

Quality of infant feeding counselling for HIV+ mothers in Brazil: challenges and achievements

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Keywords

Brazil, Breast-feeding, Counselling, Health professionals, HIV/AIDS vertical transmission, Infant feeding, Skills

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Received

30 May 2006; accepted 21 June 2006

DOI:10.1111/j.1651-2227.2007.00017.x

Abstract

Aim: This project aimed to assess the information and counselling on infant feeding in HIV+ mothers. **Methods:** A cross-sectional study, based on 118 structured observations of mothers' visits to health professionals (5–8/professional)—in 15 purposively selected HIV/Aids healthcare units in Sao Paulo. **Results:** The general quality of communication and counselling skills was good: for example, professionals responded to all mothers' questions (98%); kept eye-to-eye contact (82%); encouraged the mother to talk (77.1%). However, the information provided to mothers aimed to help their choices concerning infant feeding was of very poor quality. No mother, for example, was informed about alternatives to formula feeding and the danger of mixed feeding. None was offered the option of using banked breast milk. Only around 20% of mothers were informed about the safe preparation of formula feeding. When counselled by a nutritionist (compared with a paediatrician) more mothers were informed about the correct way to prepare bottle-feeds. No mention was made of cup feeding.

Conclusion: Although health workers have good communication skills, the information provided to HIV+ mothers is insufficient. Recommending against breast-feeding and providing infant formula may not be enough to achieve safer infant-feeding practices.

BACKGROUND

HIV-1 transmission through breast milk was identified in the mid 80s in women who, postnatally, received blood transfusion or were infected through heterosexual intercourse (1). During the 90s, these data were confirmed (2). The latest UN recommendation on how to avoid mother-to-child transmission of HIV is that replacement feeding should be recommended when it is acceptable, feasible, affordable, sustainable and safe (3).

Without specific interventions, the rate of vertical transmission is around 15–20%, but breast-feeding might increase the rate to 35–40% (4). When free formula for infants of HIV mothers is provided together with counselling, MTCT decreases (5). When informed choice on infant-feeding method is promoted, women's decisions might still be compromised by the advice given, due to some options not accurately explained by the health worker (6).

In countries like Brazil, where prevention of HIV transmission with provision of condoms and treatment of HIV/AIDS became freely and widely available, the response to the risk of HIV transmission through breast-feeding was the inclusion in the national policy of a recommendation of 'Non-breast-feeding' and facilitating the access to infant formula for HIV + mothers. Free distribution of infant formula by the public health care units has been implemented, showing that this is feasible. It has also been estimated not to represent the most expensive item of HIV/AIDS public policy. The estimated breakdown of costs of complete implementation of prevention of vertical transmission in Sao Paulo in 2002 were (7) laboratory tests: 85.8%; medical con-

sultation: 1.3% (low cost due to the general low payment of public medical services); drugs: 4.9% (costs have diminished, year after year) and replacement feeding (including infant formula for 6 months and whole powdered milk after 6 months, and bottles): 8.0%. Full implementation of preventive measures—including replacement feeding—was estimated to save up to 65% of future costs associated with not taking any measures at all (7).

Brazilian guidelines also include that HIV+ mothers, who have access to a Human Milk Bank (HMB), can be advised of the possibility of using heat-treated breast milk as an alternative for formula feeding the baby. In Brazil, there is extensive experience of HMB. These banks use pasteurised human milk, a process that kills HIV virus and represents an alternative of feeding particularly for preterm and pathologic neonates. However, the HMB experience is limited in relation to HIV exposed infants.

The breast-feeding programme in Brazil has been implemented successfully for more than 20 years (8). Data have shown a 10-fold increase in exclusive breast-feeding rates and also on total duration of breast-feeding (8). Early supplementation, however, is still common and although cultural norms are currently 'pro-breast-feeding', it is not rare to observe a baby with a bottle. This observation suggests that replacement feeding is probably acceptable, but studies might be helpful to confirm it.

Replacement feeding is affordable—formula is distributed without charge to poor population—and feasible in Brazil. But is it safe? Is it sustainable? Are health workers playing a satisfactory role in promoting its safe use?

