

# Experiences of breastfeeding and vulnerability among a group of HIV-positive women in Durban, South Africa

GILL SEIDEL,<sup>1</sup> VISHANTIE SEWPAUL<sup>2</sup> AND BABALWA DANO<sup>2</sup>

<sup>1</sup>*Upres-A5036 (CNRS), Sociétés, Santé et Développement, University of Bordeaux, France, and* <sup>2</sup>*Department of Social Work, University of Natal, Durban, South Africa*

While international guidelines are currently being drawn up about HIV and infant feeding practices, and national and regional guidelines are under discussion in South Africa, there have been remarkably few studies that have sought to elicit HIV-positive mothers' experiences of breastfeeding and of paediatric infection. There is an urgent need to document this 'grass roots' knowledge in different sites, and for this data to be used to inform policy development, and for advocacy and counselling purposes. This qualitative investigation reports on the experiences and decisions taken around breastfeeding by a peer support group of 13 HIV-positive mothers meeting at King Edward VIII Hospital, Durban. In this study, the particular focus of information-giving and decision-making as to breast or formula feed is concerned with the impact on individual HIV-positive women and their babies. The most significant finding is that at no stage during their pregnancy were any of these mothers given information about the risks of HIV transmission through breastmilk. The study data were elicited in an in-depth group discussion, and individual women were invited to re-enact their stories in a follow-up discussion for clarification purposes. The women also discussed how they dealt with problems surrounding confidentiality in cases where few have been able to disclose their status to the extended family. There have been renewed calls for further investment in counsellors, with an enhanced role for community activists as peer educators. While there are severe resource constraints and low morale among many overworked nurses, one of the general problems in hospital settings remains the vertical health paradigm. This does not accommodate women's experiences, preferences, social networks and lay knowledge, and inhibits many women from becoming full participants in decisions affecting their own and their family's health.

## 1. Introduction

Despite important clinical interventions aimed at reducing mother-to-child transmission (Brocklehurst 1998), including giving women information and the choice of whether or not to breastfeed, or for how long, it has not been considered a priority to elicit or document women's knowledge or experiences of these interventions. Indeed, few women's evaluations exist (Sherr 1997a,b). This gap needs to be addressed by micro studies. It is time to look at these issues in new ways (Kuhn and Stein 1997; Minkoff and Augenbraum 1997; Seidel 1998a,b, 1999).

Rates of HIV transmission through breastmilk are variable, calculated in studies in Africa as between 12–43% (McIntyre 1997). This means that approximately one-third of all mother-to-child transmissions could be due to breastfeeding. The median risk is put at approximately 25% for South Africa (Gray et al. 1996; Bobat et al. 1997). The risk of transmission is greater during the delivery, where caesarean sections may provide a measure of protection. However, in calculating vertical transmission rates through breastmilk in different countries, the risk of late transmission varies between studies (Ekpini 1997), and there are confounding factors (e.g. Zimmer and Garza 1997). Furthermore, not all of these trials have controlled for length of feeding.<sup>1</sup>

Clinicians in South Africa were quick to draw attention to breastmilk as an HIV transmission route (Evian et al. 1993), and to challenge WHO and UNICEF positions (see also Desclaux 1994, 1996, 2000). Statistics for exclusive breastfeeding are not generally available. However, it has been suggested in South Africa that at least an initial period of breastfeeding is seen as the norm for some 86% of African mothers (Community Agency for Social Enquiry 1995: Chapter 22), and South African trials have been concerned with quantifying the risk of breastfeeding for HIV-positive mothers (Coutsoudis et al. 1996; Bobat et al. 1997; Coutsooudis et al. 1999). The first major discussion of these issues took place at an International Conference held Durban in 1996, which produced a number of important recommendations (Pillay 1996).

However, there is great unease and, at times, confusion among many health workers in South Africa, including in KwaZulu-Natal (KZN), that breastfeeding is somehow under attack from 'the AIDS camp'. A number of agencies, like the Nutrition Directorate, are concerned that their efforts in supporting breastfeeding, and their earlier policy of 1996 (Health Systems Trust 1997), are now being called into question (Seidel 1998b). In some cases, where support for breastfeeding represents their main area of expertise, some nurses have even suggested that this new information on the risks attached

to breastfeeding for HIV-positive mothers will potentially undermine their authority as nurses and as midwives (Pillay 1996). Attitudes among nurses in Gauteng, however, may be different (Wagstaff 1992; Richter and Griesel 1998).<sup>2</sup>

At one extreme of the spectrum, according to high-profile media coverage of the opening of one hospital in KZN in 1998, intended as a model for a baby-friendly clinic in line with UNICEF's baby-friendly initiatives (WHO/UNICEF 1989), it was reported that no bottles were to be allowed on the premises. While this clinic may be exceptional, there are other indications of ambivalence towards any information, in this case HIV-related, which may challenge support for universal breastfeeding. Clinics in KZN are plastered with AIDS posters, but it is hard to find even one that focuses on transmission through breastmilk. Furthermore, those promoting breastfeeding have not been removed. The Mothers' Lodge at King Edward VIII Hospital (KE), Durban, where some of the study mothers were accommodated, is a case in point. The only poster on display depicts mothers from different backgrounds all happily breastfeeding. The caption in Zulu translates as 'Breast is best'.

### Study background

What advice should be given about infant feeding to pregnant women and HIV-positive mothers? How and by whom should decisions be taken? What of an individual woman's circumstances? And government responsibility? What information is currently available about HIV and breastfeeding in South Africa, and in KZN, to HIV-positive women, and to pregnant women who do not know their status? How ethical is it *not* to inform HIV-positive women, and pregnant women in general, of the risk? And what is the situation in KE, which has the highest rate of HIV infection among antenatal clinic attenders in the whole country (Medical Research Council 1998), and HIV rates as high as 45% among so-called 'unbooked mothers' over a 6-month period (D. Moodley, personal communication, Dept of Obstetrics and Gynaecology, Natal Medical School, December 1998)?

In this KZN study, the particular focus of information-giving and decision-making as to breast or formula feed – the key question being 'whose decision?' – is concerned with the impact on individual HIV-positive women and their babies. It seeks to elicit and account for the individual experiences of a peer support group of HIV-positive mothers who have been meeting regularly at KE for over a year (Sewpaul 1998; Sewpaul and Rollins 1998). It documents the fact that only one woman in the group had access to knowledge about this potential transmission route during her pregnancy, and this was a result of her own reading.

