



Gender Factors Influencing Participation in the **Prevention of Mother-to-Child Transmission of HIV Program** in Malawi under Option B+

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Cover photo: A family in southern Malawi (Valerie Flax, MEASURE Evaluation)

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ABBREVIATIONS

| | |
|-------|--|
| ART | antiretroviral therapy |
| FGD | focus group discussion |
| HAS | health surveillance assistant |
| LTFU | lost to follow-up |
| PMTCT | prevention of mother-to-child transmission |

EXECUTIVE SUMMARY

“If my husband leaves me, I will go home and suffer, so better cling to him and hide this thing.”

—HIV-positive woman in Malawi

In Malawi and other sub-Saharan African countries, women’s traditional gender roles center on marriage and motherhood, caring for family members and the sick, and household duties. Women are expected to consult with their husbands and obey their husbands’ decisions. Men’s traditional roles are to be the head of the family; bring in income to pay for shelter, food, and school fees; and represent the family. In contrast to women, who are expected to be faithful and monogamous, men are expected to have more than one wife or girlfriend, as a sign of their masculinity. These traditional gender roles have been noted as challenges to HIV prevention efforts. They may also constrain women’s access to health services, including their participation in the prevention of mother-to-child transmission (PMTCT) program.

Globally, all countries are working toward achieving the goal of having 90 percent of people who are diagnosed with HIV on sustained antiretroviral therapy (ART). This has been difficult to achieve in PMTCT programs in sub-Saharan African countries, owing to weak health care systems and a variety of individual, interpersonal, and cultural factors. A number of studies have examined barriers to PMTCT participation. Common constraints are fear of HIV stigma, fear of divorce or abandonment upon HIV disclosure, ART side effects, lack of funds for transport to the clinic, negative interactions with health workers, and lack of male involvement. Most studies of barriers were conducted prior to the implementation of Option B+, which initiates lifelong ART for HIV-positive pregnant or breastfeeding women. This study fills an important gap in knowledge about Option B+ programs, by examining how gender interplays with individual, interpersonal, health system, and community factors that contribute to the discontinuation of PMTCT participation.

This qualitative study took place from August 2015 to April 2016 and was a collaboration between MEASURE Evaluation and the Centre for Social Research, based in Chancellor College at the University of Malawi. We collected data at nine government health facilities (five urban and four rural) that provide comprehensive PMTCT services and the surrounding communities in the central and southern regions of Malawi. We conducted in-depth interviews with women participating in PMTCT (n=32), women who were lost to follow-up (LTFU) (n=32), health workers involved in providing PMTCT services (n=16), and stakeholders in organizations supporting PMTCT services (n=6). We also conducted focus group discussions (FGDs) with men in communities within the health facility catchment areas (8 FGDs, n=77 participants).

The interview guides for PMTCT women and LTFU women explored factors potentially related to adherence, such as HIV disclosure, stigma and violence, distance from the clinic, side effects of treatment, experiences at the clinic, women’s workload, psychosocial and instrumental support provided by family members, community perceptions of HIV-positive women, and male involvement in PMTCT programs. For LTFU women, we also probed about the factors that caused them to drop out of the program. The in-depth interviews with health workers and stakeholders focused on their perceptions of the facilitators of and barriers to PMTCT participation and their experiences with male involvement in PMTCT. The FGD question guide explored HIV disclosure, stigma and violence related to HIV, gender roles within families, male support for and involvement in PMTCT participation, ways of improving male participation in PMTCT, and community perceptions about HIV.

In-depth interviews and FGDs were digitally recorded and conducted in Chichewa by trained research assistants. The recordings were transcribed verbatim, translated into English, and uploaded to Dedoose for analysis. Two University of North Carolina-Chapel Hill (UNC-CH) research assistants and the MEASURE Evaluation investigators developed codebooks for each type of participant. The initial codebooks had deductive codes based on the question guides. We independently coded one or two transcripts for each type of participant and compared our codes, to help ensure consistency in code application. We also used this process to revise and finalize the codebooks. Thereafter, the research assistants coded the rest of the transcripts. We then met to discuss key themes that emerged from each participant group and which codes fit within the themes and developed data matrices to facilitate analysis and selection of quotations. We examined similarities and differences across participant groups and by location (rural or urban).

The themes that emerged were largely congruent across the groups, and there were few differences by geographic location. The main facilitator of PMTCT participation was knowledge of the health benefits. Women knew that taking ART could keep them healthy and prevent their children from acquiring HIV. Having a healthy child is a major motivating factor because it reinforces local gender norms related to being a good mother and a caregiver. If a woman's child is not healthy or is HIV-positive, the burden of caring for the child falls to her and she is viewed as an inadequate mother.

