

## How to change perceptions on feeding in neonatal care

The transmission of HIV through breastmilk, with the potential to infect the newborn, has had a major impact on child health worldwide. Although South African studies confirmed that exclusive breastfeeding reduced rates of mother-to-child transmission of HIV, the recommendation of formula feeding for HIV-exposed newborn infants, provided their mothers had the facilities for safe preparation of formula milk and complied with the AFASS criteria (formula feeding to be Acceptable, Feasible, Affordable, Sustainable, Safe), was introduced. Observations made by the nursing staff, fully aware of the risks of formula feeding, in the neonatal unit at King Edward VIII Hospital in 2009 showed that an increasing number of small, sick newborns were being formula fed.

By conducting focus group discussions with nurses, mothers and counsellors and teasing out the confusions and misconceptions, relevant information was imparted to the groups to allow them to re-consider their misconceptions.

Within a period of 2 months nurses were confident about re-counselling mothers with respect to appropriate feeding choices. HIV-positive mothers were trained to flash-heat their milk. Subsequently, policies for the unit were derived from the focus group discussions. In addition, regional hospitals in the Durban area (eThekweni) considered the introduction of flash-heating to their units.

The South African Department of Health opted for infants to receive prophylaxis with daily nevirapine as long as they are breastfed, and the Nutrition Directorate decided to withdraw the issue of free replacement feeds in HIV-exposed babies. KwaZulu-Natal was the first province to institute this policy. The Department of Health has recommended that neonatal units no longer encourage HIV-infected mothers to flash-heat their breastmilk unless the infant is not receiving ARV prophylaxis or the mother is not on treatment.

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### Advantages of breastfeeding

From the 1930s the advantages of breastfeeding for the baby were reported in the scientific literature.<sup>[1]</sup> Over the past 30 years it has become increasingly clear that 'optimal nutrition' leads to optimal neurodevelopment.<sup>[2]</sup> The advantages of breastfeeding in the short term for the newborn and child have been clearly established. The role of breastmilk in the reduction of necrotising enterocolitis (NEC) became especially important for low-birth-weight neonates in neonatal intensive care units. Protection of the immune system of the developing gut was shown by Newburg and Walker.<sup>[3]</sup> In 2007 Quigley *et al.* demonstrated that breastmilk protects against gut and respiratory infections,<sup>[4]</sup> and its effect on the incidence of sudden infant death syndrome was reported by Vennemann *et al.* in 2009.<sup>[5]</sup> The emergence of formula milks and breastmilk fortifiers presented a challenge to advocates of breastfeeding. Possible concerns around breastmilk fortifiers were raised in the 1990s.<sup>[3]</sup> Their role has been placed in context by Doherty *et al.*<sup>[6]</sup>

The Neonatal Unit at King Edward VIII Hospital (KEH), Durban, has advocated exclusive breastfeeding since the 1970s, which was well accepted and supported by all nursing and medical staff.

### The HIV feeding dilemma

The human immunodeficiency virus has had a major impact on the health system worldwide, specifically on child health.<sup>[7]</sup> It became evident that HIV is transmitted through breastmilk and can infect a newborn with HIV.<sup>[8]</sup>

Other important information around the risks of non-exclusive breastfeeding by HIV-infected mothers started to emerge in the late 1990s. In 1999, Coutsooudis *et al.* reported that babies who were exclusively breastfed in the first few months of life had a lower transmission rate than babies who received mixed feeding.<sup>[9]</sup> A subsequent South African study confirmed that exclusive

breastfeeding reduced rates of mother-to-child transmission of HIV and that support of mothers was vital to encourage exclusive breastfeeding.<sup>[10]</sup>

Another important scientific finding was the value of flash-heating of expressed breastmilk as a strategy to destroy the virus in milk of HIV-infected mothers.<sup>[8]</sup>

As awareness of HIV transmission through breastmilk increased, the initial response of many HIV-positive women was to avoid breastfeeding; this was reflected in studies cited by the World Health Organization (WHO).<sup>[11]</sup> Subsequently, formula feeding was recommended for HIV-exposed newborn infants provided their mothers had the facilities for safe preparation of formula milk and complied with the AFASS criteria (formula feeding to be Acceptable, Feasible, Affordable, Sustainable, Safe).

