

Loss to Follow-up Rate, Reasons and Associated Risk Factors among Mother-Infant Pairs in a Prevention of Mother-to-Child Transmission Programme (PMTCT) in Nigeria: a Case Control Study

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Summary

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Background: Close supervision of HIV infected infants is necessary because of the rapid progression of immune deterioration that may occur in the first months of life.

Objectives: To determine the loss to follow-up rate, reasons and associated risk factors among mother-infant pairs in a routine PMTCT programme.

Methods: This was a case control study that involved mother-infant pairs enrolled within 72 hours of delivery for follow-up in a PMTCT programme. Loss to follow-up was deemed to have occurred where more than two consecutive visits to the clinic had been missed. The defaulting mother-infant pairs were traced through telephone calls and home visits, where possible.

Results: One hundred and seventy-eight mother-infant pairs were enrolled between August 2002 and February 2005, out of which 18 were excluded. Fifty-eight (36.25 percent) of the remaining 160 were lost to follow-up. Among the 58 defaulters, 28 (48.27 percent) could not be traced as a result of false contact addresses. The most common reason for loss to follow-up among the 30 mother-infant pairs traced, was apparent good health in the babies. After tracking and counseling, 18 (60 percent) resumed regular follow-up. The mean ages of mothers and babies at the time of default were 28.87 years (SD \pm 4.52 years) and 15.31 weeks (SD \pm 14.05 weeks), respectively. Attainment of post-secondary education, non-membership in a support group and lack of partner notification were associated with increased risk of default.

Conclusions: The high loss to follow-up rate from this study highlights the need to improve on the postnatal follow-up of HIV-exposed babies.

Key words: Loss to follow-up, Rates, Reasons, Risk factors, PMTCT programme

Introduction

HIV/AIDS is an epidemic that has become an important child survival issue particularly in resource limited settings. Vertical transmission accounts for 90 percent of paediatric HIV infections.¹

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Approximately 20 percent of vertically infected infants display rapid progression of immune deterioration, which is the rationale for the close supervision of these infants in the first months of life.² It is estimated that 16-45 percent of infants born to HIV infected women in the absence of intervention will eventually develop the infection. Therefore, it is vital to monitor closely for any signs of the infection in these infants. Extended follow-up of these infants is therefore important for the early detection of the infection as well as the prevention of opportunistic infections with resultant reduction in mortality and morbidity.³

Follow-up of HIV-exposed infants should begin even before a definitive diagnosis of HIV infection

is made. This is even more necessary where there is lack of appropriate diagnostic tools for confirmation of the infection in children less than 18 months. Follow-up of HIV-exposed babies is therefore mandatory for growth monitoring, early detection of indicators of HIV infection, early diagnosis and prompt management. There have been various suggestions concerning the scheduling of follow-up visits of these infants. Tene *et al*⁴ suggested routine evaluation to be scheduled for a period of 18 months, initially on monthly basis and three monthly thereafter. Recent recommendation of the World Health Organization stipulates follow up at 14 days of age, then monthly for three months and then every three months or as per immunization schedule.⁵ Ginsburg *et al* undertook a review of a multi-country Prevention of Mother to Child Transmission (PMTCT) programme involving resource-limited countries and observed that only nine percent and four percent respectively, of infants born to HIV-positive mothers were identified and reported as HIV-exposed at their first and third immunization visits.⁶

Follow-up of HIV exposed infants is also essential for proper documentation of the number of children acquiring HIV both perinatally and postnatally during breastfeeding in order to review the interventions to prevent vertical transmission and improve on programme implementation. Loss to follow-up has been identified as a challenge in a PMTCT programme.⁷ The present study was undertaken to determine the loss to follow-up rate, reasons and associated risk factors among mother-infant pairs in a routine PMTCT programme in Nigeria.