Self-efficacy, agency, and social support were facilitators of participation for some women, and the absence of these factors was a barrier for others. Some women did not have the motivation or the confidence in their ability to visit the clinic every month to collect ART or to take the medicine daily. This was sometimes related to a lack of acceptance of their HIV status or to internalized HIV stigma. Gender norms reduce women's agency and control over decision-making, which are considered to be the province of men in Malawi. Some women who appear to lack motivation to participate are prevented by their husbands from going to the clinic or taking ART. These same women often do not get adequate social support from their husbands, who may threaten them because they do not want other people to know that their wives are taking ART. In contrast, other women described the encouragement and assistance—such as money for transportation to the clinic and reminders to take medicine—that they received from their husbands or other relatives.

Important barriers to PMTCT participation were fear of HIV disclosure and stigma and lack of male involvement. In this study, all the women in the program had disclosed their HIV status, whereas about one-third of the LTFU women either had not disclosed to their husbands or had not disclosed to anyone at all. Disclosure is a major issue within Option B+ because women usually attend antenatal visits without their husbands and are tested for HIV during the first antenatal visit, so the burden to disclose rests with them. Many women fear disclosure because they are worried that their husbands will leave them and they will lose their financial security. They also worry about losing other relationships; being in a family is an essential part of women's gender role in Malawian society. When women decide not to disclose their status, it becomes difficult for them to continue participating in PMTCT, because they are afraid of getting caught. HIV disclosure and stigma were interrelated, and most women disclosed only to selected individuals in order to avoid stigma. The majority of respondents stated that HIV stigma still exists in families and communities and can prevent women from participating in PMTCT. Male and female respondents reported that women who are HIV-positive are considered promiscuous, which conflicts with their role as good and faithful wives. They also discussed gender differences in the stigma that men and women experience and in how men and women react to it. In addition, they explained that the decision-making role allows men to leave the relationship if their wives are HIV-positive, but women stay in the relationship if their husbands are HIV-positive, because they lack decision-making power, want to preserve the family and their role as caregivers, and need financial support.

Nearly all respondents considered involvement in PMTCT to be an important way that husbands could support their wives in protecting their children from HIV transmission. The few women who were tested with their husbands had good experiences and felt supported. However, the majority of women were not accompanied by their husbands on clinic visits. They described the difficulty of reporting the information they were given during clinic visits because speaking up to their husbands was considered disrespectful. Men were clear about not wanting to visit the clinic with their wives because they were uncomfortable at antenatal care or PMTCT, which are female spaces, and concerned about damage to their reputations if they were seen at the clinic or known to be HIV-positive. Participants in various groups thought that men should be sensitized on PMTCT through community-based or workplace outreach.

By testing most women for HIV when they are at an antenatal care visit without their husbands, the Option B+ program burdens HIV-positive women with the task of either hiding their status or disclosing, which may threaten their relationships with spouses and families and call into question their performance as wives, mothers, and family caregivers.

On the basis of this research, we recommend that the Malawian government review the Option B+ program in light of local gender norms, recognize the program's impact on men and women separately and as couples, and restructure services to provide care that limits negative impacts on women. Some key areas for consideration:

- Strengthening peer-to-peer programs to improve self-efficacy and increase social support, especially among women who are lacking in these areas
- Identifying and scaling up evidence-based stigma-reduction programs in communities, thus making it easier for women to disclose their HIV status and to feel comfortable visiting the clinic to participate in Option B+
- Scaling up strategies to increase couples counseling and tracing and testing programs, as ways to encourage male involvement in PMTCT, thereby facilitating disclosure and improving men's support for women to regularly take their ART and to follow the feeding guidelines for infants and young children.
- Developing programs that improve gender equality by increasing women's agency and access to credit or economic opportunities, thus helping women take control over health decision-making and become less financially dependent on men

In order for Option B+ to achieve lifelong coverage, the program will need to become both gender-friendly (carried out in a way that considers negative impacts on women *and* men) and gender-inclusive (addressing the needs of both in the context of their roles in the family). In addition, future studies of PMTCT participation should be designed with knowledge of and consideration for local gender norms and analyzed in a disaggregated fashion to ensure that urban–rural differences are revealed.

