

## ORIGINAL RESEARCH

## DECISION MAKING FOR WOMEN TO ACCESS PREVENTION OF MOTHER TO CHILD TRANSMISSION SERVICES IN BLANTYRE AND BALAKA DISTRICTS, MALAWI

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## ABSTRACT

**Aim:** This study aimed to explore the influence of gender and decision making roles on the uptake of Prevention of Mother to Child Transmission (PMTCT) services in rural areas of Blantyre and Balaka Districts, Malawi. **Methods:** A qualitative study was conducted. Six focus groups were held involving 47 community members in rural areas of Blantyre (Mdeka health centre) and Balaka (Kankao health centre) districts. **Findings:** The social status of men and women play a role in the uptake of the PMTCT services. There is lack of male involvement in reproductive health service delivery such as PMTCT. This might negatively affect accessibility of such services by HIV positive pregnant women. Women who make their own decisions regarding access to PMTCT services were often victimized by their spouses due to secrecy around HIV disclosure. **Conclusions:** In order to promote accessibility of PMTCT services by pregnant women, there is need to involve men in the decision making process. Raising awareness of the programme among the community with a focus on men will promote community involvement and enhance support for women to access PMTCT services.

**Key Words:** Decision-making; Gender; HIV; PMTCT; Rural; Malawi.

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## INTRODUCTION

An estimated 370,000 children were newly infected with human immunodeficiency virus (HIV) and 260,000 children died of acquired immunodeficiency syndrome (AIDS) in 2009 worldwide. Developing countries carry most of the burden of new HIV infections (UNAIDS, 2010). Prevention of mother-to-child transmission (PMTCT) of HIV infection has been one of the main strategies in the fight against HIV/AIDS. However poor access to PMTCT services by HIV infected pregnant women remains a significant challenge in many developing countries (UNFPA, 2006; USAID, 2003; Bwirire et al., 2008). In 2009, only 53% of HIV positive pregnant women in low and middle income countries received antiretroviral medication for PMTCT (UNAIDS, 2010).

Women in developing countries are two to four times more likely to acquire HIV infection than men (MacPhail et al., 2002; Auvert et al., 2001; Buve et al., 2001). This has been attributed to several factors including their often lower socioeconomic status which influences women to engage in unprotected sexual behaviours as well as their lack of decision making power regarding reproductive health issues (Kalichman et al., 1998; Laga et al., 2001; Ajuwon et al., 2002; Jewkes & Abrahams, 2002; Wojcicki & Malala, 2001). Malawi is among the ten poorest countries most affected by the HIV/AIDS pandemic worldwide. According to the Malawi United Nations General Assembly Special Session

(UNGASS) progress report, HIV prevalence in women attending antenatal care (ANC) is around 12.6% and only 38.8% of the HIV-infected pregnant women received antiretroviral treatment (ART) for the prevention of mother to child transmission of HIV (MoH, 2010). To improve uptake of the PMTCT services, it has been suggested that other stakeholders such as close relatives and spouses should be engaged to maximize effective delivery of the PMTCT services in Malawi (Tadesse et al., 2004). However, any HIV programme introduced into the community must be adapted to local needs and structural gender differences bearing in mind that incentives, health seeking behaviour and health system barriers differ for men and women (Larsson et al., 2010).

In addition, gender has previously been shown to play a significant role in decision making. The Malawi Demographic Health Survey (MDHS) showed that 65% of married women reported that they have no influence over decisions to access health care, large household purchases, and daily household purchases (NSO, 2004). Although women constitute 52% of Malawi's population, they are under-represented in decision-making processes and have limited access to productive assets like land, credit and technology (NSO, 2004). The Malawian culture infringes on the reproductive health rights of women and girls by dictating their role to be of a lower profile and effectively prohibiting their own decisions (MHRC, 2005). The inability of a woman

to make an informed choice to access PMTCT services without consulting their spouse has been reported as a barrier to the uptake of such services (Pignatelli et al., 2006; Urassa et al., 2004; Nyasulu, 2011). This study aimed to explore the impact of gender and decision making on a woman's intention to access PMTCT services in rural areas of Blantyre and Balaka Districts in Malawi.