Our purpose in this study was to assess how the HIV/AIDS prevention policy, *particularly the infant feeding component*, is implemented in Sao Paulo and how we might correct mistakes and improve the healthcare provided in this regard. The findings can alert policy makers for not only areas of strong performance but also problems that can be faced in a setting where PMTCT can be implemented with free lab tests, free Aids treatment and free infant formula, assisting them in improving implementation plans.

THE STUDY SITTING

The city of Sao Paulo, capital of Sao Paulo State, in south eastern Brazil, is the largest city in the country, with a population of approximately 10 million inhabitants, and an Infant Mortality rate of 15 per 1000. The proportion of houses with safe water is 98.62%, with 87.23% of households with public sewage. Only 4.88% of inhabitants are illiterate. In this city, the number of paediatric HIV cases has declined from 75 in 2001, to 43 in 2002. The prevalence of HIV among pregnant women was 0.46% in 2005 (São Paulo Municipality Dpt Statistics).

Outpatient care for HIV/AIDS patients includes 18 specialized healthcare units and 8 hospital outpatient clinics, to which HIV+ women are referred by health centres, after testing positive for HIV. HIV+ women are advised during antenatal care that they should not breast-feed. During the last antenatal appointment, women sometimes receive two tins of infant formula. It is immediately after delivery, during admission to the maternity ward, however, that they receive orientation on infant feeding and drugs to suppress breast milk production. In the first visit of the baby to ambulatory care, the infant normally receives tins of formula. The policy indicates that HIV+ mothers should receive the information that an infant feeding option they may consider is to have their own milk pasteurised in HMB. There are around 160 HMBs in the country and 23 in São Paulo. Milk banks are available in some maternity hospitals, and mothers can use them if available at walking distance from home.

METHODS

This was a descriptive study carried out in health care units providing outpatient care to HIV/AIDS patients in Sao Paulo, Brazil. A sample of 15 healthcare units was purposively selected among the existing 18, using as eligibility criteria that at least one HIV+ woman on average could be seen per month. Eligible health professionals were those appointed as responsible for informing or counselling on infant feeding mothers attending the clinic for the first time after delivery (babies could be 0–90 days old). One or two health professionals per unit—paediatricians and nutritionists—were observed for 5–8 sessions each. Trained observers performed the observations, using a checklist during the consultation of the health professional with the mother. Observers were post-graduate students provided with training: initially, they observed two consultations to be familiar with the questions; after this, they observed two consultations in Health Units where the study would be performed, and fi-

nally they observed a consultation in pairs with the supervisor. Consistency was achieved while repeating observations and discussing doubts with the investigator. A structured observation checklist with 70 items was drawn up on the basis of the expected counselling process recommended by World Health Organization (WHO). It included a number of items related to infant feeding information, informed choice and provision of specific recommendations concerning mother-to-child HIV transmission and the risks of replacement feeding. Time of initiation and end of consultation were recorded.

Each item observed received a score between 0 and 1 in the analysis. The sum of these scores produced the overall score (mean and standard deviation were calculated taking into account all the observations of each health professional) for each subject. We attributed scores to the sessions and subjects according to the desirable achievements, meaning that for Subject no.1 – (risks of HIV transmission and replacement feeding) – the health professional should fulfill 22 items (information/attitudes) to obtain 100% achievement. The same is the case with the other subjects: Subject no. 2 – (The instructions of bottle-feeding preparation): 17 items; Subject no. 3 – (Feeding choices): 15 items; Subject no. 4 – (Contraception and safe sex): 4 items and Subject no. 5 – (Communication and counselling skills): 12 items.

SPSS was used for data management and analysis. Observations were also analysed by Generalised Estimating Equations (9), which were used to test if order of consultation could interfere on items observed, time of consults and achievement on specific subjects. The Research Ethics Committees of the Instituto de Saude, Sao Paulo and of the WHO approved the present study. Informed consent was obtained from health workers and mothers.

RESULTS

A minimum of five and maximum of eight observations were conducted per professional. A total of 118 observations were performed, 75 (64%) of them were of consultations by nutritionists and 43 (36%) by paediatricians.

Observation of the consultations

The consultations started with the health worker checking the use of medication by the infant and information on maternal viral load. HIV/AIDS treatment was the subject that received most attention from the health professional during consultations. The professionals consistently advised mothers against breast-feeding. The ‘do not breast-feed!’ motto was repeated at different moments or during different sessions when the woman sought the healthcare unit. On average, consultations lasted 30–40 minutes and one third of this time was spent discussing infant feeding. The duration of consultations was consistent across the study period and was not affected by the presence of observers (Fig. 1).

