfeed and they find it difficult to respond because it is a secret." (FG-RV)

"... there's a lot of thinking within the community that the babies that are fed on formula are those who are HIV-positive so sometimes you'll find that the mother will go to the clinic to collect the milk and then tear off the cover which shows what kind of milk it is because she doesn't want to be asked questions." (FG-UM)

"She fetches the milk with a bag and she will wait until the clinic is empty so that they do not see what type of milk is there." (FG-PA)

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.<sup>1</sup> 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.<sup>11</sup> In Zambia more than a quarter of women (26%) were not adherent to the even simpler single-dose nevirapine regimen.<sup>12</sup>

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,<sup>13</sup> indeed the only verb in Zulu to describe interactions with a health worker is translated as "to tell".<sup>10</sup> 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

**Box 4. Realities of free formula milk**

"I used to have problems when the milk finished early and I have no money. At the clinic they will tell me I have to come on my date." (PA-011, mother aged 30 years, infant aged 18 months, formula fed.)

"... they told me that the one that was available was over and the new stock had not arrived. They gave me a number to keep on phoning to check if it has arrived." (UM-418, mother aged 28 years, infant aged 4 months, formula fed.)

"... when the milk finishes I buy my own milk because I do not know what they will say at the clinic when I come before the scheduled date, I think that maybe they are going to shout at me." (UM-418, mother aged 28 years, infant aged 4 months, formula fed.)

"I rushed to the hospital to get formula and they said it is not available; it had finished. I went home and I did not have anything to give him. I then gave him long life milk. I think 3 weeks expired without formula having arrived." (UM-396, mother aged 23 years, infant aged 6 months, formula fed.)

"... 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)

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.<sup>14</sup> 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.<sup>15</sup> 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.<sup>16</sup> 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 all the mothers in our 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 ac-

cess 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;<sup>17–19</sup> 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. How-

ever, we chose women who had intended and had initially been successful at practising 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

**Box 5. Influence of HIV on self-efficacy**

"I chose to bottle feed because I realized that I wouldn't be able to breastfeed the way that I was told to breastfeed." (RV- 219, mother aged 24 years, infant aged 4 months, formula fed.)

"... when they see me coming with the tins they laugh at me, they say I have HIV, and I tell them I do not have AIDS it is because I have TB and a lot of people know I have TB and I hide the tins." (UM-338, mother aged 22 years, infant aged 8 months, formula fed.)

"I am even scared of going out if the people are sitting together, thinking that they are talking about me, because one day when I was going out with my mother they just laughed and the other one even pointed at me. When I asked her she said, 'I was laughing because you have AIDS and the father of the baby deserted you and left you with this disease.' I become scared of everything." (UM-334, mother aged 22 years, infant aged 8 months, breastfed.)

"... for two weeks after I heard about my situation I used to stay all by myself in the bedroom. I was asking myself if I was going to survive and also if my baby will survive, and where did the father of my child get it, maybe it is me who infected him I do not know." (UM-402, mother aged 24 years, infant aged 5 months, formula fed.)

mothers and show that these difficulties could have implications for the effectiveness of PMTCT programmes in resource-constrained settings. Additional research is needed to assess feasible interventions to improve postpartum care and support for HIV-positive mothers, in particular, strategies to increase exclusive infant-feeding practices. ■

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## Résumé

### Effets de l'épidémie d'infection par le VIH sur l'alimentation des nourrissons en Afrique du Sud : « lorsqu'ils me voient arriver avec les boîtes, ils se moquent de moi »

**Objectif** Étudier les effets de l'épidémie d'infection par le virus de l'immunodéficience humaine (VIH) sur les pratiques en matière d'allaitement des nourrissons chez les mères séropositives d'Afrique du Sud.

**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.

**Conclusion** Les pratiques en matière d'allaitement des mères séropositives ont des conséquences graves sur l'efficacité opérationnelle des programmes visant à prévenir la transmission du VIH de la mère à l'enfant. Une meilleure compréhension de la manière dont l'épidémie de VIH modifie les pratiques d'allaitement peut apporter des éléments pour la mise au point d'interventions en vue d'améliorer les conseils et le soutien apportés post-partum.

## Resumen

### Efecto de la epidemia de VIH en la alimentación de los lactantes en Sudáfrica: «Cuando me ven llegar con los tarros se ríen de mí»

**Objetivo** Estudiar cómo ha influido la epidemia de virus de la inmunodeficiencia humana (VIH) en la alimentación de los lactantes de madres seropositivas en Sudáfrica.

**Métodos** Se llevó a cabo una encuesta con entrevistas cualitativas como parte de un estudio prospectivo de cohortes. Seleccionamos deliberadamente una submuestra de 40 mujeres a partir de una cohorte más amplia de 650 madres VIH-positivas para realizar entrevistas más detalladas.