## METHODS

### Study design and sites

This was a qualitative exploratory study using a phenomenological approach based on the lived community experiences of women's decision making process to access PMTCT services. The study was conducted in rural areas of Blantyre (Mdeka health centre) and Balaka (Kankao health centre) districts. These districts are located in the southern region of Malawi with an estimated HIV prevalence of 20.5% (MoH 2010).

### Recruitment of study participants

Purposive sampling was used for selection of health facilities and participants in order to achieve a sample of participants with varying characteristics. At the time of the study, Mdeka and Kankao health centres were the only rural primary health care facilities in the region which offered PMTCT services. These services had been in existence for almost a year.

### Data collection and analysis

In order to obtain sufficient data through direct interaction whilst enabling participants to build on each other's responses, three focus group discussions (FGD) were held with different groups of people participating in each group: women living with their spouses; men living with a spouse; and key community leaders. Question guides for the FGDs covering the following areas were developed: knowledge about mother to child transmission of HIV (MTCT); availability and quality of PMTCT services at their health center; how decisions on whether or not to access PMTCT services are made and PMTCT social support services. Four data collectors (two note takers and two facilitators) with experience in conducting FGDs were hired and trained by the principle investigator on the data collection tools. The data collectors piloted the questionnaires by pairing up and facilitating mock FGDs. Each such FGD was followed by a review of the process involving the entire research team. This exercise enhanced the skills of data collectors in conducting FGDs and collecting qualitative data.

In December 2006, a total of six FGDs were conducted (three per site) in the communities of Mdeka and Kankao in rural Blantyre and Balaka districts. Before each FGD, verbal consent was obtained from the participants. Data were collected to explore issues around the demand for PMTCT services, specifically looking at gender and decision making for women to join PMTCT services in these areas. At the end, each FGD was transcribed manually by the note taker and the facilitator together. Thereafter comprehensive notes were noted electronically, incorporating all additional comments and observations captured during the FGD.

To ensure data quality, at the end of each day debriefing sessions were conducted in which emergent concepts and critical themes were identified. This process provided a guide to subsequent FGDs as well as to the nature and quality of the data being generated. The debriefing sessions also helped to establish when saturation was reached. Data were 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. Individual quotations related to certain themes were also identified.

### Ethical approval

This study was approved by the College of Medicine Research Ethics Committee (COMREC), University of Malawi. Further permission was obtained from the heads of each health facility and from the village heads in the participating communities. No attempt was made to link data to the individual identifiers and raw data were stored in a place only accessible by the investigators and data collectors.

## RESULTS

### Study participants

Men and women living with a spouse as well as key informants participated in the focus group discussions. A total of 47 community members (23 males and 24 females) participated in the FGDs.

Table 1: Description of the study participants

FGD Type	Balaka		Blantyre		Total
	Male	Female	Male	Female	
Key leaders	3	3	4	3	13
Women	-	7	-	11	18
Men	8	-	8	-	16
Total	11	10	12	14	47

Forty seven people participated in the study with a mean age of 30 years (range 24 to 68 years). Of the 47 participants, 18 women and 16 men (living with a spouse) participated. Thirteen key community leaders participated (Table 1).

Table 2 describes the five main themes identified during the study. These themes highlight issues which influenced the decision making process for mothers to actively engage in PMTCT services in rural Blantyre and Balaka districts.

### Community members' knowledge about Mother to Child Transmission (MTCT)

The majority of the FGD participants knew that HIV could be transmitted from the mother to the baby. Community members cited the most common mode of HIV transmission as being mixing of blood between the mother and the baby during pregnancy, delivery and breastfeeding.