Subjects and Methods

This was an unmatched case control study that involved follow-up of all HIV-exposed babies recruited within 72 hours of delivery into the AIDS Prevention Initiative in Nigeria (APIN) PMTCT programme at the University College Hospital, Ibadan, between August 1, 2002 and February 28, 2005. Their mothers had been diagnosed as being HIV positive and enrolled into the programme during pregnancy. According to the protocol, the mothers had received single doses of nevirapine in labour and the babies were also given single doses of the same drug within 72 hours of birth. Consent for follow up was sought from the mothers. The follow-up protocol was as follows: babies were first seen at birth or within 72 hours of life and subsequent visits were scheduled at two weeks, then monthly till one year of age and thereafter, three-monthly until two years of age. More frequent visits were scheduled where necessary and the mothers were encouraged to bring the babies for any illness episodes. During

the period of the study, the HIV status of the exposed babies was determined at 18 months by the ELISA test. Activities carried out at the visits included assessment of the feeding practices and monitoring of growth, development and immunization status. The infants were also assessed for clinical indicators of probable HIV infection, while illness episodes were treated appropriately.

The defaulting mother-infant pairs were traced through telephone calls and home visits, where possible. The mothers were also encouraged to join a Support Group coordinated by staff of the PMTCT programme and also counseled on the need to notify their partners of their HIV status.

Data analysis

Loss to follow-up was deemed to have occurred where more than two consecutive visits to the clinic had been missed. Reasons for default were stated and summarized in percentages. The ages of the babies at the time of default were also noted. Data entry and statistical analyses were performed by using the Statistical software for Social Sciences version 10.0 (SPSS Inc, Chicago, IL). The mean ages of the mothers and babies along with corresponding standard deviations were computed. Social and demographic characteristics were tested against the risk of loss to follow-up and odds ratio at 95 percent confidence intervals were computed and statistical significance testing was conducted at the 0.05 level.

Results

One hundred and seventy eight mother-infant pairs were enrolled within the study period. Out of this number, 18 were excluded for various reasons (16 died, and two mothers sero-converted from indeterminate to negative). Among the 160 cases analyzed, 58 (36.25 percent) were lost to follow-up, while 102 (63.75 percent) were regular with their followed up visits. The mean age of the defaulting mothers was 28.87 ± 4.52 years, while that of the babies at the time of default was 15.31 weeks ± 14.05 weeks. The age groups associated with the lowest number of loss to follow-up were six weeks to six months and > 12 months of age (Fig. 1). Out of the total number of mothers in the study, 22 (13.75 percent) chose to breastfeed while 138 (86.25 percent) chose to formula feed their babies. Further analysis showed that out of the defaulting mother-infant pairs, 28 (48.27 percent) could not be traced as a result of false contact addresses; therefore, their reasons for defaulting were unknown. Among the remaining mother-infant pairs, the most common reason for default was absence of illness in the baby (28 percent). Other reasons included family relocation to a new residence (10 percent), marital disharmony and death