Risk of HIV transmission and conditions for providing replacement feeding

Table 1 presents the information provided during the consultations that could help a woman to make an informed

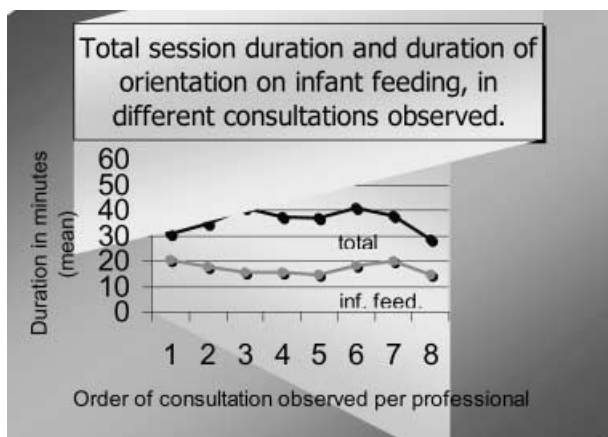


Figure 1 Total session duration and duration of orientation on infant feeding, in different consultations observed.

decision on infant feeding. It also shows that about one-half of mothers were informed (or reminded) that HIV can be transmitted through breast-feeding. In only 29.7% of sessions, did healthcare professionals check whether or how the mother understood this information. The risk of inadequate preparation of replacement feeding was very poorly explained: the need to use adequate water supply and keep prepared milk refrigerated was only mentioned in 11% of the consultations. The cost of purchasing formula was mentioned in only 11% of observations.

Instructions for preparing formula feeding

As shown in Table 2, around 80% of health professionals asked questions about the preparation of formula feeding. However, only 45% demonstrated this preparation, and only 39% of mothers were asked to show how to prepare a feeding bottle during the consultation. None of the mothers declared to opt for exclusive breast-feeding. This was not surprising as the information and counselling provided by health professionals did not include facts about the risks or benefits of breast-feeding. Only 1.7% of workers mentioned the possibility of the using the HMB. In 11.9% of the consultations, the health professional asked the mother whether she planned to give breast milk to the baby, and another 11.9% explained

Table 1 Selected items regarding the risk of HIV transmission and material conditions for replacement feeding in consultations for HIV+ mothers in Sao Paulo

Questions observed	Percent
Explained that, even if the baby is healthy, HIV may be transmitted through breast milk.	54.2
Checked whether the mother understood the risk of HIV transmission through breast milk	29.7
Mentioned expenses involved in purchasing infant formula	11.9
Investigated water supply	11.0
Investigated presence of refrigerator	11.0
Investigated bed-sharing conditions	6.8
Compared risks of bottle feeding and exclusive breast-feeding	0.8

Table 2 Instructions for the preparation of formula feeding in consultations for HIV+ mothers in Sao Paulo

Questions observed	Percent
Asked the mother how she intended to prepare the bottle	80.5
Checked the mother’s understanding of how to prepare formula	83.1
Asked the mother whether she had ever prepared a bottle	79.7
Made sure the mother had understood the instructions	78.0
Asked the mother whether she had any further questions	73.7
Mentioned the need to boil water when making formula	72.9
Reviewed how to safely prepare formula feeding	68.6
Explained the need to discard leftover milk	55.1
Demonstrated how to safely prepare formula	44.9
Asked the mother to demonstrate how to safely feed the baby formula	39.0
Mentioned the need to give formula at night instead of breast-feeding	38.1
Informed the mother that she could come to the facility whenever the supply finishes	31.4
Informed the mother about where to store formula	16.9
Discussed what to do in case the powdered milk finishes	14.4

Table 3 Communication and counselling skills in consultations for HIV+ mothers in Sao Paulo

Communication and counselling skills observed	Percent
Greeted the mother warmly during consultation	72.0
Introduced him/herself	61.9
Answered whenever the mother had a question	98.3
Used a friendly tone of voice	97.5
HW showed a comfortable and secure attitude	94.9
Did not use judgmental language	83.1
Maintained eye-to-eye contact	82.2
Used mother’s name when communicating	78.8
Encouraged the mother to talk	77.1
Sat close to the mother or at least with no barrier between them	27.1

to the mothers that it was not appropriate to ask other lactating women to breast-feed her baby; in 6.8% of observations, the worker asked whether the mother had another lactating woman nearby, and, in 10.2%, whether the mother was planning to ask another woman to breast-feed her baby.

