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Preventing HIV transmission to children: Quality of counselling of mothers in South Africa

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Abstract

Aim: To assess the quality of counselling provided to mothers through the programme to prevent mother-to-child transmission (PMTCT) of HIV in South Africa. *Methods*: Structured observations of consultations and exit interviews with 60 mothers attending clinics at three purposively selected PMTCT sites across South Africa were conducted. *Results:* Twenty-two counsellors were observed. The general quality of communication skills was very good, and 73% of HIV-negative mothers were informed of the advantages of exclusive breastfeeding (EBF). However, only one of 34 HIV-positive mothers was informed about the possible side effects of nevirapine, and none was told what to do when it occurred. Only two HIV-positive mothers were asked about essential conditions for safe formula feeding before a decision about an infant feeding option was made. None of the 12 mothers choosing to breastfeed was shown how to position the baby correctly on the breast or asked whether they thought EBF was feasible. Fewer than a quarter of mothers expressed confidence in performing the actions required, and 85% could not define the term EBF.

Conclusion: The poor quality of counselling in the PMTCT programme will reduce the effectiveness of these programmes. As they are being scaled up, there needs to be far more attention paid towards the counselling of mothers, especially with regards to optimal infant feeding.

Key Words: *Counselling, exclusive breastfeeding, observation study, prevention of maternal- to-child transmission of HIV, South Africa*

Introduction

The HIV/AIDS epidemic is reversing many of the gains in child survival. HIV/AIDS accounted for 7.7% of deaths of children under 5 y of age in sub-Saharan Africa and in certain countries, accounts for more than 40% of deaths [1]. The overwhelming source of HIV infection in young children is maternal-to-child transmission (MTCT) [2]. Prevention of mother-to-child-transmission (PMTCT) programmes have now been introduced in most countries affected by the epidemic with programmes moving (e.g. Kenya, Malawi, Uganda), or moved (e.g. Botswana, South Africa), from pilot projects to national programmes. However, initial results have been disappointing. One meta-analysis found that a median of 69% of mothers returned for their HIV test results, with a range between 33 and 95% [3]. Wilfert [4] reports that about 40% of mothers identified as HIV positive complete the full treatment even in the relatively intensively supported Elizabeth Glaser Foundation sites.

The most important component of the PMTCT programme is voluntary counselling and testing (VCT) for HIV and counselling for infant feeding. A high quality of VCT is essential for success: done well, it will result in significant reductions in child mortality through decreased postnatal HIV transmission and improved infant feeding practices; done badly, it could lead to deaths from diarrhoea and other infections, increased drug resistance, and the spread of poor infant feeding practices into the general population. There is increasing evidence that VCT reduces reported risk behaviour and prevents new infections [5]. Measuring the quality of VCT in PMTCT programmes, and the possible factors that influence quality, is therefore very important. There is surprisingly little published on this subject, especially in the context of scaling up this programme in high-prevalence areas. This paper

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presents the results of a study examining the quality of VCT in three PMTCT sites across South Africa.

Methods

Study background

South Africa introduced the PMTCT intervention to 18 pilot sites across the country in 2002. After initial evaluations these sites were given extra resources to employ lay counsellors and to conduct rapid HIV tests in antenatal clinics. Free formula for at least 6 mo is provided to those who choose not to breastfeed. Counsellors at all sites were given at least 2 wk of training covering VCT and counselling for infant feeding, though the latter is only very briefly covered (usually given less than 1 d). For this study, three of these pilot sites were purposively selected to represent the different socio-demographic typography of the country. In addition, they were well-functioning sites as reflected by the testing uptake rates, and they had been running for at least 2 y.

Site A is a peri-urban township that is a mixture of formal and informal housing. The infant mortality rate (IMR) is around 60/1000 live births. Counselling is part of the nurses' duties and, in addition, there are three full-time PMTCT lay counsellors at the hospital, one of whom specializes in infant feeding counselling. There is also a professional nurse with training in counselling who works with and supervises the counsellors. All the staff has received 5 d of training in infant feeding and HIV. The provincial PMTCT coordinator has an active role in supporting and directing the programme and is based close by. On average, 248 women are pre-test counselled each month, the testing uptake rate is 78%, 85% receive their results and 44% are HIV positive. Counselling occurs predominantly in two health centres.