The fact that 'mother-to-child transmission' is so named – as if the father played no part – seems to emphasize the mother's sole responsibility. This is unfortunate on a number of levels, and this use of language may have material outcomes. This now familiar epidemiological categorization is rarely questioned (Vidal 1998). However, when considered together with the fact that young pregnant women attending antenatal clinics tend to be the first members of their family to be tested,

it may appear to justify blaming women, especially 'un-attached' women, for spreading the disease. While all but two of these women learned of their infection through their baby becoming sick (Sewpaul and Mahlelela 1998), it is women who are seen as solely responsible for the health of their family, though conditions and events often lie beyond their control.

The situation becomes particularly complex, with the potential for further blaming of women and for their abuse, in cases where a woman has not been able to disclose her status, even to the father of the child and to the extended family (a nuclear family is not the norm in KZN). For many women, disclosure, if it takes place at all, is a slow and selective process, tending to assume a complex form of hints, retractions and denials, rather than a single 'tell-all event'. An HIV-positive pregnant woman in work or financially secure who has disclosed may be fortunate enough, in the best scenario and after adequate counselling, to be able to decide not to breastfeed, or to do so for a short period, and will be supported in her decision by her partner or family. But there are few 'best scenarios'. For those who have not disclosed, withholding the breast from the new baby will provoke questions and speculation (Cosminsky et al. 1993). This means that a non-breastfeeding mother is likely to compromise her own confidentiality in settings where breastfeeding is expected both by nurses and at home. Inadequate milk is usually offered as an explanation for not breastfeeding; and counsellors or some supportive or motivated health workers tend to assist mothers with these 'excuses' (as in the multi-centred UNAIDS Petra trials at the KE site – personal communication to GS, D. Moodley, April 1998). For the majority, there are also financial considerations ('breast is free'). However, this gendered assumption in problematic. Additional nourishing food needed by pregnant mothers, the phenomenon of 'maternal depletion' (Maher 1996) and time devoted to regular feeds, should be seen as relevant and vital factors in the important comparative costing exercises being carried out in the area of paediatric AIDS interventions.

In recent advocacy initiatives, including a full page in the *Sowetan* newspaper in May 1998 emphasizing the advantages of breastfeeding, there might appear to be some indications of a moral panic. It is as if HIV specialists and clinicians concerned with reducing transmission rates were being perceived as undermining the practice of breastfeeding altogether. This is a misreading of the situation; and perhaps not always an innocent one in so much as there are different interest groups and competing professional interests involved. There are also competing discourses at work (Seidel 1993, 1998b), with competing representations of gender (Seidel 1999), and these affect women's lives. In order to introduce to nurses and midwives this new scientific data on the transmission risks to different populations – and to explain its impact on mothers and babies – certain clinicians, paediatricians and gynaecologists, and informed counsellors, are introducing a new discourse into the hospital and HIV health-education setting. This is one of 'choice' in the sense of relative patient autonomy (Scudder 1990; Jewkes et al. 1997). While in no way seeking to undermine the advantages of a minimal period of exclusive breastfeeding in general, the statement issued by the International

Conference on HIV and Breastfeeding in Durban in 1996 (Pillay 1996), the April 1998 WHO/UNICEF/UNAIDS consensus statement on infant feeding practices and the practices adopted at the KE UNAIDS Petra study, all stress the importance of a mother *'making an informed choice'*. However, that *'choice'* is severely constrained, or represents no choice at all, if a woman has no source of income, or is without family or other support. All these issues are explored through the experiences of this mother's peer support group at KE.

This paper is in four parts. Following this introduction, part two presents the women's responses to key questions concerning their own experiences and feelings around breastfeeding, and draws on additional information available from case studies. Part three consists of a discussion and interpretation of the data. Certain linguistic issues arise here from working in both English and Zulu, where the use of both languages (but largely Zulu with English summaries) has been the language practice of this group from the start. In part four, the vulnerability of different women living with HIV/AIDS is also discussed in terms of their access to structures of support (Seidel 1999; Seidel and Coleman 1999). It is argued that women's knowledge, and their particular experiences and needs, should be taken into account when formulating policies on HIV and breastfeeding. The women's stories show that in contexts where the doctor/nurse patient communication would seem, in their experience, to be largely hierarchical, and decisions are taken *'for'* rather than *'with'* the patients, little or superficial attention is paid to their social and financial circumstances and to their own experiences of caring for their baby. Does this mean that in some health settings, the voices of women, with or without HIV, may still be unheard or unheeded?

### The research design

Permission to carry out this work, as part of a larger study (Seidel 1998a), was obtained from the Ethics Committee of the University of Natal Medical School. The study uses frameworks from social constructionism to look at the social construction of medical knowledge. It is also concerned with a bottom-up approach (Schrijvers 1992). Its main focus is patient perspectives in relation to those of health workers, and it seeks to document and analyze the processes whereby health and disease are conceptualized.

The data were obtained from two in-depth discussions of some 1<sup>3</sup>/<sub>4</sub> and 1<sup>1</sup>/<sub>2</sub> hours each. The first of these was organized along the lines of a focus group, but with the difference that these group members were well known to the two main facilitators. This meant that more detailed ethnographic information was already available. Permission had been sought and obtained earlier from the women to introduce this topic. It was agreed that confidentiality would be guaranteed in this study by using fictitious names for group members in any report, and permission was given to make audio-recordings.

The function of this group was defined by one of its members:

*'We are a support group. We are all HIV-positive. We also do peer education. We are helped by bus fare that allows us*

*to meet each week. We give each other psychological support and discuss our problems.'*

Because of the genesis of this peer support group, convened from the start by the main facilitator (VS), an English speaker, and assisted by a co-facilitator, currently a final-year social work student, bilingual in Zulu and English (BD), the language dynamics had already been established. There is also a certain amount of code switching (Zulu to English) among some members of the group, as is common in metropolitan contexts, while at least two members are fluent in English. The questions agreed by the authors were initially put to the group by the main facilitator in English, then immediately translated into Zulu. They were the following:

- (1) What have you been told about HIV and breastfeeding?
- (2) What were your feelings about this?
- (3) What questions did health workers ask you about your financial and social circumstances?
- (4) If you are not breastfeeding, can you afford formula now?
- (5) What about the confidentiality question if you are not breastfeeding?

A second in-depth discussion was held in order to confirm and substantiate some of the initial data and emphases coming out of the first, some of which were open to different interpretations. A crucial function of the second discussion was to seek to explore certain emphases, lexical and syntactic patterns, where different women's stories called for some clarification in terms of language, and where added emphasis could mistakenly be given to the English translation that was not present or intended (the recording was transcribed and translated into English by BD).

