

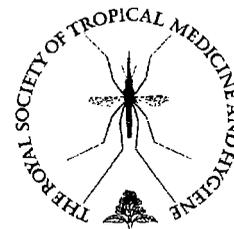


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# Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi

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**Summary** This study was conducted to identify reasons for a high and progressive loss to follow-up among HIV-positive mothers within a prevention-of-mother-to-child HIV transmission (PMTCT) program in a rural district hospital in Malawi. Three focus group discussions were conducted among a total of 25 antenatal and post-natal mothers as well as nurse midwives (median age 39 years, range 22–55 years). The main reasons for loss to follow-up included: (1) not being prepared for HIV testing and its implications before the antenatal clinic (ANC) visit; (2) fear of stigma, discrimination, household conflict and even divorce on disclosure of HIV status; (3) lack of support from husbands who do not want to undergo HIV testing; (4) the feeling that one is obliged to rely on artificial feeding, which is associated with social and cultural taboos; (5) long waiting times at the ANC; and (6) inability to afford transport costs related to the long distances to the hospital. This study reveals a number of community- and provider-related operational and cultural barriers hindering the overall acceptability of PMTCT that need to be addressed urgently. Mothers attending antenatal services need to be better informed and supported, at both community and health-provider level.

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## 1. Introduction

Mother-to-child transmission (MTCT) is the main mode of acquisition of HIV infection in children (UNAIDS, 2005). Malawi, a small resource-limited country in central southern

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Africa is faced with one of the highest HIV/AIDS prevalence rates in the world, with an adult prevalence (15–49 years) of 14% and an antenatal prevalence of 15% (MOH, 2005). Over 20 000 infants born to infected mothers in Malawi acquire HIV infection through MTCT each year. Prevention of MTCT (PMTCT) is thus considered an urgent public health priority in Malawi.

In early 2003, a PMTCT program was launched in Thyolo District in rural southern Malawi. In 2004, a formal evaluation of the program revealed a progressive loss to follow-up of HIV-positive mothers (Manzi et al., 2005); the cumulative loss to follow-up was 55% by the 36 week antenatal visit, 68% by delivery and 81% by the 6 month post-natal visit. Understanding the reasons for this high and unacceptable loss to follow-up is important in order to improve the overall acceptance of PMTCT. This study was conducted in order to identify the possible reasons for loss to follow-up from the PMTCT program in Thyolo.

## 2. Methods

### 2.1. Study setting and population

This study was conducted in Thyolo District, a rural district in southern Malawi with approximately 575 000 inhabitants. The district has one public hospital, 16 public health centers, four private clinics belonging to tea estates and 100 officially recognized traditional birth attendant (TBA) clinics offering antenatal, natal and post-natal services. The main public hospital (Thyolo Hospital), where PMTCT was being offered, was the site for the study. The study was conducted between September and December 2004.

Health center staff and TBAs are trained and supervised on a monthly basis by the district Mother and Child Health (MCH) and TBA coordinator. All clinics and TBA facilities receive basic delivery equipment and a regular monthly supply of consumables and drugs, such as ferrous sulfate, folic acid and antimalarials.

Antenatal and PMTCT services in public health facilities in Thyolo are offered free of charge. However, TBAs charge about 100 kwacha (approximately 0.7 USD) per delivery and often receive a present from the family as part of the local tradition.

### 2.2. The PMTCT program

All antenatal mothers are offered routine HIV testing and counseling. Those found to be HIV-positive are referred to the antenatal clinic (ANC) for ongoing management of pregnancy, HIV infection and inter-current illness.

The procedures and steps for PMTCT in Thyolo Hospital have been described previously (Manzi et al., 2005). In brief, the mother is given a single dose of nevirapine (200 mg) at 36 weeks to take at the onset of labor (often at home) and the patient is requested to return to Thyolo Hospital for safe delivery. Nevirapine for the baby is only accessible at the Thyolo District Hospital and is given within 72 h of delivery. Both exclusive artificial and breastfeeding options are available as infant feeding choices. Artificial milk is provided free of charge.

### 2.3. Focus group discussions and analysis

The study employed qualitative research methods: mainly observation and focus group discussions (FGDs) (Dawson et al., 1993). Three separate FGDs were carried out on respondents who were purposively sampled to source information from mothers in the antenatal and post-natal periods as well as nurse midwives (the latter to gather information from the provider perspective).

The group discussions were led by two social communicators and one nurse midwife, who were trained by a social researcher. Specific efforts were made to ensure that 'saturation point' was reached within FGDs. Although we had also aimed to conduct additional FGDs to achieve 'overall saturation', this was not feasible due to operational limitations of tracing additional mothers and fears of stigma and disclosure linked to participation in the study.