INTRODUCTION

Background

Gender equality is considered an important development goal, given its relevance to health and human rights. It has long been recognized as key to understanding and addressing HIV and AIDS. In many African societies where patriarchy remains strong, gender roles and relations continue to legitimize women's subordination. At the same time, they foster models of masculinity that justify and perpetuate men's dominance over women (Greig, Peacock, Jewkes, & Msimang, 2008). The resulting gender inequality permeates all spheres of life, including how health services are accessed. To respond to it in health programs, gender norms and their impact must be examined in a specific local context (Magar, 2015).

In Malawi and other sub-Saharan African countries, women's traditional gender roles center on marriage and motherhood, household duties, and caring for household members and the sick (Kyomuhendo & McIntosh, 2006). Women are expected to be the second in command within the family and to consult with their husbands and accede to their husbands' decisions (Gipson, Muntifering, Chauwa, Tauro, & Tsui, et al., 2010). Men's primary roles are to be the head of the family; bring in income to pay for shelter, food, and school fees; and represent the family (Gipson, et al., 2010). Whereas women are expected to be faithful and monogamous, men frequently have more than one wife or girlfriend, as a sign of their masculinity (Fleming, DiClemente, & Barrington, 2016; Thiessen, 2005). These gender roles have been noted as challenges to HIV prevention efforts (Mantell, et al., 2009; Thiessen, 2005). They may also constrain women's participation in the PMTCT program (Njunga & Blystad, 2010).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and other international organizations are promoting the 90-90-90 targets for ending the AIDS epidemic (UNAIDS, 2014). The goals are that 90 percent of all people living with HIV will know their status, 90 percent of all people diagnosed with HIV will receive sustained ART, and 90 percent of all people receiving ART will have viral suppression. These goals apply to all HIV programs, including PMTCT. PMTCT programs in low-income countries contribute to the first 90 by routinely testing pregnant women for HIV unless they opt out by stating that they do not want to be tested (Chandisarewa, Stranix-Chibanda, Chirapa, Miller, & Simoyi, et al., 2007). The second 90 has been difficult to achieve in PMTCT programs in sub-Saharan Africa owing to weak health systems and a variety of maternal, interpersonal, and cultural factors (Tweya, Gugsu, Hosseinipour, Speight, & Ng'ambi, et al., 2014). Incomplete uptake and poor adherence to the recommendations—that is, regular use of ART and adoption of recommended infant feeding practices (World Health Organization [WHO], United Nations Children's Fund [UNICEF], United Nations Population Fund [UNFPA], & UNAIDS, 2010)—limit the full realization of health benefits for mothers and children.

To streamline the process of getting HIV-positive women into PMTCT care, nearly all high-HIV-burden countries have adopted a strategy known as Option B+ (IATT, 2016), under which HIV-positive pregnant or breastfeeding women start triple ART when diagnosed and continue lifelong treatment regardless of their CD4 count. In 2011, Malawi became the first country to adopt Option B+, and the program has been scaled up nationally. The most recent HIV-prevalence data for Malawi are from 2010, prior to Option B+ implementation. At that time, prevalence was 12.9 percent for women and 8.1 percent for men (National Statistical Office [NSO] Malawi & ICF Macro, 2011). Malawi's 2015 HIV report indicates that 79 percent of pregnant women know their HIV status and 72 percent of HIV-positive pregnant women receive ART (Malawi National AIDS Commission, 2015). The difference between these percentages shows that some women are lost to follow-up (LTFU) during pregnancy. Of women on ART under Option B+, 17 percent had stopped taking their drugs by 6 months, and 23 percent had stopped by 12 months (Malawi Ministry of Health, 2012). Women who stop taking their

ART or are LTFU from the PMTCT program are of particular concern, because they may not be accessing the care they need to suppress their viral load, and their children are at risk of acquiring HIV.

The literature reports reasons for LTFU at the individual, interpersonal, health system, and community levels (Bwirire, et al., 2008; Chinkonde, Sundby, & Martinson, 2009; Kim, et al., 2016; Tweya, et al., 2014). The majority of studies on PMTCT participation were conducted before Option B+ was implemented, but the literature on facilitators of and barriers to Option B+ implementation and participation is growing. Among the constraints at the individual level are fear of stigma, domestic violence, divorce, or abandonment associated with disclosure (Bwirire, Fitzgerald, Zachariah, Chikafa, & Massaquoi, et al., 2008; Chinkonde, Sundby, & Martinson, 2009; Duff, Kipp, Wild, Rubaale, & Okech-Ojony, 2010; Iroezi, Mindry, Kawale, Chikowi, & Jansen, et al., 2013; Kalembo & Zgambo, 2012; Murithi, Masho, & Vanderbilt, 2015; Webb & Cullel, 2013); lack of PMTCT knowledge (Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013); a perception that PMTCT is more for the child's health than the mother's (Bwirire, et al., 2008; Ngarina, Tarimo, Naburi, Kilewo, & Mwanyika-Sando, et al., 2014); side effects of ART (Ngarina, et al., 2014; Tweya, et al., 2014); reluctance to start lifelong daily medication prior to disease progression (Gourlay, et al., 2013; Webb & Cullel, 2013); and challenges associated with taking medicine daily for the rest of one's life (Ngarina, et al., 2014). The opportunity to have HIV-negative babies is an incentive for participation in PMTCT programs (Iroezi, et al., 2013; Murithi, et al., 2015), but several studies have noted mothers' intentions to stop taking ART when they stop breastfeeding and the fear of vertical transmission has passed (Clouse, Schwartz, Van Rie, Basset, & Yende, et al., 2014; Ngarina, et al., 2014; Webb & Cullel, 2013).