This clarification was done in two ways: by asking direct questions to elicit the exact phrasing used in a given context, and by inviting women to re-enact certain doctor-patient interactions. Where possible, the latter encompassed paralinguistic features (facial expression and body language). For some, this included the doctor-patient dyad with a third party, the nurse-interpreter (another source of potential bias), or in interaction with a family member at home.

Sewpaul designed and facilitated this second exercise after a discussion with the other authors about patterns in the initial data and how drama could be used to act out scenes. Enactment was a technique she had used in group work as part of social work practice in a multi-cultural setting. For Seidel, this was a way of introducing basic Boal-theatre techniques (Boal 1995), devised in a multi-cultural setting, which she had originally envisaged in the place of a focus group format. The enacting was used as part of a heuristic exercise, and in this setting it proved to be a useful research tool as well as a methodological compromise.

## 2. Findings: the patterns of women's responses

Of the 13 women present at the first discussion:

- seven had been told not to breastfeed (although not initially),

- one had read the HIV literature and decided against breastfeeding,
- one overheard the nurse and acted on this information, and
- four made a choice not to breastfeed – three because they were working at that point or seeking work (of whom one was actively encouraged not to breastfeed by her mother for this reason).

The most important and strictly unambiguous finding to emerge from this study is that at no time were any of these women informed during their pregnancy, or even immediately after, of the risks of HIV transmission through breastfeeding. Only two women knew their HIV status during pregnancy, while the others learned of it after their baby became sick. Breastfeeding only became an issue for most of the group when they were advised to stop, or at least discontinue for a while, after their baby had been treated for severe diarrhoea at KE; or in some cases when they as mothers, or close female relatives, had observed what they perceived to be a direct relationship between breastfeeding and diarrhoea, and acted on this knowledge. They expressed considerable regret, and in some cases controlled anger, that this information about breastfeeding as a possible transmission route had not been made available to them at an earlier point.

Take the case of Thandi whose only baby died at 19 months.

‘I was never told anything about HIV and breastfeeding. I breastfed my baby for 11 months. If I knew anything, I would not have fed him poison (‘i-poison’ in Zulu), and maybe my baby would have lived for a longer time. I feel sorry for myself for the time I wasted breastfeeding. I thought I was breastfeeding, but I was breast-poisoning.’

Because of the lack of adequate information, Thandi is assuming that her child was necessarily infected through her breastfeeding, whereas she could have been infected during the birthing process, or through ingesting blood if her mother’s nipples were bleeding.

Patience also lost her baby. She had decided that she would bottle-feed him, simply because she had no milk. But the nurse intervened and insisted the baby be breastfed.

‘I had bottle-fed him since he was born – until another nurse forced me to breastfeed him. (. . .) I think that when a child has diarrhoea, it gets worse when he is breastfed. This is what happened to my child. That is why I stopped breastfeeding.’

Barbara’s boy, now aged 7, is sick with the familiar signs of wasting, and has no energy.

‘My baby was breastfed for the first two weeks. I stopped breastfeeding him because he did not like the breast. I decided to stop breastfeeding myself – no-one advised me. Nurses told me that breastmilk is the healthiest milk you can give a baby. Nurses were forcing me to breastfeed the baby regardless of my status.’

It is possible, however, that the nurses were unaware of this woman’s HIV status.

Nolundi also took the decision herself to stop breastfeeding because her baby was having bouts of diarrhoea. Zanile’s experience is similar, as is that of Patience, who was allowed to exercise her own judgement and knowledge derived from observation. The decision to stop breastfeeding was their own as, from their intimate experience and observation, there seemed to be a clear link between breastfeeding and persistent diarrhoea. For Hope, it was her aunt who had observed the assumed relationship. She intervened, advising her niece to stop breastfeeding. Zanile was also told to stop, following her baby’s prolonged diarrhoea, on the advice of a doctor – but only to stop for 10 days. It was her own decision to discontinue all together.

Maria’s baby loved to breastfeed. But her mother told her to stop because very soon she needed to look for work. Her baby was also developing sores in the mouth.

‘When I came to the hospital, the doctor told me to stop breastfeeding.’

Nonhlanhla’s story differs slightly:

‘I was not told by anyone to stop breastfeeding. I decided to stop because my breast was having sores and the milk turned into water . . . So I decided to discontinue breastfeeding because she was HIV positive.’

At that time her baby was three and half months. She did not mention any bleeding from the nipples as such, but just ‘sore(s)’, a very general term in Zulu (‘*isilonda*’). The baby is now gaining weight. However, he has a serious skin rash and vomited through most of the first discussion, after being bottle-fed. Nonhlanhla is now pregnant again, and is unlikely to breastfeed.

The case of Happiness is quite distinct from all the rest in terms of ‘class’ and social status: she is the only married woman in the group. Happiness agonized over the decision to have a second baby, when the risks had been fully explained to her. She was also counselled about the possibility of a termination, but opted not to proceed. Her second child, a girl, now nearly four, has had serious bouts of illness. Happiness had earlier shared her experiences with the group. She is currently without financial support as she is seeking a divorce and is taking court action to secure maintenance.

Happiness had read up about HIV on her own initiative. She knew the risks, and had decided not to breastfeed. She had managed to disclose to her husband, but not to the extended family. She had prepared bottles and hid these in the wash-room. In the ward, she would surreptitiously bottle-feed the baby adopting the position of breastfeeding from under her blankets. One day she was caught, and an explanation was demanded as to why she was not breastfeeding. In order to explain what was seen as disobedient behaviour, she felt obliged to reveal her HIV status, and expressed concern about this ‘outing’. After that, she was allowed to bottle-feed.

At this point, Happiness took control of the discussion. She appealed to group members for more information:

‘What I want to know is that after you stopped breastfeeding, did the diarrhoea always stop? I did not breastfeed my baby, but she had diarrhoea for a full three months.’

Thandi in reply recounted her story:

‘No, it did not get better. My baby had diarrhoea when he was 11 months. He died at one year, seven months after very serious diarrhoea.’

However, medically, there is no simple, direct link between the two.

### **Women’s feelings about breastfeeding and stopping, and reactions of partners and family**

While experiences were not identical, there were indications that breastfeeding, encouraged by women and men, was widely seen as the norm. In these hierarchical settings in which major social differentiation is based on biologically defined gender categories, any deviation from these expectations is by no means simple. In some cases, departure from this norm was a matter for recrimination and punishment. For Happiness, challenging the hospital culture of ‘compliance’ meant being inventive and ‘devious’.

