

ORIGINAL RESEARCH

BARRIERS TO THE UPTAKE OF PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT) SERVICES IN RURAL BLANTYRE AND BALAKA DISTRICTS, MALAWI

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ABSTRACT

Objectives: The aim of this study was to establish the barriers to the uptake of Prevention of Mother to Child Transmission (PMTCT) services by women in rural Blantyre and Balaka districts in Malawi. **Methods:** A qualitative study was conducted with data collected through in-depth interviews and focus group discussions. A total of 52 participants were interviewed. **Results:** The main barriers to uptake of the PMTCT services were: stigma and discrimination against those with HIV-infection, opposition from male partners commonly leading to divorce, long waiting time at voluntary counseling and testing centres, fear of being bewitched, cost of infant feeds and lack of privacy and confidentiality when a woman joins a PMTCT programme. **Conclusion:** In order to promote utilization of PMTCT services by HIV-infected women, male involvement need to be enhanced. In addition to this, there is need to raise awareness of PMTCT services in the community, enhance provision of free infant supplementary feeds, prolong breastfeeding and improve services in health care facilities such as reduction of waiting time, improve confidentiality, provision of quality counselling services including couple counselling.

Key Words: Nevirapine, Sexual health; HIV; VCT; Rural Malawi, Africa.

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INTRODUCTION

In 2009 globally an estimated 370 000 children were newly infected with HIV and 260 000 children died from AIDS-related illnesses. Almost all of these HIV infections among children occurred in developing countries (UNAIDS, 2010). Chopra and others demonstrated that more than 90% of infections were the result of mother-to-child transmission (MTCT) during pregnancy, labour and delivery, or breastfeeding. It has been estimated that without interventions, there is a 20% to 45% chance that a baby born to an HIV-infected mother will become infected (Chopra et al, 2002).

For some African countries including Malawi, it is current policy to aim and Prevent Mother to Child Transmission (PMTCT) by the a antiretroviral drug called Nevirapine which is taken by the mother at the onset of labour and given to the baby within 72 hours after birth and with the right feeding choices (WHO/UNIADS/UNICEF/UNFPA, 2003). With a single dose of Nevirapine, it was estimated that 47% of infant HIV infections could be averted (Coutsoudis et al, 2001; Guay et al, 1999; Heiko et al, 2006; Jackson et al, 2004; Moodley et al, 2003).

Even though Nevirapine has proved to be effective to PMTCT, access to the services by HIV positive pregnant mothers has shown to be a challenge and only 53% [40%–79%] of women in low- and middle-income countries worldwide received PMTCT antiretroviral medication in 2009

(UNAIDS, 2010). Barriers to PMTCT uptake include stigma and discrimination, unavailability of services and opposition from male partners (Bajunirwe & Mizoora, 2005).

Malawi is one of the ten countries most affected by the HIV/AIDS pandemic worldwide with an estimated HIV prevalence of 12.6% among women attending antenatal clinics (Ministry of Health, 2010). The Malawi MoH 5 year PMTCT scale up plan (2006-2010) had set a target of 75% coverage of pregnant women with a comprehensive package of PMTCT services (Ministry of Health, 2005). Nonetheless, only 38.8% of HIV positive pregnant women received antiretroviral therapy (ART) for PMTCT in 2009 (Ministry of Health, 2010).

The Malawi government in collaboration with other partners like GOAL Malawi established PMTCT programmes in Primary Health centres towards the end of 2005 in order to increase PMTCT uptake. GOAL, an Irish Organization working in Malawi was implementing a comprehensive HIV/AIDS programme in Blantyre and Balaka districts. The programme endeavored to strengthen existing health systems and offered the community more access to PMTCT services. Low uptake of PMTCT services was one of the programme's biggest challenges as only 22% of pregnant mothers who tested HIV positive during antenatal care visits joined the PMTCT services in the Blantyre and Balaka rural facilities (GOAL Malawi, 2006). The objective of this study was to investigate the barriers to the uptake of PMTCT

services in rural areas of the Blantyre and Balaka districts in Malawi.

METHODOLOGY

Study design and site

This was a qualitative study conducted in rural areas of Blantyre (Mdeka health centre) and Balaka (Kankao health centre) districts. Blantyre and Balaka districts are in the southern region of Malawi which has the highest HIV prevalence (20.5%) in Malawi. The HIV prevalence for the northern and central regions of Malawi are 10.2% and 10.7%, respectively (Ministry of Health, 2010).