**Resultados** La epidemia de VIH ha trastocado el contexto de la adopción y aplicación de decisiones sobre la alimentación de los lactantes. Las madres VIH-positivas de este estudio -en su mayoría jóvenes, solteras y sin trabajo- se esforzaban por conservar su autonomía decisional. La incertidumbre existente respecto a la seguridad de la lactancia materna ha dado más poder e influencia a los trabajadores sanitarios, que actúan ahora como guardianes no sólo de esos nuevos conocimientos sino también de recursos esenciales como las preparaciones para lactantes. El temor a revelar la serología VIH y a verse estigmatizadas ha hecho que muchas

mujeres cedieran más fácilmente a algunos hábitos familiares y comunitarios arraigados que fomentan la pronta introducción de líquidos y alimentos y cuestionan la decisión de no dar el pecho. Las mujeres que optan por alimentar a sus niños exclusivamente con preparaciones tienen dificultades para acceder a ellas, debido a la escasa flexibilidad de las políticas aplicadas y a la falta de suministros en los consultorios. El limitado apoyo puerperal recibido conduce a las madres a la marginación social y a dudar de su capacidad para cuidar a los hijos.

**Conclusión** Las experiencias de alimentación de los lactantes de madres VIH-positivas tienen serias implicaciones para la eficacia operacional de los programas encaminados a prevenir la transmisión del VIH de la madre al hijo. Una comprensión más cabal de la influencia que está teniendo el VIH en las prácticas de alimentación de los lactantes permitirá fundamentar mejor el desarrollo de las intervenciones de mejora del asesoramiento sobre la alimentación del lactante y el apoyo puerperal.

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### References

1. Medley A, Garcia-Moreno C, McGill S, Maman S. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bull World Health Organ* 2004;82:299-307.
2. Coutsoudis A, Pillay K, Kuhn L, Spooner E, Tsai WY, Coovadia HM, et al. Method of feeding and transmission of HIV-1 from mothers to children by 15 months of age: prospective cohort study from Durban, South Africa. *AIDS* 2001;15:379-87.
3. Iliff PJ, Piwoz EG, Tavengwa NV, Zunguza CD, Marinda ET, Nathoo KJ, et al. Early exclusive breastfeeding reduces the risk of postnatal HIV-1 transmission and increases HIV-free survival. *AIDS* 2005;19:699-708.
4. National Department of Health. *South African Demographic and Health Survey 1998*. Pretoria: Department of Health/Medical Research Council/ Macro International; 1999.
5. National Department of Health. *Protocol for providing a comprehensive package of care for the prevention of mother to child transmission of HIV (PMTCT) in South Africa*. Pretoria: National Department of Health; 2001.
6. Chopra M, Doherty T, Jackson D, Ashworth A. Preventing HIV transmission to children: quality of counselling of mothers in South Africa. *Acta Paediatr* 2005;94:357-63.
7. Doherty T, Besser M, Donohue S, Kamoga N, Stoops N, Williamson L, et al. *Case study reports on implementation and expansion of the PMTCT programme in the nine provinces of South Africa*. Cape Town: Health Systems Trust; 2003.
8. Linkages. *Formative research: skills and practice for infant and young child feeding and maternal nutrition*. Washington: AED/Linkages; 1993.
9. Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ* 2000;320:114-6.
10. Seidel G, Sewpaul V, Dano B. Experiences of breastfeeding and vulnerability among a group of HIV-positive women in Durban, South Africa. *Health Policy Plan* 2000;15:24-33.
11. Creek T, Ngashi N, Mogopi L, Smith M, Mahzani L, Shaffer N, et al. *Next steps to improve the effectiveness of the prevention of mother-to-child transmission programme in Botswana*. Gabarone: UNICEF; 2003.
12. Stringer JS, Sinkala M, Stout JP, Goldenberg RL, Acosta EP, Chapman V, et al. Comparison of two strategies for administering nevirapine to prevent perinatal HIV transmission in high-prevalence, resource-poor settings. *J AIDS* 2003;32:506-13.
13. Jewkes R, Abrahams N, Mvo Z. Why do nurses abuse patients? Reflections from South African obstetric services. *Soc Sci Med* 1998;47:1781-95.
14. Rutenberg N, Kalibala S, Baek C, Rosen J. *Evaluation of United Nations-Supported Pilot Projects for the prevention of mother-to-child transmission of HIV: Overview of findings*. New York: UNICEF; 2003.
15. Luo C. Evaluation of a pilot programme and a follow up study of infant feeding practices during the scaled-up programme in Botswana. *Eval Program Plann* 2002;25:421-31.
16. Painter TM, Diaby KL, Matia DM, Lin LS, Sibailly TS, Kouassi MK, et al. Women's reasons for not participating in follow up visits before starting short course antiretroviral prophylaxis for prevention of mother to child transmission of HIV: qualitative interview study. *BMJ* 2004;329:543.
17. Haider R, Ashworth A, Kabir I, Huttly SR. Effect of community-based peer counsellors on exclusive breastfeeding practices in Dhaka, Bangladesh: a randomised controlled trial. *Lancet* 2000;356:1643-47.
18. Bhandari N, Bahl R, Mazumdar S, Martinez J, Black RE, Bhan MK, et al. Effect of community-based promotion of exclusive breastfeeding on diarrhoeal illness and growth: a cluster randomised controlled trial. *Lancet* 2003;361:1418-23.
19. Morrow AL, Guerrero ML, Shults J, Calva JJ, Lutter C, Bravo J, et al. Efficacy of home-based peer counselling to promote exclusive breastfeeding: a randomised controlled trial. *Lancet* 1999;353:1226-31.