For Patience:

‘my boyfriend was cross with me. He said I wanted to look younger and for my breast not to fall [sag].’

Grace was physically abused for refusing to breastfeed. The abuser was her brother,<sup>3</sup> not her partner. In this case, there is a suggestion of male bonding and putting combined pressure of various kinds on Grace to force her to breastfeed. One interpretation for this abuse is the unwillingness of her partner, or his inability, to pay for baby formula.

‘I had a problem with my brother, though he is not supporting me financially. He used to beat me and forced me to put hot towels on my breast when I told him I had no milk. Here is the scar where he beat me [indicates eye area]. He said I wanted to be a young girl, to look younger, so that men would look at me as if I’m a bitch [‘isifebe’]. My boyfriend was complaining that the formula is so expensive.’

This story was met with a prolonged and sad silence.

To break that silence, a rather leading prompt was given: ‘*Did you feel guilty or bad about not breastfeeding?*’ There was no response. Instead, replies, initially at least, were only forthcoming about other people’s reactions – as if their own feelings were of little consequence. After a pause, Barbara ventured a comment that, although medically sound, did in this setting have the ring of a learned, textbook response:

‘It is painful not to breastfeed because not doing so can give your baby diseases and he catches many infections.’

Another comment was in much the same vein:

‘It breaks the bond between mother and baby.’

Rejoice was relieved to stop because she felt she had no milk left in her breast. In Maria’s case, her mother told her to buy N, a commercial product. She had no objection to her daughter stopping breastfeeding. For Maria, a petty trader in the market, stopping breastfeeding was a source of new-found freedom:

‘I can now leave the baby with others and do other things in my life.’

Her response to the non-leading question ‘*How did you feel about this?*’ [no longer breastfeeding] was the only clear intimation of a possible conflict between the interests of a particular mother (redefined along less conventional gender lines as having a legitimate function and activities outside the home in her own right) and those of her baby.

Moving beyond the purely medical perspective to consider social constructions, are constructions of motherhood in South Africa (Gaitskell 1989) in the process of changing in the context of the HIV epidemic? Clearly, this question cannot be answered within the confines of this small study. However, it is interesting that this sentiment is expressed here by Maria, a relatively independent woman, although a minority voice in this group. Her partner occasionally attends peer group meetings as the only man present, and helps with the bottle, appearing to bond with the child.

Within the peer group setting, where many issues have been discussed (gender relations, sexuality and safer sex, euthanasia, income generation schemes, and their anger at their treatment by many health and social workers), the women are still quick to judge others whom they perceive as ‘non-coping’ mothers or as breaking the rules of the group when they are now trained as peer educators and to some extent are seen, and are encouraged to see themselves, as role models. Hence getting pregnant, implying unsafe sex, was seen as deeply problematic by most of the group and by the first facilitator, and the woman concerned was heavily censored.

One member, overwhelmed by the sickness of her mother while her son was developing symptoms of AIDS, took him to be cared for by his father in another city. This was seen as unacceptable mothering behaviour by most women in the group, and again they were harsh in their judgements of her. In some cases, such attitudes, values and judgmental behaviour of younger women, who exercise what may appear to be more autonomous choices, may predate their knowledge of their HIV infection. Such values, including the role of the father, have been challenged in discussions with the facilitator at times. But these kinds of values are most resistant to change. It is possible that they are being enhanced among this group of beleaguered mothers as part of their creation of new, or rather renewed, meanings and behaviours, and that these values, in many ways ‘traditional’, may be forming the basis of an emergent group identity? In any event, this emphasis on being seen to be a ‘good mother’ may leave only a restricted

discursive and psychological space in which to express ambivalence, the everyday problems of trying to 'cope' unaided, and the raw experience of looking after a seriously ill baby (and other close relatives) who will not get better. In both a local and broader social context, where motherhood tends to be if not idealized then certainly affirmed and the only broadly socially acceptable pathway for women, critical representations may not be seen as appropriate or even mentionable (Seidel 1998b).

### **Women's social and financial circumstances and their access to formula milk**

It has been suggested that women's individual, social and financial circumstances must be taken into account by health workers when helping a woman come to a decision about feeding her baby with formula milk. What happened in the case of these women? What information was elicited? Here again, there is some variation in the stories, and some details lack specificity. Nevertheless, there is an overall pattern in their experiences.

For Nonhlanhla, the case is clear cut: no social questions were asked.

'They just asked the reason why I needed to stop breastfeeding.'

For Rejoice:

'The doctor never asked anything about social circumstances. These questions were being asked in the administration.'

Both these responses call for more clarification. One interpretation of Rejoice's response is that basic social and financial data were included in the initial case-taking by a doctor on admission. Patience's response was identical to that of Rejoice. However, it was clear that where such case histories were taken, they contend that these notes were not on hand for doctors to consult. It is difficult for the authors to verify these statements.

Women's access to formula milk proved to be the most controversial and emotionally laden dimension of the entire discussion. All the women talked at once. There were heated arguments about the willingness of certain doctors, and stubborn refusal of others, to make tins available to them, as well as the amounts involved. They argued that that only two doctors supply 'milk formula'.

Khatazile is quite adamant:

'I asked the doctor myself what am I going to feed my baby with at home since he told me to stop breastfeeding, because he only gave me four tins of formula feeding [of 500 grams each], and I told him that I'm not working. The doctor told me he would write a letter to give to the social workers.'

However, he failed to do so.

There was considerable disagreement at this point, and the recording is not always clear. Some suggested that this amount was altogether inadequate – that one tin lasts only for three days. One unemployed woman, with no other source of support, says she is obliged to find money for additional formula, and in-between she feeds the baby on rooibos tea (a South African commercially produced herbal drink) or porridge. Some women claim that they have not been issued with milk formula at all. Another woman interrupts: 'I was given six tins.'

This revelation and the perceived inequality of treatment generated more heated discussion. Some of the information and statements the women made about formula milk and different doctors' dispensing practices are confusing. In fact, severe cutbacks in the regional health budget have meant that, according to official hospital policy, no formula milk is to be issued, other than to inpatients when specifically requested by a doctor. The main question at issue here, and which proved so controversial, seems to be the lack of distinction drawn between conventional commercial formula milk (not normally issued to outpatients) and specially prepared formula milk. The latter is issued in special cases, not assessed on the basis of poverty, as a medical treatment and part of a lactose-reduced diet for babies with severe diarrhoea. And perhaps some formula was given at an earlier point.