Recruitment of study participants:

Purposeful sampling was used for selection of health facilities and participants. This procedure was used to achieve selection of participants with varying characteristics. A total of 52 participants: 16 men who participated in the Focus Group Discussions (FGD), 16 health workers (2 males and 14 females) and 20 mothers who participated in in-depth interviews.

Data collection

Question guides for FGD and in-depth-interviews were developed. Four data collectors with experience in conducting FGD and in-depth interviews were employed and trained. The data collectors practiced on the questionnaires by pairing up and interviewing each other followed by a critique. This exercise promoted familiarization to the tools by the data collectors and improvement of their skills in collecting qualitative data.

Focus group discussions with men living with their spouses and in-depth interviews for PMTCT up takers, non-uptakers and service providers were conducted in December 2006 by the trained data collectors. At the end of each interview,

questionnaires were assessed to verify responses. This was done to identify and correct inconsistencies and errors immediately.

Data analysis

Data were analysed manually through construction of themes and matrices. Throughout the data collection process the main author (JN) was present in the field. At the end of each day the author facilitated debriefing sessions identifying emergent concepts and critical themes in the early stages of data generation to guide subsequent FGD and in-depth interviews. The debriefing sessions also established when saturation had been reached. Data was then coded and later categorised into themes. The themes were developed based on the interpretation of underlying meaning on a higher analytical level as compared to the more descriptive categories. Relevant individual quotations related to certain themes were also identified.

Ethical approval

This study was approved by the University of Malawi - College of Medicine Research and Ethics Committee (COMREC). Eligible participants were assured that their participation was entirely voluntary and all signed an informed consent form when they agreed to participate in the study. Further consent was obtained from the heads of each health facility involved and the village heads in each community involved.

RESULTS

There were a total of 52 participants; 16 men who participated in the FGD, 16 health workers and 20 mothers who participated in in-depth interviews. Mean age for the participants was 30 years with an age range between 21 and 46 years.

Table: Main themes highlighted as barriers to PMTCT uptake by 20 mothers in this study.

Theme	Description
1 Opposition from male partners	Some husbands did not allow the women to join the PMTCT programme so that people do not look at the couple as being HIV positive.
2 Cultural practices related to breastfeeding	Replacement infant feeding or exclusive breastfeeding with abrupt weaning at 6 months recommended in the PMTCT program is not the cultural breast feeding norm in Malawi.
3 Stigma and discrimination	Stigma and discrimination against those with HIV/AIDS
4 Shortage of health workers	Shortage of health workers leading to lack of time available for health workers to counsel the mothers and the long waiting time at VCT centers
5 Cost related barriers	Cost attached to both replacement feeding and exclusive breast-feeding with early cessation
6 Fear of being bewitched	Others feared witchcraft - if witches knew that they are HIV positive they will easily bewitch them and people will interpret the sickness as being due to AIDS and not witchcraft
7 Lack of privacy and confidentiality	Difficulty in maintaining privacy and confidentiality of one's HIV positive status after joining PMTCT program

In-depth interviews with mothers who joined PMTCT and received Nevirapine

A total of 10 (5 from Blantyre and 5 from Balaka districts) mothers who had tested HIV positive and received Nevirapine during labour participated in the in-depth interviews. The most commonly cited barrier by all mothers who joined PMTCT was stigma and discrimination against

those who are HIV positive. Even when the spouse is supportive, relatives can also stigmatize and discriminate an HIV positive woman.

"The greatest problem is stigma and discrimination. One day I went for a funeral and we were given nsima for five people but all the women left because they were afraid to contract

the HIV virus from me. My relatives did not allow me to touch their kitchen utensils so that they don't contract the virus. But am not worried because my husband is very supportive" (mother's in-depth interview, Kankao)

On the other hand, some mothers reported violence and abuse by their spouses after they had learnt of their HIV positive status. For those who joined PMTCT, four out of ten mothers reported divorce due to joining the PMTCT programme after their HIV positive status diagnosis.

"I told my husband of my HIV positive status and asked him to go for testing but he totally refused and was not happy that I joined the PMTCT programme. After delivery of my baby the doctors assisted me very well and both the baby and I received Orofin (meaning Nevirapine) but my husband started to go out with another girl. After a month, he decided to abandon me and went for another woman. I have never received any support from my husband from the time he knew of my HIV status. Now am struggling on my own bringing up my 3 children the baby inclusive" (mother's in-depth interviews, Mdeka).

Furthermore, mothers also felt that it was difficult to maintain privacy and confidentiality of one's HIV positive status after joining PMTCT services. They said people are bound to know that the mother is HIV positive especially when she starts following the health workers advice on stopping breastfeeding earlier than the cultural norm and when the mothers are followed up by health workers or support group members.