Participants were asked to give their own opinion and to discuss possible reasons for drop-out that they may have noticed. Discussions were conducted in the local language (Chichewa) and audio recorded. These were fully transcribed and translated into English. The FGDs were guided by a question guide, which changed during the course of the study to incorporate new emerging issues. Consent was sought before participation.

Using the open coding technique, a content analysis was done by creating diverging and common main themes, categories and quotes from which similarities and differences between respondents were drawn as well as reasons for loss to follow-up from the program.

## 3. Results

The study population included ten antenatal mothers registered and still participating in the PMTCT program, six post-natal mothers who dropped out and nine nurse midwives. A total of three FGDs were carried out with the 25 respondents (aged between 20 and 55 years). Table 1 shows a summary of the main reasons for loss to follow-up of HIV-positive mothers from the PMTCT program.

## 4. Discussion

This study reveals a number of important community- and provider-related operational and cultural barriers hindering the overall acceptability of PMTCT in our setting. The findings from this study have helped to make several specific programmatic changes.

First, mothers were not prepared for HIV testing and its implications before their first PMTCT visit. Of particular concern was the fact that they perceived HIV testing as being an obligatory procedure. Although opt-out testing might result in a high rate of HIV testing (MMWR, 2002), if wrongly perceived as being obligatory this might adversely influence antenatal attendance rates. Mothers thus need to be informed that they can opt out of HIV testing until they feel prepared to take the HIV test (Mills and Rennie, 2006; Rennie and Behets, 2006). Discussions have been led with the counseling team to ensure that the counseling approach is no longer to make mothers feel coerced into undergoing HIV testing.

**Table 1** Reasons for loss to follow-up among mothers attending a prevention of mother-to-child transmission (PMTCT) prevention program in Thyolo, Malawi

Theme	Category	Quote
1. HIV testing in PMTCT	Mothers feel an obligation to suddenly undergo HIV testing when attending an antenatal clinic for which they feel inadequately prepared	"When you arrive at PMTCT you are given some information on the importance of PMTCT and then you are suddenly tested for HIV. We are not prepared for this." (Defaulter)
2. Stigma and disclosure of HIV status	Fear of discrimination, conflict, blame and even divorce	"In the community few people accept HIV-positive mothers. They think that you are HIV positive because you were just moving around and sleeping with a lot of men. They keep on gossiping about you. Some even do witchcraft against you so that you die faster. It is thus better that you keep your HIV status for yourself without telling others." (Defaulter)
3. Partner support	Husbands do not want to undergo HIV testing and are not supportive	"The big problem is with the men, if we tell them that lets go for HIV test they do not want. This really lets us down. Because if you get tested yourself when the husband refuses HIV testing then when you come with your positive results to him he may divorce you." (Defaulter) "When I told my husband that I had joined the PMTCT program he divorced me and I am now living alone with our children." (Defaulter)
4. Artificial feeding	Mothers perceive artificial feeding as being the only acceptable feeding choice	"The PMTCT nurse said that every mother should not breastfeed their child. Even when a child cries in a bus and you give the artificial milk, you hear a lot of insulting comments from fellow passengers." (Nurse midwife) It was hard for mothers to hear that "In PMTCT when you are HIV positive and pregnant they will tell you that you should not breastfeed." (Defaulter)
5. Benefit for mother	PMTCT is a program that benefits the baby but not the mother	"PMTCT is too much about the baby and not enough about the mother." "The benefit of joining PMTCT programme is that the child will be healthy, the child will not be falling sick frequently and will not be malnourished." (Defaulter)
6. ART in PMTCT program	ART is not seen as part of the package for mothers in PMTCT	"I am weak, I cannot support my child effectively but until now the doctors haven't put me on ART. I think that they are making an error on me, at least if they had put me on ART I could take care of my baby up to the second year and be sure by the time I die the baby would be able at least to live with others easily. I have tried to talk to them but till now I haven't started the medicine."
7. Long waiting times at the ANC	Long delays in getting service at the hospital antenatal clinics	"I feel like mothers benefiting from PMTCT must be assisted quickly at the antenatal clinic unlike what we see today. We keep waiting from early in the morning to late in the evening without being attended to. We remain hungry all day long and our children keep crying out of hunger as well. At the ANC there is not even a place to lay down and rest."