It is difficult to speculate whether this difference between the two preparations was explained to individual women. In any event, they were in an extremely vulnerable state. It is unlikely, therefore, that all would have remembered a more detailed explanation, assuming that a full explanation was provided. If it was given, was the Zulu-English translation adequate where a nurse-translator acts as interpreter principally for the doctor, and as culture-broker? Meanwhile, the dilemma that these women cannot afford to buy conventional milk formula to feed their baby on a regular basis remains unresolved. Only two of the group are currently in work, in the informal sector, while two are assisted by a boyfriend.

### **3. Discussion**

All the women in the group delivered at KE, and all but one had babies that were treated, and in many cases admitted, into the acute infections and diarrhoea ward where a research study into severe infant diarrhoea and HIV infection is underway.

At delivery, it was other health workers that interacted with the mothers. In these wards, according to these women's statements, the ward nurses insisted that all women breast-feed, irrespective of their individual situation or preferences. This approach has been identified in a Zimbabwean study as 'a ritualistic approach to breastfeeding' (Misairabwi et al. 1997). However, in a broader view, what is not known, and not possible to ascertain, is whether these reportedly over-zealous nurses knew about individual women's HIV status.

This emphasis on a minimal period of exclusive breastfeeding is clearly very important in poorly resourced contexts where

water supplies tend to be contaminated. Throughout the world support to breastfeeding mothers appears to have reduced child morbidity and infant deaths. Many health workers would support the nurses' practice whether or not they were aware of the women's status. However, the practice of breastfeeding is now being called into question because of the known HIV risk. And there are indications of some resistance to this change.

If the nurses did know their patients' HIV status and still proceeded as usual, could it be that these young, mainly unmarried, non-breastfeeding women are being categorized as 'bad mothers' (a common attitude of nurses in Burkina Faso towards sexworkers who are also mothers – personal communication to GS, A. Desclaux, December 1997) on account not only of the HIV stigma but because they are seen to be 'corrupting' good nursing practice and 'what happens naturally'? At the same time, it must be said that there is real difficulty in conveying the notion of risk, or of probability (Seidel 1995; Kuhn et al. 1998), especially when there are so many confounding factors (like re-infection during breastfeeding). Explaining these problems raises real ethical issues that should not be underestimated.

Whatever the explanations, many nurses are still insisting that the presence of HIV is not reason enough to oblige them to rethink their practice or to challenge the former WHO/UNICEF orthodoxy. The additional problem is that this stance may carry with it other social and political representations in terms of gender: it may ignore or trample on an individual mother's experience and wishes. Furthermore, in some contexts, as our data exemplifies, women in this study were blamed and made to feel guilty for exercising their own judgement, or for complying with that of a close female relative. They also felt devalued and humiliated by some health workers because they had acted on their own initiative, applying what they saw as empirical knowledge.

In the second discussion with the peer group, re-enactment was used primarily because of the possible ambiguity attached to the English translation of the Zulu verb, 'to tell': *'utshela'*. *'Udoctola ungitshela ukuthi ngeze lokhu'* is translated as 'the doctor told me to do this'. English has a number of synonyms that construct how, in what way, with what emphasis, and in what kind of social relationship, a health worker gives advice to, or informs, a patient about x. These include she/he 'ordered', 'suggested', 'recommended', 'thought I should', 'told me to', etc. It would appear, however, that Zulu uses only *one* verb, translated in the data as 'tell'.

We sought other examples: 'A mother *told* her child to do this' (in Zulu: *'Umama utshela ingane yakhe ukuthi yenze lokhu'*). This suggests a form of moral obligation, and while a refusal is possible, a direct refusal or direct confrontation is not anticipated. Similarly, 'telling', using the same verb, *'utshela'*, is also used when a civilian is obliged to carry out a military order.

Because of the need to disambiguate the social relations in which a number of women in the group were 'told' not to breastfeed after their baby had severe diarrhoea, women were invited to act out the scenes. This left no further ambiguities

about whether stopping was merely 'suggested'. It became clear from the enactment in every case, and our checking (*'Was it like this? – No? Then show us how it was'*) that the 'telling' was tantamount to an order (as from a superior to an inferior). And while the more vocal Nyami wanted to know how she would feed her baby, this does suggest that while the outcome or impact of some doctors' decisions may be questioned (and it helps that Nyami can make herself understood in English), the decision itself was seen as non-negotiable.

#### 4. Conclusions and recommendations

This hospital-based micro-study has drawn attention to a number of important issues that are vital components in policy formulation:

- (1) The absence of information given to HIV-positive women and to pregnant women generally in the antenatal wards about the risks of breastfeeding.
- (2) It has pinpointed different understandings of 'formula milk', which in this context (prescribed to women whose last baby was known to be HIV-positive) included special low lactose diet, not commercial formula and even more expensive, but which some mothers still sought to purchase when their supply ran out. However, virtually none of these women, whose financial and support situation deteriorated over a short period of time, had the means to afford commercial infant formula on a regular basis as a replacement feed.
- (3) Although confirmatory data are lacking about whether or not the nurses all knew the women's HIV status, for those who did, the study has highlighted what could be seen as form of denial of HIV and its transmission through breastmilk by many nurses trained to support breastfeeding, and who may feel undermined, even marginalized, by HIV agendas and concerns. In any event, according to these women's statements, a number of nurses they encountered in the wards seem to resent and despise mothers who wish to bottle-feed.
- (4) Women who do not breastfeed are blamed and may be abused by male family members.
- (5) Women's knowledge and experience gained by empirical observation of the relationship between breastfeeding and severe diarrhoea – although there is not a simple relationship between the two (N. Rollins, personal communication, June 1998) – was apparently disregarded. While nurses remain primarily directive, patients' experience will mitigate against women's broader participation in their baby's care. This situation was experienced as humiliating by the mothers, since they say they would go to any length to promote the well-being of their baby.

According to these women's testimonies, patients, in this case mainly vulnerable young women, may be being 'dispensed' medical knowledge in a one-way communication. At the same time, because they are vulnerable and the majority of health workers are hard pressed, working in difficult conditions and with low morale, it is possible that the information provided at any one time was not always explained, or if it was, may have been only partially remembered. Even with these important caveats, it would still appear that these women have not been

assisted in making informed decisions (Karim et al. 1998) about breastfeeding and hence about the health of their baby. Rather, they have been 'told' what to do. In this vertical model, there is a tendency to 'put down' women and mothers, their experience, their representations of infection, and their processes of decision-making. While there are always problems of negotiating 'lay' and biomedical knowledge, professional medical knowledge and medical culture tend to assume a unique status and to represent the only legitimate voice.