Site B is a peri-urban/rural site situated in an area of commercial farming. The IMR is around 40/1000 live births. Five lay counsellors are responsible for the PMTCT counselling, and they received 8 additional hours of in-service training on infant feeding and HIV. This site has an average of 289 new antenatal bookings per month. The average testing uptake rate for this site is 100%, with all mothers receiving their test results, of whom 9% are HIV positive. Counselling occurs in one health centre.

Site C is in one of the poorest rural areas of South Africa with an IMR of 99/1000 live births. The hospital has an antenatal clinic and delivers approximately 170 women per month. The testing uptake rate is 86%, of whom 91% receive their results. The antenatal HIV-positive rate is 28%. Counselling is performed by three midwives and two professional nurses. Counselling occurs mainly in the hospital antenatal clinic and a health centre.

Study design and data collection

This was a descriptive cross-sectional study of three PMTCT pilot sites. Data collection methods included structured observations of counselling sessions and exit interviews with antenatal clients. Between five and seven counsellors who provide PMTCT counselling were selected per site; this constituted nearly all the counsellors at the sites. Four observations were conducted per counsellor, with a mix of pre-test, post-test and follow-up counselling sessions at each site.

A structured observation checklist was drawn up based upon the expected content of counselling sessions found in the training guides used by the two largest VCT training institutions [6,7] and review of the South African PMTCT protocol for the pilot sites [8]. A structured questionnaire to elicit the opinion and knowledge of mothers as they left the session was also formulated. Both tools were pre-tested and modified before use. The two observers were experienced in conducting structured observations and were familiar with the issues regarding VCT and PMTCT. They were instructed simply to observe and not to interfere with the counselling session.

Reliability was assured through the training of the observers until they had achieved over 90% inter-rater reliability for at least two joint observations consecutively between themselves. A definition list and detailed observation and interview rules were developed. Data collection sheets were collected daily after completion of fieldwork and checked. Any discrepancies were immediately discussed with the team.

Data were cleaned and analysed using the EPI-INFO 2002 statistical package (CDC, Atlanta, GA, USA). Uncorrected χ^2 or Fisher's exact tests were used to test for statistical differences across groups.

Ethical permission

The ethical committee of the University of the Western Cape approved the study, and permission was obtained from the provincial and facility managers and health workers before the study commenced. Written informed consent was obtained from the clients before any observations were conducted.

Results

Twenty-two counsellors (14 lay staff and eight nurses) were observed with a mean of four observations per counsellor. A range of counselling sessions were observed at each site (Table I). Sixty exit interviews were also conducted. The mean duration of the counselling sessions was 18 min; 34 (57%) of the sessions observed were with HIV-positive mothers, 12 (20%) were with HIV-negative mothers and 14 (23%) had an unknown HIV status.

Table I. Completed observations during the study in three pilot sites A, B and C.

		A ($n=24$)	B ($n=16$)	C ($n=20$)
Type of consultation	Pre-test	6 (25%)	3 (19%)	5 (25%)
	Immediate post-test	8 (33%)	5 (31%)	3 (15%)
	Follow-up	10 (42%)	8 (50%)	12 (60%)
Length of session	Mean (min)	21	12	21
Mother's HIV status	Positive	13 (54%)	7 (44%)	14 (70%)
	Negative	5 (21%)	6 (37%)	1 (5%)
	Unknown	6 (25%)	3 (19%)	5 (25%)
Mother's stage of gestation	Mean (wk)	31	27	34

Communication

The communication skills of the counsellors were good across all three sites. They used a warm tone of voice and language that the mother understood. In over 80% of observations, the mother was given time to respond and an opportunity to ask questions. However, in only a third (32%) of cases were inaccurate beliefs of the mother corrected.