Table 1 (Continued)

Theme	Category	Quote
8. Access to a hospital PMTCT program	Transport cost is a barrier to attending PMTCT	"...in fact there is lack of transport money for mothers to go for frequent visits to the hospital, even to health facilities when labour starts. In most circumstances we cannot walk long distances or to use bicycles to go to the hospital. So we prefer to go to TBAs who are nearby for assistance."
9. Burnout of PMTCT staff	Nurses and midwives working under PMTCT have got knowledge that could help to improve the quality of care for mothers attending ANC in Thyolo but are unable to do so	Nurses admitted that by trying to cope with the large workload "we end up making errors". "We also feel we don't provide enough information to mothers" and "the service should be more patient-friendly".

ANC: antenatal clinic; ART: antiretroviral therapy.

It is also clear that despite the existence of information, education and communication (IEC) activities, stigma within the community is still an important reality. There is thus an urgent need to encourage greater involvement of traditional and religious leaders, who have an important influence in this community in activities linked to IEC. Such groups are now actively involved with IEC sessions.

Second, the question of partner counseling and HIV testing remains a real challenge in our setting, as in many others in sub-Saharan Africa (Maman et al., 2001; Manzi et al., 2005; Medley et al., 2004), as less than one out of three partners undergo HIV testing. In Africa it is rare for men to accompany mothers during antenatal visits or during delivery, and there is thus a 'disconnect' in the potential opportunity of offering HIV testing to the mother and father at the same time. This study suggests that the potential risks of disclosure of HIV status at home are serious and could even culminate in divorce (Karamagi et al., 2006; Kiarie et al., 2006; Maman et al., 2001; Medley et al., 2004). Although there does not seem to be a clear way forward in addressing this issue, there are some studies suggesting behavioral modification strategies to address 'risk of disclosure to spouse' and attempts to include these in the counseling process is underway (Heyward et al., 1993; Kilewo et al., 2001).

Third, although the PMTCT program offers both artificial and breastfeeding, the reality seems to be that mothers perceive artificial feeding as the only acceptable feeding choice. This is most likely due to an overenthusiastic attitude of nurses to promote artificial feeding. Greater consideration of the social environment in which the mother is embedded and particularly issues around disclosure associated with bottle feeding will need to be considered in the needs assessment and counseling process within such settings. In any case, all districts in Malawi, including Thyolo, have decided to drop the artificial feeding option (as part of national policy) and focus on breastfeeding alone and thus 'breach of confidentiality' associated with bottle feeding is no longer a problem.

Fourth, mothers felt that PMTCT is too much about the baby and not enough about the mother. Particular concern was expressed about antiretroviral therapy (ART) not being available. It is thus understandable that mothers who perceive themselves as being ill and seek care for their own health find the offer of PMTCT (without an ART offer) incomplete and unsatisfactory. Since 2004, efforts have been made to introduce ART within the PMTCT facility, and now all mothers are systematically offered ART according to WHO guidelines. However an HIV-positive status does not necessarily imply the immediate need for ART, and this information must be part of the counseling process. However, there is a recent trend toward earlier ART start at higher CD4 counts, and this might have a beneficial effect on the acceptability of the program perceived by mothers (Braithwaite et al., 2008).

Fifth, the issue of long waiting times at the hospital ANC is of serious concern. On one hand there is an urge to scale up PMTCT services, but on the other hand human resources are inadequate to cope up with the caseload. Malawi is facing a serious shortage of trained health staff (Kober

and Van Damme, 2004; MOH, 2002) and opportunities for task-shifting and greater involvement of peer groups and people living with AIDS are being explored. 'Lay' trained counselors are now included as part of the counseling team (Zachariah et al., 2006a).

Sixth, the problem of transport costs to a centralized facility is a burden in the rural setting (Zachariah et al., 2006b). Efforts to decentralize PMTCT and ART services to health centers and TBAs (Green, 1998) are underway and should help alleviate this problem. Finally, this study shows that staff working in PMTCT also need support to cope up with their workload, and peer support and counseling for counselors and health staff have been introduced in Thyolo.

This study revealed several important operational and cultural barriers, at both community and provider level, that need to be addressed. PMTCT is the earliest potential 'entry-door' for PMTCT HIV transmission as well as early access to clinical treatment and care of infected children, and this can be achieved only if retention within PMTCT is high. Furthermore, current WHO guidelines propose the use of antiretroviral regimens of longer duration that require closer follow-up of mothers. The imperative to find ways to reduce the current high loss to follow-up is thus all the more urgent. In this line, programs such as the one in Thyolo will simply have to face up to and accommodate these shortcomings.

**Authors' contributions:** LDB, MF, MMA and MMo designed the study protocol; LDB, MF, VC and MMA implemented the study and were involved with data analysis; RZ, KK, EJS and MF contributed to the study design, data analysis and intellectual content; LDB and RZ wrote the first draft of the manuscript and handled the different editions and revisions. All authors read and approved the final manuscript. RZ and MMA are guarantors of the paper.