The recent consensus statement of WHO, UNICEF and UNAIDS on infant feeding (Draft Press Release, 27 April 1998) emphasizes a woman's right to make an informed decision (Evian 1998; Maposhere 1998; Pillay and Coovadia 1998). While this document is a considerable advance on earlier positions, it proceeds from a number of implicit assumptions in relation to the culture of rights and women's access to resources, and the process of decision-making which in some rural contexts may also involve significant others (like the mother, and mother-in-law, in settings where the father is absent or, most frequently, elusive). But is the move towards creating enabling conditions that will promote women's informed choice in settings of poverty entirely constrained by the question of resources? Perhaps a more pertinent question concerns how use of this restricted budget is optimized, on the basis of what models and priorities (Paalman 1998), and using gender-sensitive indicators (Comerford 1997) where women's lack of support structures must be part of the equation (Seidel 1996b; Seidel and Coleman 1999).

The skill constraints, and the situation pertaining in each hospital and clinic, need to be taken into account by policy-makers when developing a package for follow-through counselling and care; resource and training needs in different health care settings are never uniform. There has also been a demand for more training for health workers; and a call from non-government organizations and many health professionals for government and UNAIDS commitment to make cheaper generic formula, that could be redefined as medicine (Pillay 1996), available to needy mothers. Hitherto, this call has not been heeded. However, indications are that some wealthier provinces are making their own decisions in relation to the supply of AZT to HIV-positive pregnant women, together with reduced-cost formula milk, as shown in the recent decision taken by the Western Cape in January 1999 (See *CDC Daily Update*, 5 January 1999).

There have been widespread calls for further investment in counsellor training (Tallis 1997), but with different emphases and more patient- than test-orientated (McCoy 1995). However, there have been tensions between this relatively new professional status and the place for community and peer counsellors (Seidel 1996). Peer educators and counsellors are now assuming a higher profile in urban KZN. The Youth Commission, with their Positive Ambassadors initiative, are also more involved in setting up a network of support groups. These young people from affected and infected families are more likely to have a greater understanding of the precariousness of most of their clients, predominantly young single women, if they are from the same community or social class. Individual women's financial and personal circumstances

vary enormously and may change within a period of weeks or months. It is important that research takes account of this time frame, where a single 'snapshot' of a woman's situation at one point in time, of the kind sought in conventional questionnaires, purely empirical work, and noted on hospital forms, is unlikely to yield useful or dynamic social data. It may even produce misleading information, particularly if used as a basis for projections. A fuller picture may only be obtained through painstaking ethnographic work. This can also charter pregnant women's other pathways to care (Varga and Veale 1997), but remains undervalued in contexts where positivist approaches still hold sway.

However, in addition to counselling and training needs, a major problem is the inheritance and continuation of the *vertical health paradigm*. This has many dimensions. At one level, this verticality encompasses the physical and intimidating hospital structures; at another, it been sustained by nurses and by distinct patterns of authority. These have been further shaped by local settings and gender constructions, where young and especially unmarried mothers do not enjoy the respect and status given to 'senior mothers'. Informal accounts of young women being scolded by nurses because of teenage pregnancy, or because they are seeking contraceptive services (Woods et al. 1997), irrespective of HIV status, are commonplace. Low nurse morale, increasing patient numbers (KE deals with 10 000 deliveries a year) and a tendency of nurses to moralize in predominantly Christian settings, plus the cumulative weight of this medico-moral discourse (Seidel 1993), may be contributory factors. Meanwhile, studies of patients' narratives of hospitalization (Jewkes et al. in preparation), and how they experience this objectification, are sparse. One of the mothers put it:

'I come here [to peer group meetings] because I can talk with women like me. I need this. In the hospital, nurses do not understand [my circumstances]. It is so stressful for me and my baby. It makes me feel so very bad. I care so much for my baby – but I feel the nurses are blaming me.'

In this tertiary care setting, the barriers between doctors and nurses, and patterns of medical culture, heightened by the lack of a shared language and other social differences, constitute additional factors creating distance (Jewkes et al. 1998; see also Marks 1998). The impact of these overlapping but not homogeneous social models, their different tensions, and the values they reproduce in hospital wards, may mean that the maintenance of maximum social distance between health workers and patients, and especially young women patients, could be seen by many nurses and midwives as non-problematic and even desirable. While participation might be development discourse, it has been argued that in most settings hierarchy remains its dominant practice (Kabeer 1994; Brett 1996).<sup>4</sup>

## Endnotes

<sup>1</sup> In the multi-centred UNAIDS Petra trial (with two sites in South Africa: KE, Durban, and Chris Hani Baragwanath Hospital, Soweto), 80% of the enrolled mothers, after being clearly informed of the possible risks and advantages of breast- and formula-feeding, elected to stop breastfeeding after a short period (unpublished data;

D. Moodley, personal communication, June 1998), and have been provided with half-price formula supplied to the hospital at cost. They will be followed up over 18 months.

<sup>2</sup> The attitudes of nurses in Gauteng, in Chris Hani Baragwanath, Soweto, may be different, where in any case, Gray has suspended breastfeeding for HIV-positive women. An earlier study carried out in Soweto clinics suggests that nurses are becoming more tolerant of bottle-feeding because of the local realities – women's need to work and absences from the home (Richter and Griesel 1998). Similarly, some schoolgirl mothers in parts of semi-rural KZN around Pietmaritzburg, who have support, are also opting for replacement feeding; there are particular gender representations here in that this method also allows young women to continue with their education (Seidel 1999, submitted). This is not to underestimate the health risks to babies that bottle-feeding may present in under-resourced settings (Evian 1998): the non-sterilization of bottles and teats (cup and spoon is preferable), and over-dilution of formula to make it go further. Bobat et al. (1997) suggested that the quality of breastmilk of some HIV-positive mothers might not always be adequate in terms of micro-nutrients to prevent immunosuppression. However, this hypothesis has not as yet been fully investigated.

<sup>3</sup> This is in a setting where brothers may be put in charge by a parent, or otherwise may assume the charge of a sister or female cousin irrespective of whether the woman is older than the brother, her sense of independence or level of education.

<sup>4</sup> By contrast, the philosophy of primary health care in South Africa is concerned with 'grass-roots' priorities, extending participation, achieving greater gender equity and better service delivery, especially for rural women.