Infant feeding counselling

The assessment for the best infant feeding option for HIV-positive mothers was poor across all three sites (Table II). Only 12 of 34 mothers were informed of the risks of HIV transmission in the womb, during delivery and by breastfeeding, and in only three cases was the mother asked about access to clean water, fuel and a fridge before deciding upon a feeding option. Advice about the different options was patchy and incomplete (Table III), and the mother was mostly left to make her own decision. There were significant differences between the sites for counsellors getting agreement from mothers and the infant feeding option chosen (Table IV). Mothers who were provided with at least four pieces of information concerning exclusive breastfeeding (i.e. items 4–7, 16–20) were 5.5 times (RR CI: 2.3–12.5) more likely to choose breastfeeding than those who were given less than this amount of information (71.4% vs 13.2%).

For HIV-positive mothers choosing to formula feed ($n=15$), the instructions on how to prepare the formula were sparse. Only five mothers were asked if they had previously prepared formula and were then provided with instructions. No mother at any site was shown how to prepare formula or asked if they understood the instructions given. There were no discussions about how the mother would explain to others the lack of breastfeeding or what she would do when the baby cried at night. Fewer than half the mothers (7/15) were given instructions on when and how to collect further supplies of formula from the clinic or hospital, and only five mothers were given the option of reconsidering their feeding method. Finally, none of these mothers was asked if they had considered any forms of contraception, and none was provided with any advice on contraceptive options.

For HIV-positive mothers who chose to exclusively breastfeed (EBF) ($n=12$), the counselling provided to women at site A was considerably better compared with the other two sites, and only women at this site (3/8) were asked if they knew the meaning of EBF and were then informed of its meaning. Few mothers (2/12)

Table II. Information on risks for HIV-positive mothers ($n=34$).

Yes for each item below	A ($n=13$)	B ($n=7$)	C ($n=14$)	Total *n* (%)
1. Explains that HIV can be passed to the baby in the womb?	8	1	3	12 (35)
2. Explains that HIV can be passed to the baby during delivery?	6	2	1	9 (26)
3. Indicates the risk of HIV infection during pregnancy and delivery?	7	2	2	11 (32)
4. Explains that HIV can be passed in breast milk?	7	1	2	10 (29)
5. Checks mother understands risk of HIV through breast milk?	2	0	0	2 (6)
6. Explores mother's concerns?	1	0	0	1 (3)
7. Explores plans to return to work/school and child care/feeding?	3	0	1	4 (12)
8. Probes water source?	5	0	1	6 (18)
9. Probes fuel source for cooking?	5	0	0	5 (15)
10. Probes access to fridge?	3	0	0	3 (9)
11. Probes bed-sharing between mother and baby?	1	1	0	2 (6)
12. Discusses possible stigma of exclusive formula feeding?	2	1	1	4 (12)
13. Explores possible family attitudes to not breastfeeding?	4	0	1	5 (15)
14. Asks whether mother could safely formula feed?	1	0	0	1 (3)

Table III. Advice on infant feeding for HIV-positive mothers ($n=34$).

Yes for each item below	A ($n=13$)	B ($n=7$)	C ($n=14$)	Total n (%)
15. Indicates that the risk is very small if baby is breastfed exclusively?	4	0	1	5 (15)
16. Explores mother's understanding of exclusive breastfeeding (EBF)?	3	0	0	3 (9)
17. Explains that no water or formula needed if baby is EBF?	6	0	3	9 (26)
18. Discusses good positioning and attachment for good breast health?	1	0	0	1 (3)
19. Explains need to stop breastfeeding at about 4 mo?	5	0	3	8 (23)
20. Discusses option of introducing replacement feeding at 4 mo?	3	0	2	5 (15)
21. Mentions need to boil water to make formula	3	0	2	5 (15)
22. Indicates there are risks of serious illness with formula	3	0	1	4 (12)

were asked if they understood the practice of EBF, and no-one was asked if they thought it was feasible. Expressing breast milk was explored with three mothers. No-one was shown how to position the baby on the breast. However, the majority of the mothers (8/12) were informed about when to attempt to stop breastfeeding and the importance of avoiding unsafe sex. In only two cases were contraceptive options discussed with the mother.

For HIV-negative mothers and those of unknown status ($n=26$), three were informed of the risks of HIV transmission in the womb, during delivery and by breastfeeding, and only one of the high risk of transmission if she became infected whilst breastfeeding. The majority (19/26) were informed of the advantages of exclusively breastfeeding but only one on the need to continue for 4 to 6 mo. In only one case was the possibility of continuing to breastfeed when the mother had to return to school or work discussed.