The majority of mothers live in conditions where the AFASS criteria cannot be met, and yet a large-scale move away from breastfeeding occurred even among mothers who without knowing their status feared being HIV-infected and refrained from breastfeeding, further eroding breastfeeding practice.<sup>[7]</sup>

Observations made by the nursing staff in the neonatal unit at KEH in 2009 showed that an increasing number of small, sick newborns were being formula fed despite the staff's full awareness of the risks of formula feeding, particularly in small, vulnerable infants. It became evident that even though the AFASS criteria for advising formula feeding were a scientific and medical attempt to discriminate between risk categories, counsellors, nurses and doctors could only promote breastfeeding half-heartedly when there was a real possibility that HIV infection could be transmitted to babies via breastmilk. Mothers are always likely to choose what they believe to be the option of greatest hope for HIV-free survival. The underlying

fear of HIV in breastmilk appeared to influence counsellors to advise mothers in favour of formula feeding.

The dangers of inappropriate choice of formula feeding by mothers who did not satisfy the AFASS criteria were cause for great concern. Doherty *et al.* noted that three criteria were specifically associated with HIV-free survival among formula-fed infants, namely piped water, electricity or gas for fuel, and disclosure of HIV status. The infants of women who chose to formula feed without fulfilling these three criteria had the highest risk of HIV transmission and death.<sup>[12]</sup>

The availability of free formula feeds on the South African Prevention of Mother-to-Child Transmission (PMTCT) programme, coupled with the fear of HIV, led to a further erosion of exclusive breastfeeding. Furthermore, a 'spill-over' effect resulted in formula feeding becoming more acceptable even for HIV-negative mothers. These effects were observed in the mortality data reflected in the paediatric outpatient department at KEH – the majority of babies who died had not been breastfed (unpublished KEH mortality statistics, 2007).

### Changing attitudes towards feeding

With the PMTCT programme in place, the roll-out of highly active antiretroviral therapy for treatment of mothers with low CD4 counts and the option of flash-heating, it was decided that the neonatal unit had to address the issues around misconceptions about infant feeding. It was also clear that these misconceptions and confusion existed among mothers, nurses (neonatal nurses and nurses in antenatal clinics and obstetric wards) and counsellors.

It was decided to conduct focus group discussions (see Appendix I) to tease out the misconceptions and confusion around infant feeding. Focus group discussions are well accepted in the social sciences to address these very issues.<sup>[13,14]</sup> The focus group discussions were conducted with the three categories interviewed, viz. mothers, nurses and counsellors (three counsellors were involved in the unit).

Concerning flash-heating, nurses tended to view possible stigmatisation of mothers performing the procedure as a major concern. However, the mothers themselves seemed less concerned about the stigma, as they felt they were 'doing good' for their babies.

The discussions with counsellors revealed that they were young, their knowledge of HIV was poor in general, and they appeared to fear HIV despite having attended a 2-week counselling course organised by the Department of Health. In addition, they often did not fully understand issues of confidentiality. They also could not relate to a mother's feelings when she is found to be HIV-positive after a rapid test – they were not able to comprehend that mothers need time to accept the new situation before being able to continue to test for the CD4 count.

Following each focus group discussion, relevant information was imparted to the group to allow them to re-consider their misconceptions. Nursing staff, mothers and counsellors were guided through discussions on HIV, breastmilk transmission of the virus, and factors that reduce the transmission rate through breastmilk, such as antiretrovirals given during pregnancy for prophylaxis and therapy, and flash-heating. Issues surrounding confidentiality and consent were further addressed.

### Subsequent developments

The occurrence of NEC in low-birth-weight sick babies born to HIV-positive mothers who had chosen formula feeding influenced the decision to promote breastfeeding by the nurses and medical staff as well as by mothers who were present in the unit at the time.

Even mothers who met the AFASS criteria began to request flash-heating of their breastmilk while their babies were in the neonatal unit. Background information was provided and demonstrations of

flash-heating were conducted. Risks and benefits were presented, feeding choices were re-assessed, and feasibility was re-explored. Once the method was accepted the counsellors were able to promote flash-heating as well.

The results of focus group discussions were compiled and presented to the nursing staff and the counsellors, and further suggestions were considered to ensure the introduction of breastfeeding as a safer option. Within a period of 2 months nurses were much more confident about re-counselling mothers with respect to appropriate feeding choices. The choice of flash-heating was further discussed and accepted. When flash-heating was initially introduced, nurses remained uncertain that mothers would accept the method. Within a few weeks it was clear that the mothers were pleased that they could 'do something for their babies', and they were teaching other mothers the flash-heating method. As flash-heating became a successful practice in the unit, minimal numbers of babies suffered from NEC. Confidence in this method of pasteurisation grew.