Communication and counselling skills

Table 3 shows that the overall communication skills of health professionals were high. Health workers almost always used a friendly tone with the mothers, and tried to use all of the communication skills included in the observation form, except for the fact that they placed barriers between themselves and the mothers in 27.1% of the consultations observed.

Health professionals’ achievements during sessions

This section presents information on the structured observations of consultations according to a score given to each subject or issue covered in Tables 1–3 above, and taking into account the order of consultations observed; initially the idea is to determine, with this analysis, whether there

Table 4 Proportion (%) of adequate information achieved, according to subject and order of consultations observed, among health professionals attending HIV+ mothers in Sao Paulo

Subject	Risk of HIV	Preparing formula	Communication skills
Order of consultations			
1	15	49	71
2	20	53	75
3	22	53	78
4	22	53	78
5	20	56	81
6	13	55	86
7	17	54	80
8	24	61	80

Table 5 Proportion of achievements (mean) in the different areas, according to type of professional

	Nutritionist	Pediatrician
Subject no.1—Risks	21%	16%*
Subject no.2—Instructions	67%	31%**
Subject no. 5—Counselling	83%	71%

* $p < 0.0396$.** $p < .0001$.

were any changes in the behaviour of health professionals between the first consultation he or she was observed and subsequent consultations due to the presence of an observer. As already mentioned, time spent in session, on average, did not differ among observed sessions. In content, the achievements can be seen in the Table 4. In summary, communication and counselling skills, and, partially, the instructions for preparing formula feeding are the subjects that the health professionals are apparently better prepared.

To determine who would be responsible for this level of performance in these two areas, *the nutritionist or the paediatrician*, another type of analysis was carried out, estimating the differences between each consultation according to type of health professional. For Instructions for preparing formula feeding, it was clear that the nutritionists achieved a better performance; but this was not significant with regard to Communication and counselling skills (Table 5).

DISCUSSION

The main findings of our study were to show that health workers in the Brazilian AIDS program have very good counselling skills but have their performance on counselling HIV-infected mothers on infant feeding impaired by lack of specific knowledge on infant feeding. This might be jeopardizing their ability to prevent MTCT.

This was the first study on the provision of infant feeding information and counselling to HIV+ mothers in Brazil. Nevertheless, we should note some limitations: this was not a randomised sample of all health professionals of Sao Paulo City, neither a sample of all their sessions/consultations with mothers. Despite this limitation, we included all the health professionals providing infant feeding information.

Another limitation was the data collection carried out post-natally, when mothers were already implementing their feeding choices.

Many indications of the need to update and train health professionals became clear through the study. The key points that can be observed in the relationship between health worker and mother are to inform and counselling the mother about the dangers of mixed feeding, an issue already observed in South Africa (10), proper and safe preparation of infant formula, and safer feeding with the use of a bottle, reinforcing the mother's choice and ensuring that there is no deviation in terms of mixed feeding, given that it has been shown to increase the risk of HIV transmission (11). It is interesting to note that stigmatisation for not breast-feeding was almost entirely forgotten as a potential concern, despite breast-feeding having returned to be a norm in Brazil and being practiced by over 95% of mothers in maternity wards.

Using similar instruments, observing 22 nurses and community workers sessions in South Africa (12), with the same objectives of our study, it was founded that communication skills were good, but, like in Sao Paulo, information were poorly transmitted. This article also shows mothers interviewed after session,¹ concluding that most mother's knowledge about infant feeding remained poor after the end of counselling session.

Given the national norm, we did not expect health workers to offer the mother a free choice with respect to infant feeding. Indeed, health professionals were never neutral with respect to this issue, and very few of them were concerned with the possibility of the mother breast-feeding, or even giving the baby to another lactating woman. Providing helpful instructions about formula feeding was the weakest area of performance. Not a single mention was made of cup feeding. Very few questions about conditions at home for the safe preparation of infant formula were asked by the health professionals. This might be explained by the fact that the City of Sao Paulo provides safe water in addition to electricity with practically 100% coverage. However, we are aware that there are homeless persons living in poor conditions, and among HIV+ women, the majority are poor (13).