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**Conflicts of interest:** None declared.

**Ethical approval:** General measures are provided in the Thyolo PMTCT program to ensure patient confidentiality, consent for HIV testing, and counseling and support for those who receive a positive HIV test result. The Malawi National Health Science Research Committee (NHRC) formally approved the Thyolo PMTCT program and evaluation of its different components. The Malawi Ministry of

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## References

- Braithwaite, R.S., Roberts, M.S., Chang, C.C., Goetz, M.B., Gilbert, C.L., Rodriguez-Barradas, M.C., Shechter, S., Schaefer, A., Nuclefora, K., Koppenhaver, R., Justice, A.C., 2008. Influence of alternative thresholds for initiating HIV treatment on quality-adjusted life expectancy: a decision model. *Ann. Intern. Med.* 148, 178–185.
- Dawson, S., Manderson, L., Tallo, V.L., 1993. *A Manual for the Use of Focus Groups*. International Nutrition Foundation for Developing Countries (INFDC), Boston, USA.
- Green, E.C., 1998. Can collaborative programs between biomedical and African indigenous health practitioners succeed? *Soc. Sci. Med.* 27, 1125–1130.
- Heyward, W.L., Batter, V.L., Malulu, M., Mbuyi, N., Mbu, L., St Louis, M.E., Kamenga, M., Ryder, R., 1993. Impact of HIV counseling and testing among child-bearing women in Kinshasa, Zaire. *AIDS* 7, 1633–1637.
- Karamagi, C.A., Tumwine, J.K., Tylleshar, T., Heggenhougen, K., 2006. Intimate partner violence against women in eastern Uganda: implications for HIV prevention. *BMC Public Health* 6, 284.
- Kiarie, J.N., Farquhar, C., Richardson, B.A., 2006. Domestic violence and prevention of mother-to-child transmission of HIV-1. *AIDS* 20, 1763–1769.
- Kilewo, C., Massawe, A., Lyamuya, E., 2001. HIV counseling and testing of pregnant women in sub-Saharan Africa: experiences from a study on prevention of mother-to-child HIV-1 transmission in Dar es Salaam, Tanzania. *J. Acquir. Immune Defic. Syndr.* 28, 458–462.
- Kober, K., Van Damme, W., 2004. Scaling-up access to antiretroviral treatment in southern Africa. Who will do the job? *Lancet* 364, 103–107.
- Maman, S., Mbwambo, J., Hogan, N.M., Kilonzo, G.P., Sweat, M., 2001. Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counselling and testing. *AIDS Care* 5, 595–603.
- Manzi, M., Zachariah, R., Teck, R., Buhendwa, L., Kazima, J., Bakali, E., Firmenich, P., Humblet, P., 2005. High acceptability of voluntary counselling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission program in rural Malawi: scaling up requires a new way of acting. *Trop. Med. Int. Health* 10, 1242–1250.
- Medley, A., Garcia-Moreno, C., McGill, S., Maman, S., 2004. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bull. World Health Organ.* 82, 299–307.
- Mills, E., Rennie, S., 2006. HIV-testing and individual rights. *Science* 20, 417–419.
- MMWR, 2002. HIV testing among pregnant women, United States and Canada, 1998–2001. *MMWR* 51, 1013–1016.
- MOH, 2002. The status of human capacity development for an effective response to the HIV/AIDS epidemic in Malawi (evaluation report). Ministry of Health and Population, Lilongwe, Malawi.
- MOH, 2005. HIV and Syphilis Sero-Survey and National HIV Prevalence Estimates. Ministry of Health and Population, Lilongwe, Malawi.
- Rennie, F., Behets, S., 2006. Desperately seeking targets: the ethics of routine HIV testing in low-income countries. *Bull. World Health Organ.* 84, 52–57.
- UNAIDS, 2005. Report on the Global AIDS Epidemic, 2005. Geneva, Switzerland, UNAIDS.

Zachariah, R., Teck, R., Buhendwa, L., Labana, S., Chinji, C., Humblet, P., Harries, A.D., 2006a. How can the community contribute in the fight against HIV/AIDS and tuberculosis? An example from a rural district in Malawi. *Trans. R. Soc. Trop. Med. Hyg.* 100, 167–175.

Zachariah, R., Harries, A.D., Manzi, M., Gomani, P., Teck, R., Philips, M., Firmenich, P., 2006b. Acceptance of anti-tetroviral therapy among patients infected with HIV and tuberculosis in rural Malawi is low and associated with cost of transport. *PLoS ONE* 1, e121.