Any concerns of nurses in the neonatal unit, the confusion experienced by mothers, and education of counsellors were resolved by discussion groups held repeatedly over time. Successful implementation of exclusive breastfeeding became practical through consensus of all parties.

Subsequently, policies for the unit were derived from the focus group discussions. All mothers were to be encouraged to breastfeed their low-birth-weight sick babies, whether HIV-positive or -negative. HIV-positive mothers were trained to flash-heat their milk. The concern of stigma surrounding mothers who flash-heated their milk did not hinder implementation. Mothers were confident that they could help their babies by using the best possible approach. An interesting spill-over of all the experience with flash-heating has been that this same method was instituted in our unit as a means of pasteurising donor breastmilk.<sup>[15,16]</sup> The success with this low-technology but safe method of pasteurisation has led to a few other hospitals in KwaZulu-Natal (KZN) requesting assistance with setting up donor breastmilk banks.

Following these developments, the regional hospitals in the Durban area (eThekweni) also investigated the introduction of flash-heating to their units; one of the three hospitals has succeeded in doing so.

### Further developments in infant feeding subsequent to this exercise of changing practices

With increasing evidence on the benefits of breastfeeding for improving HIV-free survival, considerable research was invested in investigating the administration of antiretrovirals, either to the mother or to the infant, as prophylaxis against breastfeeding transmission. These trials proved successful, resulting in the WHO changing its guidelines on HIV and infant feeding and encouraging 12 months of breastfeeding while either the mother or infant receives ARVs.<sup>[17,18]</sup>

The South African Department of Health opted for infants to receive prophylaxis with daily nevirapine as long as they are breastfed, and the Nutrition Directorate decided to withdraw the issue of free replacement feeds in HIV-exposed babies. KZN was the first province to institute this policy. It has now become unnecessary for HIV-infected mothers who are expressing breastmilk to flash-heat the milk, and the Department of Health has recommended that neonatal units no longer encourage HIV-infected mothers to flash-heat their breastmilk unless the infant is not receiving ARV prophylaxis or the mother is not on treatment.

### Conclusions

It became clear that action research is a powerful tool for bringing about change in clinical practice. We realised the benefit of involving

all levels of staff as well as the end-user (in this case the mother) to first analyse what problems were being experienced and then investigate why these problems were occurring and what could be done to change practice. By taking note of the concerns and suggestions, as well as interrogating routine audits being conducted in our neonatal unit, we were able to implement changes in the unit that have had an influence on several hospitals in our province, resulting in higher numbers of women (including HIV-positive ones) exclusively breastfeeding.

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## Appendix I. Details of focus group discussions

### Discussion for nursing staff focus groups (10 - 15 participants)

These discussions were conducted for the neonatal unit staff, antenatal nursing staff and postnatal nursing staff.

- Why are you concerned about formula feeding?
- What are the risks?
- What are the benefits of breastfeeding?
- What is the benefit of breastfeeding even if the mother is HIV-positive?
- Why do you think mothers choose formula instead of breastfeeding?
- Why do you not believe that you could reverse the mother's decision by re-counselling?
- What would your approach be to solving the problem?
- What are your feelings about and understanding of the flash-heating technique?

### Discussions for mothers' focus groups (6 - 10 participants)

- What had you decided would be the method of feeding for your baby?
- Who guided you to this decision?
- Why are you uncertain about breastfeeding?
- What are the benefits of breastfeeding?
- What are the risks of formula feeding?
- Are you aware that you require specific facilities for preparing formula (these were elucidated during the discussions)?
- HIV-related issues were raised and discussed, including disclosure of HIV status.
- Mothers were asked if they were aware that antiretrovirals protect against HIV transmission in breastmilk.
- Flash-heating was discussed.
- Mothers could take time to consider their choices and arrive at final decisions.
- They were free to discuss with staff at any time.

### Discussions with counsellors

- The ages of the participants were assessed.
- The duration of their training was requested.
- Their understanding of the role of breastfeeding was discussed.
- The role of formula feeding was discussed.
- What requirements for formula feeding have to be in place?
- HIV issues were discussed, including the presence of the virus in breastmilk.
- Their personal impressions and fears of the virus were discussed.
- Risks and benefits of feeding choices were considered.
- Questions around confidentiality were introduced.
- Final assessment of their understanding of mothers' feeding options was made.

### Flash-heating discussions

The procedure was explained to all groups. Questions considered were:

- Do you think it is a cheap option?
- Do you think it is feasible?
- What do you see as possible stumbling blocks to the success of implementing it?