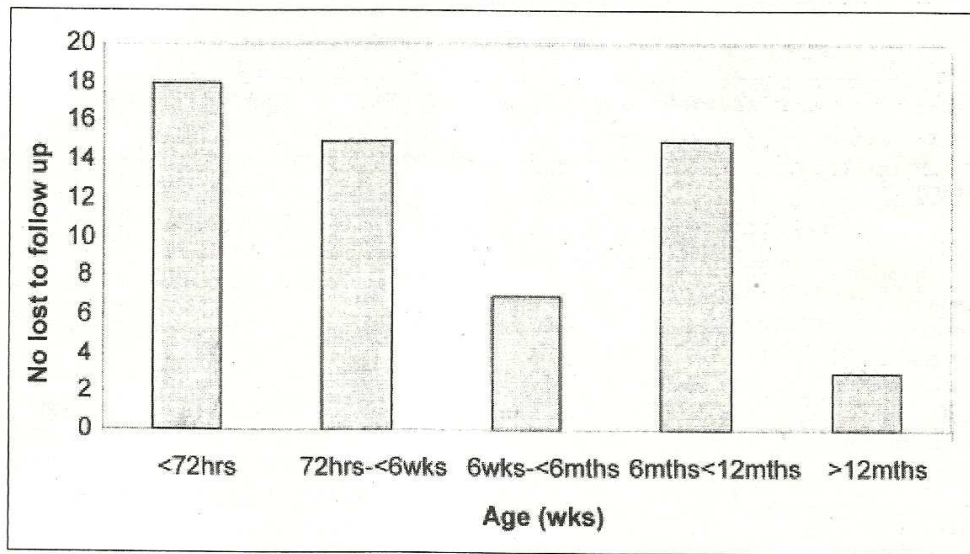


Fig 1: Ages of babies at times when they were lost to follow-up

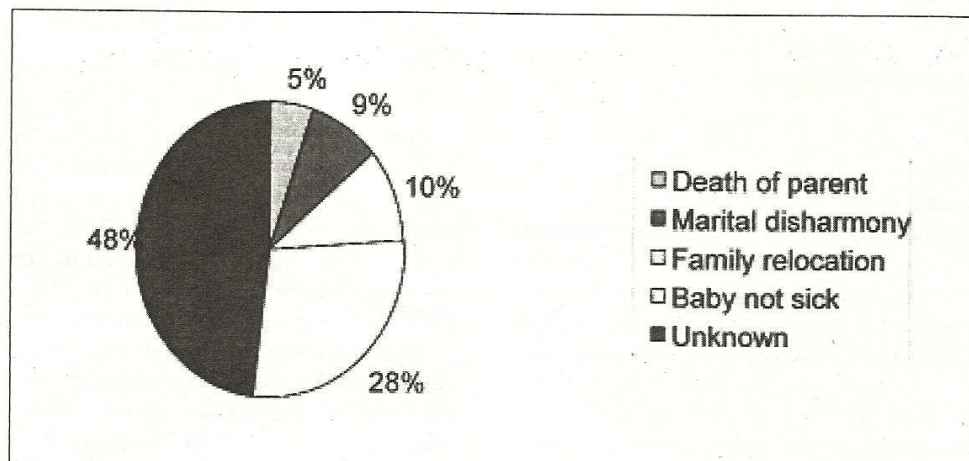


Fig 2: Reasons for loss to follow-up among HIV-exposed infants

of a parent (Fig. 2). It is noteworthy that out of the 30 babies traced, 18 (36.4 percent) resumed follow up visits after tracking and counseling.

Table I shows the social characteristics and risk factors associated with loss to follow-up. The attainment of post-secondary education, non-membership in a support group and lack of partner notification were significantly associated with increased risk for loss to follow-up; conversely, age and feeding choice were not.

Discussion

Follow-up of HIV exposed babies is one of the challenges in a PMTCT programme. The loss to follow-up rate of 48.27 percent observed in this study

was high and highlights an urgent need to improve on the postnatal follow-up of HIV exposed babies in order to reduce mortality and morbidity among such infants. A lower rate of default was however, recorded among two age groups, namely, six weeks to six months and >12 months. The age group of six weeks to six months corresponded to the period in which infant formula was supplied to mothers who had opted for replacement feeding. This appears to act as an incentive as the follow up appointments corresponded to the timing for picking up milk supplies. In the age group of more than 12 months, the low default rate may have been as a result of the fact that the babies were closer to 18 months at which time they were expected to undergo ELISA test to

Table 1
Risk Factors associated with Loss to Follow-up (N = 160)

<i>Risk Factors</i>	<i>Loss to Follow-up (No)</i>	<i>Regular (No)</i>	<i>Total</i>	<i>Odds Ratio</i>	<i>95% CI</i>	<i>P value</i>
Age (years)						
21 – 30	34 (35%)	63	97			
31 – 40	24 (38%)	39	63	1.14	(0.59 – 2.20)	0.718
Level of education						
> Secondary	28 (53%)	25	53			
≤Secondary	30 (28%)	77	107	0.35	(0.18 – 0.69)	0.003
Feeding choice						
Infant formula	23 (17%)	115	138			
Breast feeding	4 (18%)	16	20	1.25	(0.38 – 4.08)	0.751
Partner notification						
No	26 (49%)	27	53			
Yes	32 (30%)	75	107	0.44	(0.23 – 0.87)	0.023
Support Group						
Non-members	44 (54%)	38	82			
Members	14 (18%)	64	78	0.19	(0.15 – 1.73)	<0.001
*Partner status						
Discordant	20 (34%)	38	58			
Concordant	4 (21%)	15	19	0.51	(0.15 – 1.73)	0.394

* Some partners could not be tested

determine their HIV status. Loss to follow-up during an evaluation of the pilot research-based PMTCT programme in South Africa was reported to be 50 percent.⁸ Similarly, Sherman *et al*⁷ in their assessment of the efficacy of a PMTCT programme in a routine service setting also in South Africa, reported that more than one-third of infants never returned for follow-up and more than 70 percent were lost to follow-up by four months of age. The similarly high rates of loss to follow up that were obtained in this study may be a result of inadequate community-based support and scarce human resources which should both aid in home visits and tracking of mothers. In contrast to these high default rates, a low rate of 6.8 percent was reported in a prospective cohort study in Abidjan that involved HIV-infected pregnant women who were observed for two years following birth.⁹ This could have occurred as a result of their inclusion criteria in which only women that lived within the city limits were recruited. Furthermore, there was sustained provision of infant feeding materials which were free of charge.