Drugs and disclosure

Mothers who were known to be HIV positive were not given complete information about the antiretroviral nevirapine, as shown in Table V. Whilst most mothers were told what the drug was for and when and how to take it, only one mother was told of the side effects, and no-one was informed about what to do if they experienced side effects.

Overall, 13 out of 34 HIV-positive mothers were asked if they had a partner and if they knew their partner's status. In all these cases, the counsellor then went on to explain the possible advantages of informing her partner, but in only seven cases was this taken to the stage where the client made a decision about whether to disclose. Of those testing HIV negative ($n=12$), five were asked if they knew the HIV status of their partner, and in three cases the advantages of informing her partner of her status were discussed.

Mothers' knowledge

Most mothers' knowledge about infant feeding remained poor at the end of the counselling session. Half of the mothers (31/60) were planning to practice suboptimal methods of feeding, one-third (20/60) were intending to discuss their infant feeding decision with somebody, and only eleven mothers were able to define EBF. However, two-thirds (40/60) of mothers correctly identified the dangers of mixed feeding for HIV

Table IV. Feeding options and choices.

Yes for each item below	A ($n=13$)	B ($n=7$)	C ($n=14$)	Total n (%)
23. Gets agreement about feeding option?	1[a]	6[b]	3	10 (29)[c]
24. Checks mother's understanding of her feeding choice?	0	2	2	4 (12)
25. Tells mother she can come back to the clinic for more information/support for feeding option	4	2	2	8 (23)
26. Decision achieved by:				
only one option offered?	0	0	1	1 (3)
told which option to take?	0	0	0	0
mother left to make own decision?	13	5	11	29 (85)
mother helped to make informed decision?	0	0	1	1 (3)
N/A	0	2	1	3 (9)
27. Decision taken:				
Formula feeding?	3[d]	6[e]	6	15 (44)[f]
Exclusive breastfeeding?	8[g]	0[h]	4	12 (35)[i]
Undecided/unknown?	2	1	4	7 (21)

[a] A vs B&C, $p<0.051$, Fisher's exact test; [b] B vs A&C, $p<0.001$, Fisher's exact test; [c] $p<0.01$, χ^2 across all sites; [d] A vs B&C, $p<0.052$, Fisher's exact test; [e] B vs A&C, $p<0.03$, Fisher's exact test; [f] $p<0.03$, χ^2 across all sites; [g] A vs B&C, $p<0.052$, Fisher's exact test; [h] B vs A&C, $p<0.03$, Fisher's exact test; [i] $p<0.02$, χ^2 across all sites.

Table V. Counselling about antiretrovirals for HIV-positive mothers ($n=34$).

Yes for each item below	A ($n=13$)	B ($n=7$)	C ($n=14$)	Total *n* (%)
28. Explains that nevirapine reduces chance of baby contracting virus?	7	3	2	12 (35)
29. Explains what it is for?	10	3	8	21 (62)
30. Says when to take it?	11	4	9	24 (70)
31. Says how to take it?	9	4	8	21 (62)
32. Checks mother's understanding of when to take and how?	5	2	7	14 (41)
33. Explains what to do if nevirapine is lost?	5	4	6	15 (44)
34. Explains what to do if mother takes nevirapine too early (false labour)?	2	3	6	11 (32)
Explains what to do if mother takes nevirapine too late (<2 h before delivery)?	2	3	8	13 (38)
35. Says what the side effects of nevirapine are?	1	0	0	1 (3)
36. Explains what to do if these occur?	0	0	0	0
37. Explains about baby's dose and how to get this?	7	5	9	21 (62)

transmission and other infections. In reply to the more open-ended questions, nearly all participants were positive about the counselling session. On further probing, a common theme was the need for more information, especially with respect to their own health and to formula feeding.

Discussion

According to traditional indicators of VCT quality, these three sites rate very well, with high rates of acceptance of counselling and HIV testing. However, whilst the general quality of communication skills was very good, there were several gaps in the content of VCT sessions across all three sites that could have serious implications for the effectiveness of this programme.