The financial cost of infant formula supply is estimated as \$136 dollars on average for 6 months (7). The costs of fuel, safe water, utensils etc were never considered during our observations, although it is clear that they are also important for low-income families. Appropriate hygiene, dilution and storage procedures were not discussed with mothers in approximately half of the consultations observed. An important literature review on this issue has showed the potential harm of inadequate preparation of infant formula (14). Another remarkable finding regards nighttime feeding: small babies do not have a fixed schedule for feeding, and feed day and night if the baby wakes up hungry; therefore, it is important to ask what mothers are planning to do about feeding during the night, because it can be much more tempting give the breast to the baby. In only 38% of the consultations observed the mother was asked about the need to give formula during nighttime as well as during the day.

The relative risk of replacement feeding is likely to be reduced by factors such as access to safe water, uninterrupted supply of infant formula, good hygiene, a supportive home environment, a regular clinical follow-up with early intervention for growth faltering and illness, besides intensive counselling and skills training of health professionals regarding home preparation of replacement feeding (10). This last factor deserves greater attention from the HIV/AIDS programme in Sao Paulo, because the counselling skills identified as good were not translated into adequate infant feeding instructions.

Counselling is not always present in health centers, and, if it is, not always fulfill women's needs: in a study carried out in Porto Alegre, south of Brazil, 1658 mothers were interviewed and offered HIV tests during antenatal care, only 39.3% received counselling after testing (15). Another study in two cities of Sao Paulo State with 1068 HIV infected women in AIDS Units, assessed how the women perceived counselling: among others, the results showed that they complained of limited receptiveness for discussing child-bearing issues (16).

Studies to evaluate counselling skills according to the HIV/AIDS Brazilian guidelines were done and have showed limitations, although not related to infant feeding: one qualitative study observing 43 health workers consultations for HIV clients concluded that the reception of the patient is good; however, mechanical attitude following a cold guideline was observed, where 'listening' (an essential component of counselling) was not always present (17); this was different from our findings where generally, health professionals showed good counselling and communication skills more closely related to searching adherence to treatment.

CONCLUSIONS

Our findings show clear indications that the information on infant feeding provided to HIV+ mothers with exposed children are insufficient, and might jeopardize the prevention of MTCT. The single statement 'You cannot or should not breast-feed' is apparently the information most frequently provided in counselling sessions. Choices are not discussed with the mothers, neither do they receive information on safer breast-feeding practices; if the mother decides to breast-feed, this choice is not considered by the health worker and they do not inquire whether the woman will have the means not to practice breast-feeding and to properly replace it. If infant formula continues to be distributed free of charge (Affordable), it is integrated into our culture (Acceptable), and people have the necessary resources to prepare and store it (Feasible)—then the way to prepare it safely must be taught, demonstrated and emphasized by all of those who provide feeding counselling. Sustainability should be always reviewed with programme managers in order to avoid shortage.

We can point out the need for investigation on the domestic use of the milk distributed by the health care system; it would be important to document how the bottle is prepared (dilution, hygiene), with whom the milk is shared—issues cer-

tainly better researched with ethnographical methods. Other important subject that came out for research is the 'spill over' effect—how far is the interference of this 'Do not breast-fed' approach to the other HIV negative mothers also present in the specialized AIDS care unit—where STD patients are also seen. Another research issue needed is the feasibility of HIV+ mothers to use the heat-treated milk by HMBs.

The challenge of achieving zero-transmission while improving child survival will require health professionals be competent to instruct mothers on safer feeding practices. The success in developing communication skills in Sao Paulo health workers dealing with HIV should be complemented with training on feeding counselling for infants of HIV+ mothers.

ACKNOWLEDGEMENTS

We thank Dr Jose Martines, CAH - World Health Organization, for his kind support and suggestions. We also thank Rita C. Ciconi, Patrícia Crucello, Natalia Monteiro, Fernanda Marcolino, Hagar Inácio, Luiz A. Trevellin (field workers) and Lílian Cotrim, Lucélia Fernandes (data coding). The Statistical services and Dr Ana M. Segall-Correa of the School of Medicine, UNICAMP. Dr Fabio Mesquita of Sao Paulo Health Dept.

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