Half of the mothers-infant pairs who were lost to follow-up in this study were difficult to trace due to falsified addresses. This may be related to the stigma associated with the disease. Home visits at the first contact (after consent has been obtained) may facilitate tracing of 'non-specific' addresses. Fear of discovery of the HIV sero-status by relatives or neighbours through possible breach in confidentiality

and possible encounter with a familiar health worker was identified in previous studies as a reason for mothers not returning for follow up after post-test counseling.^{10,11} This observation reflects the current perception of HIV-positive women of the risk of stigmatization associated with the use of services for PMTCT. Site-specific research is necessary to provide a better understanding of this behaviour. It also emphasizes the need for discretion among hospital staff while performing their responsibilities to HIV/AIDS patients. The 27.54 percent of the mothers that defaulted as a result of lack of illness in their babies underscores the observation that mothers are usually unwilling to bring apparently healthy children to health facilities since they believe that follow up is not necessary when a child is not ill.

Family relocation accounted for 10.34 percent of loss to follow-up in this study. In a similar study conducted among 104 infants in South London, 26 percent were lost to follow-up for a similar reason.³ With the recent expansion of PMTCT services in Nigeria, it should be possible to refer such infants to other centres to continue follow-up. Networking with other PMTCT centres is therefore important for continued follow-up, especially for relocated families. There should also be close coordination with voluntary agencies and social services.

There was marital disharmony in nine percent of the defaulters. HIV positive women have been reported in some studies to be prone to partner abuse

and violence.¹²⁻¹⁴ In extreme cases, such women are deserted by their partners. This may result in inability of the mother to keep regular follow-up appointments for the baby and may also impair care of the infant. There is therefore a need for good social support systems to handle such marital problems and also to empower the women and infants who are often disadvantaged. Involvement of men in perinatal programmes may also help in increasing the number of women and infants who are compliant with interventions to reduce mother to child transmission of HIV.

The present study has demonstrated that most of the mothers who defaulted did not belong to any support group. Membership in a support group was associated with better compliance with follow up. It is therefore crucial to encourage mothers to join support groups where people living with HIV/AIDS will be an important source of support and encouragement. They also stand to benefit from the health talks on infant welfare matters which are discussed at the group meetings.

Jones *et al*¹⁴ have reported that some socio-economic factors such as unemployment had an effect on the capacity of families to comply with the PMTCT follow-up programme. Their study however, did not highlight the effect of the level of education of mothers on the compliance with the programme. In the present study, contrary to expectations, mothers with post-secondary education had a higher risk of default. Thior *et al*¹⁵ in their study to determine uptake and socio-demographics predictors of acceptance of voluntary counseling and testing (VCT) among post-partum women in Botswana reported that more educated women were less likely to undergo VCT. They had suggested that women who were educated feared HIV testing due to their evaluation of risks or implications of a positive HIV result. Negative experiences that mothers encounter while interacting with programme staff and their views about the programme must also be taken into consideration.¹⁵ It is also possible that women with higher levels of education are less able to cope with the challenge of stigmatization. The long period of follow-up and the frequent visits under the schedule could also be a hindrance for working mothers. With the current practice of early infant diagnosis using DNA PCR, such mothers may be motivated to continue the follow-up visits.

Extrapolation of these results will most probably be limited as a result of the small sample size. It would have been more appropriate to include the HIV transmission rate which gives a measure of the effectiveness of the PMTCT programme. This could

not be done because the number of babies who had attained 18 months was small.

Conclusion

The high loss to follow-up rate from the study highlights an urgent need to improve on postnatal follow-up of HIV exposed babies in order to reduce mortality and morbidity among such infants. Mothers should be encouraged to join support groups and efforts should be made to reduce the stigma associated with the disease in order to improve on tracking of defaulting mother-infant pairs and to reduce loss to follow-up among women with high level of education.

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