Poor counselling and lack of encouragement to disclose could affect adherence to infant feeding advice and to drug therapy. Lack of adherence to antiretrovirals is seriously compromising the effectiveness of many PMTCT programmes. Only 32% of identified HIV-positive mothers in well-resourced sites in Botswana reported taking more than 4 wk of treatment with zidovudine [9]. Stringer et al. [10] report that 26% of HIV-positive mothers were not adherent to the simpler nevirapine regimen in Zambia. In most PMTCT settings, levels of disclosure appear to be low, mostly due to fear of consequences, but research has found that disclosure can also lead to other positive outcomes. A study in Kenya [11] found that, among women in a stable relationship, 31% informed their partner and, in 73% of cases, the partners were understanding and supportive; however, 7% of the women experienced violence following disclosure. In Tanzania, one study found that, in most cases (92%) in which the woman informed her partner of her HIV status, the relationship continued [12]. In Rwanda, condom use was almost twice as high when the partner was informed of the test result [13].

The poor quality of the infant feeding counselling, and, once a decision was made, the minimal specific advice and support to promote adherence to the chosen method, is an important finding. Poor counselling and lack of subsequent support for the infant feeding decision almost inevitably leads to mixed feeding [14,15], which has been shown to increase the risk of MTCT [16]. Poor infant feeding counselling is a finding across many PMTCT programmes. In Ndola, Zambia, in only half the sessions observed did health workers "satisfactorily" discuss MTCT with HIV-positive mothers, and infant feeding options were discussed with mothers in a third of the sessions [17]. Across Zambia, out of 42 providers, only 10 inquired whether the mother had money to buy formula, and only six asked whether the client had access to adequate supplies of water and fuel [18].

Suryavanshi et al. [19] found that the hospital counsellor had an important role to play in assisting HIV-positive women in adhering to their feeding choice, especially in the period immediately after delivery when many mothers initiated other feeds. In this Indian setting, 21 of 148 (14.2%) participating infants born to HIV-positive mothers during the study period required hospitalization within the first 6 mo of life, and all of them were giving some sort of replacement feed [20].

Inadequate knowledge of MTCT was widespread amongst mothers, even after counselling. Even at many very poor rural PMTCT sites in South Africa, a majority of HIV-positive women are opting for free formula milk [21]. Given the inadequate assessment of risks, the limited information provided to women regarding safe formula feeding and the low level of knowledge regarding MTCT amongst mothers, it is likely that opting not to breastfeed is endangering many infants.

Limitations

Performance bias due to the presence of an observer was minimized by the observer being unobtrusive and sitting through multiple sessions. Nevertheless, these findings probably reflect best practice. Generalizability is limited by the small number of sites and observations. However, they were purposively selected to represent the different contexts across South Africa

and have been functioning for just over 2 y. A majority of counsellors were observed, and the results were internally consistent.

Improving counselling

Lack of knowledge and confidence about the risks of MTCT could be one cause for the poor performance. Chopra et al. [22] found that health workers in a pilot project in South Africa were generally confused about the key infant messages they should be disseminating. This is being exacerbated by the dramatic decline in support for breastfeeding in many countries [23]. The present level of training, especially with respect to infant feeding and HIV, is obviously inadequate. In this study, site A gave more information to mothers, especially regarding breastfeeding. At this site, lay counsellors had received intensive training on HIV and infant feeding. They also receive on-going support and training from a dedicated mentor and supervisor.

Counselling cards may assist counsellors by providing a reminder of key issues to be covered. Consideration should also be given to prioritizing the topics covered, as there is currently a huge amount of information that counsellors are expected to cover in the pre- and post-test counselling session. This also means that a wide range of nursing staff need to be orientated to the PMTCT programme, including HIV and infant feeding, as mothers will often be in contact with them instead of the dedicated PMTCT staff. A checklist could remain in the client's folder so that at each visit the health worker attending to the client would be able to check which topics have been covered. Space for notes could be included.

Conclusion

The quality of infant feeding counselling provided through the PMTCT programme was poor at all three sites. Even though the counsellors had good communication skills, they were observed to lack confidence to take mothers through a logical process of assessing home circumstances and presenting the risks of different infant feeding options. The results highlight the need to develop appropriate training materials and improve training courses to achieve proficient support for infant feeding choices.

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