"The other problem I have observed is lack of privacy when you join PMTCT. Even if you try to hide, people will still know especially when you stop breastfeeding your baby earlier or when the nurses try to follow you up (mother's in-depth interviews, Mdeka).

In-depth interview with mothers who did not join PMTCT after testing HIV positive

Similarly, when mothers who declined to join PMTCT were asked for reasons why they had not joined the PMTCT programme, stigma and discrimination against those who are HIV positive was the barrier most frequently mentioned. The other reason was fear of their husbands as well as cost related factors. The mothers said that their husbands did not allow them to join the PMTCT programme so that people do not look at the couple as being HIV positive. As a result, HIV positive women chose not to deliver at a health facility as a confirmation to their spouses that they had not joined the programme.

"I was afraid because my husband does not want us to get tested for HIV. Even now if he learns that I came here to have an HIV/AIDS related interview with you I will be in problems. I therefore deliberately had my delivery at home so that my husband should be sure that I have not taken Nevirapine. I would have lost my marriage! I was in a confused state. I did not know what to do." (mother's in-depth interviews, Kankao).

Interestingly, other mothers were afraid of witchcraft. They felt if people knew that they were HIV positive, they would bewitch them and the community would think that their sicknesses were due to HIV/AIDS.

"In our family witchcraft is very common. If some witchcraft members learnt that I was HIV positive, they will get their way through and bewitch me so that in the end they say I died of AIDS" (mother's in-depth interviews, Mdeka).

Focus group discussion with men living with a spouse

Male FGD participants emphasized on the negative consequences a woman would end up in if they decided on their own to join the PMTCT programme. Women's independent decision to join PMTCT was interpreted as a lack of submission to their spouses which may result in abandonment and divorce.

"The man is the head of the family and the woman cannot just go for an HIV test without informing the husband! If a woman is really submissive, she has to talk to her husband about it and men cannot refuse for it is for the better mate of their unborn baby. The problem is that if the woman goes on her own and the husband finds out, the marriage will end up into divorce" (Kankao male, FGD).

Men also mentioned the financial implications the PMTCT programme has on the beneficiaries. The participants felt that the community members cannot afford neither replacement feeding nor exclusive breastfeeding with abrupt weaning as per health workers counselling advise. The main concern for the participants was the fact that milk was very expensive. They said that they would rather spend their little resources on their essential basic needs for the whole household than buying infant feeds. If the health facilities provided the infant feeds, this was not going to be a challenge.

"The most difficult part is where to find money to buy baby milk as it is very expensive. It is therefore better off not to know your HIV status and just breastfeed the baby rather than knowing that you are infecting the baby by breastfeeding. If we fail to manage buy flour for nsima how can you afford the milk? The child will end up being malnourished and may die! It would have been much better if our clinic was providing free infant feeds" (Kankao male, FGD)

In-depth interviews with health workers

When health workers were asked what they perceived to be barriers to PMTCT uptake, fear of husbands and spouse related problems were mentioned by all health workers. Shortage of trained nurses in VCT resulting in long waiting times at VCT centres with little counselling times and mothers who report at night in the labour ward while in labour not tested hence denied the opportunity of accessing Nevirapine if HIV positive. Other PMTCT barriers mentioned were inability to source infant foods and lack of knowledge in PMTCT.

"We do have critical shortage of staff especially in health centres. Imagine I am the only PMTCT provider at this health centre and I am supposed to be at the health facility 2 weeks of every month as my post is at Chilomoni health centre. I do not have time to provide proper counselling to the mothers. If am not on night duty then the mother who comes in labour without an HIV test and comes at night will not be tested and receive Nevirapine" (PMTCT provider, Lundu health centre).

DISCUSSION

The aim of this study was to establish the barriers to the uptake of PMTCT services in rural Blantyre and Balaka districts in Malawi. We identified a number of reasons for the low uptake of PMTCT services in these rural districts including stigma and discrimination, fear of spouse, cost for buying infant milk, lack of privacy provided by the PMTCT services model, and shortage of health workers. Interestingly fear of witchcraft was also mentioned as a barrier to PMTCT uptake in this study.

Opposition from male partners

The study results showed that male partners were decision makers and women on their own did not have the power to decide independently to join the PMTCT programme. Similarly to other studies, spouses have shown to be significant stakeholders in women's reproductive health programmes (Kishindo, 1994; Tadesse et al, 2004). This cultural practice that is negatively affecting women's autonomy about reproductive health matters by dictating their role to be of lower profile and denying them to make their own decisions, is well recognized in Malawi (Malawi Human Rights Commission, 2005).