## References

- Appropriate Health Resources and Technologies Action Group (AHRTAG). 1997. *Caring with Confidence. Practical information for health workers who prevent and treat HIV infection in children*. Nottingham, UK: Russell Press.
- Amero H. 1990. Women's reproductive rights in the age of AIDS. In: Gerber-Fried M (ed). *From abortion to freedom. Transforming a Movement*. Boston, USA: South End Collective.
- Boal A. 1995. *The Rainbow of Desire*. London: Routledge.
- Bobat R et al. 1997. Breastfeeding by HIV1 infected women and outcome in their infants: a cohort study from Durban, South Africa. *AIDS* **11**: 1627–33.
- Brett R. 1996. The participatory principle in development projects: the costs and benefits of cooperation. *Public Administration and Development* **16**(1): 5–20.
- Brocklehurst P. 1998. Interventions aimed at decreasing the risk of mother-to-child transmission of HIV infection (Cochrane Review). In: The Cochrane Library, Issue No 4. Oxford: Update Software.
- Comerford KM. 1997. HIV and breastfeeding: a model for sensitive midwifery. *Australian College of Midwives* **10**(3): 27–31.
- Cosminsky S, Mhloyi M, Ewbank D. 1993. Child feeding and practices in a rural area of Zimbabwe. *Social Science and Medicine* **36**(7): 937–47.
- Community Agency for Social Enquiry (CASE). 1995. *A National Household Survey of Health Inequalities in South Africa*. Henry Kaiser Family Foundation.
- Coutsoudis A et al. 1996. Determinants of mother-to-child transmission of human immunodeficiency virus infection in a cohort from Durban, South Africa. *Paediatric Infectious Diseases* **15**(7): 604–10.
- Coutsoudis A et al. 1999. Influence of infant feeding patterns on early mother-to-child transmission of HIV-1 in Durban, South Africa. *The Lancet* **353**: 471–6.
- Desclaux A. 1994. Le silence comme politique de santé publique? Allaitement maternel et transmission de VIH. *Sociétés d'Afrique et Sida* **6**: 2–4.
- Desclaux A. 1996. Depistage et conseil aupres des femmes enceintes: une strategie de prevention? *Sociétés d'Afrique et Sida* **14**: 3–4.
- Desclaux A (ed). 2000. *L'allaitement dans le contexte du VIH en Afrique de l'ouest: de l'anthropologie à la santé publique*. Paris: Harmattan (in press).
- Ekpini ER et al. 1997. Late post-natal mother-to-child transmission of HIV1 in Abidjan, Cote d'Ivoire. *Lancet* **349**: 1054–9.
- Evian C et al. 1993. *Primary AIDS Care*. Johannesburg: Jacana Editions.
- Evian C. 1998. Policy guidelines for feeding of infants of HIV positive mothers. Prepared for the HIV Transmission and Breastfeeding Task Group on behalf of the HIV/AIDS and STD Directorate, Department of Health, Pretoria.
- Gaitskell D. 1982. Waiting for purity. In: Marks S, Rathbone S (eds). *Industrial and Social Change in South Africa*. London: Longmans.
- Gray G, McIntyre JA, Lyons SF. 1996. The effect of breastfeeding on vertical transmission of HIV1 in Soweto, South Africa. Proceedings of the XI International Conference on AIDS, Vancouver, July 7–12 1996 (Abstract No. Tu.C.342).
- Health Systems Trust. 1997. *South African Health Review 1997*. Durban: Health Systems Trust.
- Jewkes R, Abrahams N, Mvo N. 1997. Study of health centre feeding practices and pregnant women in Cape Town. Report 1, CERSA, Medical Research Council, Cape Town, South Africa.
- Jewkes R et al. 1998. Why do nurses abuse patients? Reflections from South Africa obstetric services. *Social Science and Medicine* **47**(11): 1781–95.
- Kabeer L. 1994. *Reversed realities: gender hierarchies in development thought*. London: Verso.
- Karim QA et al. 1998. Informed consent for HIV testing in a health care setting: is it truly informed and truly voluntary? *American Journal of Public Health* **88**(4): 637–40.
- Kuhn L, Stein Z. 1997. Infant survival, HIV infection, and feeding alternatives in less developed countries. *American Journal of Public Health* **87**: 926–31.
- Maher V. 1996. Breastfeeding and maternal depletion. In: Maher V (ed). *Natural Law or Social Construct?* London: Berg.
- Maposhere C. 1998. Breastfeeding in the HIV/AIDS era in Zimbabwe. Abstract 44266, Twelfth World AIDS Conference, Geneva, July 1998.
- Marks S. 1998. *Divided Sisterhood. Race, Class and Gender in the South African Nursing Profession*. Johannesburg: University of the Witwatersrand Press.
- Medical Research Council. 1998. Summary results of the eight national survey of women attending antenatal clinics of the public health services in South Africa in 1997. Durban: MRC.
- McCoy D. 1995. Appropriate HIV testing and counselling. *AIDS Scan* **7**(4): 3–4.
- McIntyre J. 1997. Report back on the Ghent Working Group on Mother-to-Child transmission of HIV1: 'Affordable options for the prevention of mother to child transmission of HIV1 from research to clinical care', Conference, National AIDS Programme and Perinatal HIV Research Unit, 19–20 November 1997, Johannesburg.
- Minkoff H, Augenbraum M. 1997. Anti-retroviral therapy for pregnant women. *American Journal of Obstetrics and Gynaecology* **176**(2): 478–89.
- Misihairabwi P et al. 1997. HIV and breastfeeding: individual and policy dilemmas. *SafAIDS News* **5**: 3–4.
- Paalman M et al. 1998. A critical review of priority setting in the health sector: the methodology of the 1993 World Development Report. *Health Policy and Planning* **13**(1): 13–31.
- Patton C. 1994. *Last served? Gendering the HIV pandemic*. London: Taylor and Francis.
- Pillay K. 1996. Report on Workshop on Breastfeeding Choices for the HIV-positive mother, Durban (May 20–21).
- Pillay K, Coovadia H. 1998. Should South Africa be preparing for interventions to reduce mother-to-infant transmissions of HIV1? (Opinion) *South African Medical Journal* **88**(4): 434–6.
- Richter LM, Griesel RD. 1998. Breastfeeding and infant care in the context of HIV/AIDS. *Psychology in Society* **24**: 40–57.
- Schrijvers J. 1992. Dialectics of a dialogical ideal: Studying down,