*"The baby can get the virus during breastfeeding because breast milk is mixed with blood and even during pregnancy and delivery because the mother's and baby's blood can be mixed" (No 1 Mdeka male FGD).*

*"We should all agree here that parents are passing HIV to children. Many children in our community are observed suffering from HIV together with their parents" (No5 Kankao key leader FGD).*

However, a few participants showed lack of knowledge and said that MTCT cannot occur as evidenced from this statement reported verbatim:

*"Yes I hear on the radio that an HIV positive mother can pass the virus to the baby but I do not believe this, I feel it is not possible!" (No3 Mdeka male FGD).*

Table 2: The five main themes identified by the study

Theme	Findings
1 Knowledge about availability of PMTCT services	Most female participants were aware of the PMTCT services available at their health facilities whilst the majority of male participants had no knowledge of the services.
2 Lack of friendliness of PMTCT services towards men	FGD participants especially men, pointed out the general unfriendliness of the health facilities towards men.
3 Decision making to join PMTCT services	Almost all FGD participants (including women) felt that a woman should not make a decision on her own without consulting the spouse.
4 Women's financial empowerment and decision making	Some women reported that a lack of financial empowerment was the main reason that women would not be able to decide on their own.
5 Strengthen spouse and community support for PMTCT services	Involvement of husbands and community sensitization was the most commonly cited action to strengthen support for PMTCT services.

#### Knowledge on availability of PMTCT services at the health facilities

The majority of males who participated in the FGDs were not knowledgeable about the availability of PMTCT services at their primary health care facilities. Some participants even asked the facilitator to inform the establishment of a PMTCT programme at their primary health care facility. The male participants felt the main contributing factor to their lack of knowledge was a lack of publicity about the PMTCT services. They believed that this lack of knowledge had been facilitated by the secrecy surrounding HIV/AIDS issues and maintaining the confidentiality of peoples' HIV status.

*"The services are not available at Kankao health centre but we do hear about it on the radio that in Mwanza district they do give HIV+ mothers drugs to protect the unborn baby from contracting the virus. What we can ask for is that you should assist us in establishing the services for our women at our health centre! The problem is that even if they start offering the services here, women are too secretive to tell someone of their HIV status." (No 1 Kankao male FGD)*

On the other hand, some participants especially women were well aware that the health facilities provide PMTCT services. They pointed out that men did not know about the availability of PMTCT services because they did not like to attend community meetings aimed at raising awareness of the members of the communities on the availability of health services rendered at the health centre.

*"Ayi amfumul (Meaning: "No, chief!") These services are provided at our Mdeka health centre. I know that a group of women who received the drugs from Mdeka health centre conduct sensitization meetings in the community with support from GOAL Malawi. The problem is that men do not like attending such meetings hence they may not know much!" (No 2 Mdeka key leader FGD).*

Another contributing factor to men's lack of knowledge about the availability of PMTCT services might be the reported unfriendliness of the health facilities towards men.

Participants indicated that men were in most cases not welcome and not given an opportunity to be part of women's health related services.

*"The main problem is that the health facility is mainly accessed by women hence we men, do not feel welcome whenever we escort our wives to the health centre" (No 4 Mdeka male FGD).*

#### PMTCT decision making and consequences

Almost all FGD participants (including women) said that a woman should not make a decision on her own without consulting their spouse. The participants emphasized the significant role the husband plays in deciding whether the wife should access PMTCT services or not. The commonly mentioned consequence of women making their own decision was divorce.

*"I personally think the woman should not decide on her own. The husband has to decide because the unborn child belongs to both the husband and wife. This may cause disagreements in the family and the woman may end up being divorced! Who then will take care of the woman and the children?" (No 7 Mdeka female FGD).*

*"The man is the head of the family; a woman cannot just go for a test without prior informing the husband! If a woman is really submissive she has to talk to the husband about it and men cannot refuse for it is for the good of their unborn baby. The problem is that if the woman goes on her own and the husband finds out the marriage will end into divorce" (No 2 Kankao male FGD).*

In these rural communities of Malawi, there was a perception that the spouse will be HIV positive if the woman is found to be HIV positive. People in these communities viewed being HIV positive as shameful particularly when other community members were aware of the person's status.

*"If a woman breaks the news to me that she is HIV positive ndiye kuti andiyalutsa! ("Has brought shame on me!").*

*Usually in such circumstances I will start selling my livestock and all investments then that's the end of marriage!" (No 7 Mdeka male FGD)*

Despite this emotional statement some participants, especially females, strongly felt that women have own personal rights and should be able to make own decisions. However lack of financial empowerment was the main influential factor mentioned hindering decision making to access PMTCT services among women.