Some women who were HIV positive experienced domestic violence from their spouses through lack of support, being chased out of their homes and divorce. Likewise, in another study conducted in Malawi, all mothers who participated in the in-depth interviews/case studies reported that their families were disrupted after they had disclosed their HIV status to their partners, i.e. their partners abandoned them (Njunga & Blystad, 2010). When women have consented to an HIV test without the husband's approval, they often suffer domestic violence as a consequence (Bajunirwe & Mizooro, 2005).

Cultural practices related to breastfeeding, stigma and discrimination

Stigma and discrimination against those with HIV/AIDS were found to be major barriers to PMTCT uptake in this study. The cause identified seems to be the loss of confidentiality of one's HIV status when following PMTCT practice. For instance if a mother is HIV positive and joins PMTCT services, the feeding option and general follow up of the mother by health workers will lead to loss of confidentiality of the mother's HIV status. Due to fear of stigma and discrimination, HIV positive mothers ensured that their spouses and the community did not know of their HIV positive status by not joining PMTCT services. In fact, Malawian women have shown an overwhelming fear of being associated with immoral behaviour, while HIV is being

linked to promiscuity, infidelity, and prostitution. As such, HIV positive women fear that their family would no longer care for them. They also fear that friends would cut ties and gossip about them (Combs, 2006).

Shortage of health workers

The shortage of health workers is leading to a lack of time available for counselling mothers and to the long waiting time at VCT centres. Health workers need to assess an individual mother's circumstances to ascertain what is most feasible and safe for her. Time is required to explain factors that increase the risk HIV transmission and the morbidity from replacement feeds, and to give suggestions to reduce these risks (WHO, 2000). Without appropriate staff time for counselling, PMTCT programmes cannot be effective (WHO & UNICEF, 2003).

Cost related barriers

Cost attached to both replacement feeding and exclusive breast-feeding with early cessation was also identified as a barrier to PMTCT uptake. Unless the PMTCT programme recommends prolonged breastfeeding or provides free infant feeds, most mothers will not be able to afford the recommendations. In 2006, the WHO infant feeding guidelines recommended exclusive breastfeeding for 6 months, followed by abrupt weaning. For the entire period of bottle-feeding infant milk must be accessible and affordable, and it must be possible to prepare it safely with clean water and utensils (WHO/UNIADS/UNICEF/UNFPA, 2003). In developing countries, an HIV positive infant that is breastfed - even just for a little time frame - is more than twice as likely to survive the 1st year compared to one that is not breastfed at all (Ahiadeke et al, 1996).

Study limitations

In this study, purposeful sampling was used for recruiting study participants. As a consequence the results cannot be generalized to the wider population. Even though qualitative research cannot generalize results to other communities because of cultural diversity and differences, the material can have relevance for contexts, in this case for PMTCT programmes, far beyond the ones explored in this particular study.

Conclusion

This study has confirmed that stigma and discrimination, opposition from male partners, women's fear of disclosure of HIV status to their partner, cost of infant feeds and fear of being bewitched, factors which were previously found in others studies, were also relevant in rural Malawi. The WHO recommendations of replacement feeding or early rapid cessation have proved to be contradictory and impractical to Malawian culture according to findings from this study. In order to succeed in PMTCT programmes, there is need to involve partners and other significant stakeholders. Therefore, couple counselling, family as well as community involvement are key to appropriate service delivery and successful PMTCT programmes.