- Studying sideways, and Studying up. In: Nencel L, Pels P (eds). *Constructing Knowledge: Authority and Critiques in Social Sciences*. London: Sage Publications.
- Scudder JR, Jr. 1990. Dependent and Authentic Nursing: Implications of Heidegger for nursing care. In: Leininger M, Watson J (eds). *The Caring Imperative in Education*. New York: National League for Nursing.
- Seidel G. 1993. The competing discourses of AIDS in Africa. *Social Science and Medicine* **26**(3): 175–94.
- Seidel G. 1995. Gender and AIDS – a neglected dimension. Report on CERSA, MRC Workshop, Durban, July 1995. *AIDS Analysis Africa* **6**(4), December 1995/January 1996.
- Seidel G. 1996a. Stories to optimise care for HIV+ women and extending the gendered rights' discourse, with illustrations from a pilot study in rural KwaZulu-Natal. Paper presented to the International Symposium on Social Sciences and AIDS in Africa, Senegal, 4–8 November. In: Becker C et al. (eds). *Experiencing and understanding AIDS in Africa*. Paris: Codesria, IRD and Karthala.
- Seidel G. 1996b. Confidentiality and HIV status in KwaZulu-Natal: implications, resistances, challenges. *Health Policy and Planning* **11**(4): 418–27.
- Seidel G. 1998a. HIV/AIDS and strategies to prevent mother–child transmission in KwaZulu-Natal, South Africa: a study of practices, representations, discourse, gender, ethics, rights, and policy, with particular reference to breastfeeding, Research Protocol, University of Natal Medical School, Durban.
- Seidel G. 1998b. Making an informed choice – discourse and practices surrounding breastfeeding and AIDS in South Africa. *Agenda* (Durban) **39**: 645–81.
- Seidel G. 1999. Reconceptualising the issues surrounding HIV and breastfeeding and the information given to women – findings from sociological research in KwaZulu-Natal, South Africa. In Desclaux A (ed). 2000. *op cit*.
- Seidel G, Coleman R. 1999. HIV, women and support networks – a pilot project in rural KwaZulu-Natal using storytelling techniques. In: Aggleton PJ, Hart G, Davies P (eds). *Families and Community Responses to AIDS*. London: UCL Press.
- Stein L et al. 1998. Child feeding practices and attitudes of HIV-seropositive mothers in Cape Town, South Africa. (Research paper).
- Sewpaul V. 1998. The RDP. Implications for social work practice and social welfare policy development in South Africa. *Social Work (RSA)* **33**(1): 1–9.
- Sewpaul V, Rollins N. 1998. Applications of the Principles of Developmental Social Work: The Implementation of an HIV/AIDS Project. Unpublished Paper presented to the Joint World Congress of the International Association of Social Work and the International Federation of Social Workers, Jerusalem, 5–9 July.
- Sewpaul V, Mahlalela T. 1998. The power of the small group – from crisis to disclosure. *Agenda* (Durban) **39**: 34–43.
- Sherr L. 1997a. Over-view of the Vancouver AIDS Conference. *AIDS Care* **9**(1): 69–77.
- Sherr L. 1997b. Preventing HIV transmission during pregnancy and delivery: a review. *AIDS/STD Health Promotion* **9**: 4–6.
- Tallis V. 1997a. Issues regarding women. *Positive Outlook* (Pietermaritzburg, SA), Summer, **4**(3): 4–5.
- Tallis V. 1997b. An exploratory investigation into the psycho-social impact of an HIV-positive diagnosis in a small sample of pregnant women, with special reference to KwaZulu-Natal. Master's Thesis, Dept of Social Work, University of Natal, Durban.
- Tallis V. 1998. The psycho-social impact of HIV and pregnancy. Abstract 24237, Twelfth World AIDS Conference, Geneva.
- Varga CA, Veale DJH. 1997. *Isihlambezo*: Utilisation patterns and potential health effects of pregnancy-related traditional herbal medicine. *Social Science and Medicine* **44**(7): 911–24.
- Vidal L. 1998. La transmission: le Sida et ses savoirs. *L'Homme*, Paris, forthcoming.
- Wagstaff L. 1992. The use of breastmilk substitutes in Soweto. *South-ern African Journal of Epidemiological Information* **7**(3): 84–8.
- WHO/UNICEF. 1989. *The Baby Friendly Hospital Initiative*. Geneva: WHO.
- WHO/UNICEF/UNAIDS. 1998. Consensus statement on HIV and infant feeding practices, 27 April, Geneva.
- Woods K et al. 1998. Adolescent sex and contraceptive experiences: perspectives of teenagers and clinic nurses in the Northern Province. CERSA, Medical Research Council, Cape Town.
- Zimmer P, Garza C. 1997. Maternal considerations in formulating HIV-related breastfeeding recommendations (editorial). *American Journal of Public Health* **87**(6): 904–6.

### Acknowledgements

All the authors would like to thank the peer group members at King Edward (the *Bambanani* support group). GS would also like to thank the *Agence Nationale de Recherches contre le Sida* (ANRS), Paris for financing this research, members of the Department of Paediatrics and Child Health at the University of Natal, Durban, who hosted the work, the associated French team in Bordeaux: *Upres A5036 (CNRS), Sociétés, Santé et Développement*; and Janet Bujra and Ken Tidswell, University of Bradford, UK, and Clive Evian, Johannesburg, for their support.

VS would like to offer particular thanks to Nigel Rollins, Department of Paediatrics, whose initiative and concerns led to the setting up of this support group.

### Biographies

Gill Seidel, DPhil, former Reader in Discourse Analysis, University of Bradford, UK, is a member of the University of Bordeaux team (CNRS), *Upres-A5036, Sociétés, Santé et Développement*. Her current research into HIV and breastfeeding in South Africa is financed by the *Agence Nationale de Recherches contre le Sida (ANRS)*, Paris. She has been researching into aspects of gender and AIDS since 1987 and has published extensively.

Vishantie Sewpaul, PhD, is Senior Lecturer in the Dept of Social Work, University of Natal, Durban. Her doctoral thesis (1995) is entitled: *Confronting the pain of infertility: feminist, ethical and religious aspects of infertility and the new reproductive technologies*. She is the first facilitator of the *Bambanani* support group.

Babalwa Dano is a final year student in the Dept of Social Work, University of Natal, Durban, an AIDS counsellor, and the co-facilitator of this support group. She is concerned with the relationship between health, gender and human rights.

*Correspondence*: Email: g.seidel@bradford.ac.uk