*"Ayi azimayi! (Meaning: "No, ladies!") The woman has to decide on her own because most men are a problem. If we women had finances we would not have been afraid of divorce. But the government has to support and protect women who are HIV positive from such abuse so that they can be self reliant." (No 1 Kankao female FGD).*

#### **How to strengthen spousal and community support for PMTCT services?**

When participants were asked what they thought could be done to promote PMTCT accessibility to mothers, involving husbands and community sensitization were mentioned several times as being the most appropriate approach to enhance PMTCT access.

*"I think the Headman is the right person because when I call for a meeting as a Group Village Headman, people rush to attend so that they hear for themselves what I have for them. We leaders have the powers even to discipline the men who are ill-treating their wives! Why not train us and then see how far we can go!" (No 5 Kankao key leader FGD).*

#### **DISCUSSION**

The aim of the study was to explore the role of gender and decision making for women to access PMTCT services in rural Blantyre and Balaka districts, Malawi. The results of this study showed consistent findings from six focus groups involving married men, women and key community leaders. In this discussion triangulation of the three different data sources (men, women and key leaders) will be reflected.

Community members, mostly males, from our study sites were unaware that a PMTCT programme was offered by their health centres and what the programme entailed. The main reason for this lack of awareness was thought to be the secrecy surrounding HIV disclosure among HIV positive pregnant women attending such services. Lack of awareness about the services may lead to a lack of support by a man for his wife's decision to access these services. Stronger community involvement in PMTCT is recommended so that more members of the community are willing to support the mothers and accept the fact that a woman may choose not to breastfeed her child (Chopra, 2002). The study showed that men have a major role in women's decision making to access the PMTCT services. The focus group discussion highlighted that if a woman was to make her own decision, she would potentially meet strong resistance from her spouse. Decision making power, gender inequalities and social pressure especially from spouses and

other relatives have previously been documented to significantly affect the use of maternal and child health care services including PMTCT (Becker et al., 2006; Say and Raine, 2007).

It is evident from the results of this study that many women are unable to decide for themselves whether or not to use PMTCT services. Women may decline to making decisions on their own to access PMTCT services due to fear of divorce and due to lack of financial support from their spouses following as a consequence. To quote a female participant: "if a woman was financially empowered and self reliant, she would be in a position to make independent decisions". This is consistent with findings from the Malawi Demographic Health Survey, 2004, which stated that 65% of married women had no say in their own health care, and that women in Malawi were under-represented in decision-making processes (NSO, 2004). Other studies have pointed out that educated women tended to be economically empowered and were more likely to take decision on their own when compared with uneducated women (Say and Raine, 2007).

Participants, especially men, felt that the set up of the health facilities were not male friendly. However, both male and female participants felt that increased male involvement was the best way forward to promote PMTCT services. Even though involving men and families has been shown to be key for appropriate service delivery and will increase demand for maternal and child care services (Becker et al., 2006), MTCT services have been criticized for being too female focused. However, this is due to the fact that most of these services are linked to antenatal clinics. Without the knowledge and support of their male spouses, women are likely to miss out on the advice about feeding practices or family planning (WHO, 2000). Evaluation of family planning programs have shown that the highest uptake of services was achieved where male partners approved and provided support for such services (Kishindo, 1994). In order to achieve effective male involvement, HIV counselling and testing for couples has been recommended (Grinstead et al., 1998).

#### **Study limitations**

In this study, purposive sampling was used for recruiting study participants hence limiting generalization of the results to the wider population. Use of qualitative research methodology also limits generalization of the results to other communities due to the diversity of cultures.

#### **Conclusions and recommendations**

This study has shown that there is a lack of involvement of women in the decision making process regarding access to reproductive health services, such as PMTCT services for HIV positive pregnant women. This finding might be due to cultural factors as well as a lack of awareness among men on the availability of PMTCT services in the community and a lack of involvement of men in the delivery of such services. In order to enhance accessibility of PMTCT services for HIV positive pregnant women, increased male involvement is required as men play a significant role in decision making regarding accessibility of reproductive health services in

Malawi. Empowerment of women is essential in order to enable women make decisions concerning their own health. Raising awareness of the PMTCT programme among the community with a focus on men will help to promote community involvement in general and encourage provision of support for women to join the PMTCT programme.

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