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REFERENCES

- Ahiadeke, C., Gurak, D.T., Schwager, S.J. (1996) Breastfeeding and infant survival in Nigeria Ithaca, New York, Cornell University, Department of Rural Sociology, Population and Development Program, 13, [6] p. (Population and Development Program Working Papers Series No. 96.01).
- Bajunirwe, F., Mizoora, M. (2005) Barriers to the implementation of programmes for the prevention of mother to child transmission of HIV: A cross-sectional survey in urban and rural Uganda; Mbarara Uganda. PMID: 16255776. *AIDS Research and Therapy* 2005, 2:10 doi:10.1186/1742-6405-2-10
- Bwirire, L.D., Fitzgerald, M., Zachariah, R., Chikafa, V., Massaquoi, M., Moens, M., Kamoto, K., Schouten, E.J. (2008) Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi. *Médecins Sans Frontières, Thyolo District, Malawi. Transactions of the Royal Society of Tropical Medicine and Hygiene*; 102(12):1195-200.
- Chopra, M., Piwoz, E., Sengwana, J., Schaay, N., Dunnett, L., Saders, D. (2002) Effect of a mother-to-child HIV prevention programme on infant feeding and caring practices in South Africa. *South African Medical Journal*; 92(4): 298-302.
- Combs, T. (2006) HIV/AIDS related stigma: Experiences from women enrolled in Mother to Child Transmission of HIV/AIDS in Malawi; MPH dissertation disseminated at HIV Research net conference, October 2006 (2008, 18 September).
- Coutsoudis, A., Pillay, K., Kuhn, L. (2001) Method of feeding and transmission of HIV-1 from mothers to children by 15 months of age: Prospective cohort study from Durban, South Africa. *AIDS*; 15(3): 379-87.
- GOAL Malawi (2006) AIDS Prevention Positive Leaving and Empowerment - Annual programme progress report. Unpublished.
- Guay, L., Musoke, P., Fleming, T., Bagenda, D., Allen, M., Nakabiito, C., Sherman, J., Bakaki, P., Ducar, C., Deseyve, M., Eme, L., Mirochnick, M., Fowler, M., Mofenson, L., Miotti, P., Dransfield, K., Bray, D., Mmiro, F., Jackson, J.B. (1999) Intrapartum and neonatal single-dose compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomized trial. *Lancet*; 354(9181): 795-802.
- Heiko, K., Andrea, K., Gabriele, P., Paulina, M., Kizito, M., Gundel, H. (2006) Outcome of different Administration Strategies in Preventing Mother-to-Child Transmission (PMTCT) Programs in Tanzania and Uganda. *Medscape General Medicine*; 8(2): 45.
- Jackson, D.J., Chopra, M., Doherty, T., Ashworth, A. (2004) International Conference on AIDS Quality of counseling of women in South African PMTCT pilot sites; Bangkok, Thailand International AIDS Conference. 2004 Jul 11-16; 15: abstract no. ThPeE7998.
- Jackson, J.B., Musoke, P., Fleming, T., Guay, L.A., Bagenda, D., Allen, M., et. al. (2003) Intrapartum and neonatal single-dose compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: 18-month follow-up of the HIVNET 012 randomized trial. *Lancet*; 362(9387):859-68.
- Kishindo, P. (1994) Family planning and the Malawian male. *Journal of Social Development in Africa* 1994; 9(2):61-9.
- Malawi Human Rights Commission (MHRC) (2005) Cultural practices and their impact on enjoyment of Human Rights particularly the rights of women in Malawi. Lilongwe 3 (Unpublished report).
- Ministry of Health (2005) Malawi HIV/AIDS monitoring and evaluation report. Lilongwe: Malawi.
- Ministry of Health. (March 2010) Malawi HIV and AIDS Monitoring and Evaluation Report: 2008-2009 UNGASS Country Progress Report.
- Moodley, D., Moodley, J., Coovadia, H., Gray, G., McIntyre, J., Hofmyer, J., Nikodem, C., Hall, D., Gigliotti, M., Robinson, P., Boshoff, L., Sullivan, J.L., South African Intrapartum Trial (SAINT) Investigators (2003) A multicenter randomized controlled trial of versus a combination of zidovudine and lamivudine to reduce Intrapartum and early postpartum mother-to-child transmission of human immunodeficiency virus type 1. *Journal of Infectious Diseases*; 187(5):725-35.
- Njunga, J. & Blystad, A. (2010) The divorce program: gendered experiences of HIV positive mothers enrolled in PMTCT programs - the case of rural Malawi; Centre for International Health, University of Bergen, Norway - International Breastfeeding Journal; 5:14 doi:10.1186/1746-4358-5-14.
- Tadesse, E., Muula, A.S., Misiri, H. (2004) Likely stakeholders in the prevention of mother to child transmission of HIV/AIDS in Blantyre, Malawi. *African Health Sciences*; 4(3):155-9.
- UNAIDS (2010) Global report: United Nations Programme on HIV/AIDS (UNAIDS) report on the global AIDS epidemic 2010.
- WHO (2000) New data on the prevention of mother-to-child transmission of HIV and their policy implications. Conclusions and recommendations. WHO technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS Inter-Agency Task Team on Mother-to-Child Transmission of HIV. Geneva.
- WHO, UNICEF (2003) Global strategy for infant and young child feeding. Geneva, WHO. Ref Type: Report.
- WHO/UNICEF/UNFPA (2003) HIV and infant feeding, guidelines for decision makers; Geneva, WHO. Ref Type: Report.