Most interpersonal factors affecting PMTCT participation were related to the lack of male partners' involvement and community norms. Some women reported that they might lose their husbands' economic support if they disclosed their status (Chinkonde, et al., 2009; Duff, et al., 2010); they might stop taking ART to avoid disclosure (Hsieh, et al., 2014); they were not able to negotiate safe sex regardless of disclosure (Chinkonde, et al., 2009; Duff, et al., 2010); and they could not persuade their husbands to get tested or to disclose their own HIV status (Chinkonde, et al., 2009; Murithi, et al., 2015; Webb & Cullel, 2013). FGDs conducted in Malawi and Uganda revealed that concern about conflict with partners and domestic violence increased when mothers but not their partners received ART under Option B+ (Webb & Cullel, 2013). Although pregnant women in Malawi and Uganda have been encouraged to attend antenatal care with their partners (Webb & Cullel, 2013), and one study found that male partner involvement was associated with improved ART acceptance (Wettstein, Mugglin, Egger, Blaser, & Vizcaya, et al., 2012), other analyses found that men feel uncomfortable in the maternal and child health clinic setting (Dunlap, Foderingham, Bussell, Wester, & Audet, et al., 2014) and may not prioritize attendance at antenatal care services owing to lack of transportation and the desire to spend their time earning money (Duff, Rubaale, & Kipp, 2012). In addition, poverty may create food insecurity that interferes with treatment adherence and optimal infant feeding practices (WHO Regional Office for Africa, 2014) and may prevent paying for transportation to clinics (Duff, et al., 2010; Iroezi, et al., 2013; Tweya, et al., 2014). Some married men believe that women who have their own source of income may feel more empowered to initiate ART, regardless of their husbands' viewpoints (Duff, et al., 2012). Women in Malawi and Uganda specified that income-generating activities could help them attain proper nutrition and pay for health care (Webb & Cullel, 2013).

Health system factors affecting PMTCT participation are staff shortages at facilities, leading to low-quality counseling and long waiting times (Bwirire, et al., 2008; Gourlay, et al., 2013); poor staff-client interactions related to stigma, scolding, and lack of confidentiality (Duff, et al., 2010; Gourlay, et al., 2013; Iroezi, et al., 2013; Tweya, et al., 2014; Webb & Cullel, 2013); and lack of privacy (Kalembo & Zgambo, 2012). Higher rates of LTFU have been noted at urban as opposed to rural clinics (Shaffer, Abrams, & Becquet, 2014; Tenthani, Haas, Tweya, Jahn, & Oosterhout, et al., 2014), but poor tracking systems (Gourlay, et al., 2013) and mobile populations (Tenthani, et al., 2014) may account for these (Tweya, et al., 2014). Travel for work or to help relatives may also disrupt drug adherence schedules

(Tweya, et al., 2014). High numbers of LTFU were documented when ART was initiated during pregnancy or breastfeeding rather than for women's own health needs (Tenthani, et al., 2014; Tweya, et al., 2014), and when ART began on the day of testing rather than at any time thereafter (Tenthani, et al., 2014). One reason may be that women do not feel prepared to begin lifelong drug treatment before they have had time to accept and disclose their status to their partners and relatives (Bwirire, et al., 2008; Chinkonde, et al., 2009). Thus, they may accept the drugs but not use them, and they may fail to return for follow-up care (WHO Regional Office for Africa, 2014). The distance to health facilities has also been cited as a barrier (Gourlay, et al., 2013), and it remains to be seen whether decentralization of services will alleviate this challenge (Iroezi, et al., 2013). The quality of staff interactions with women in PMTCT programs may also inhibit women's continued participation.

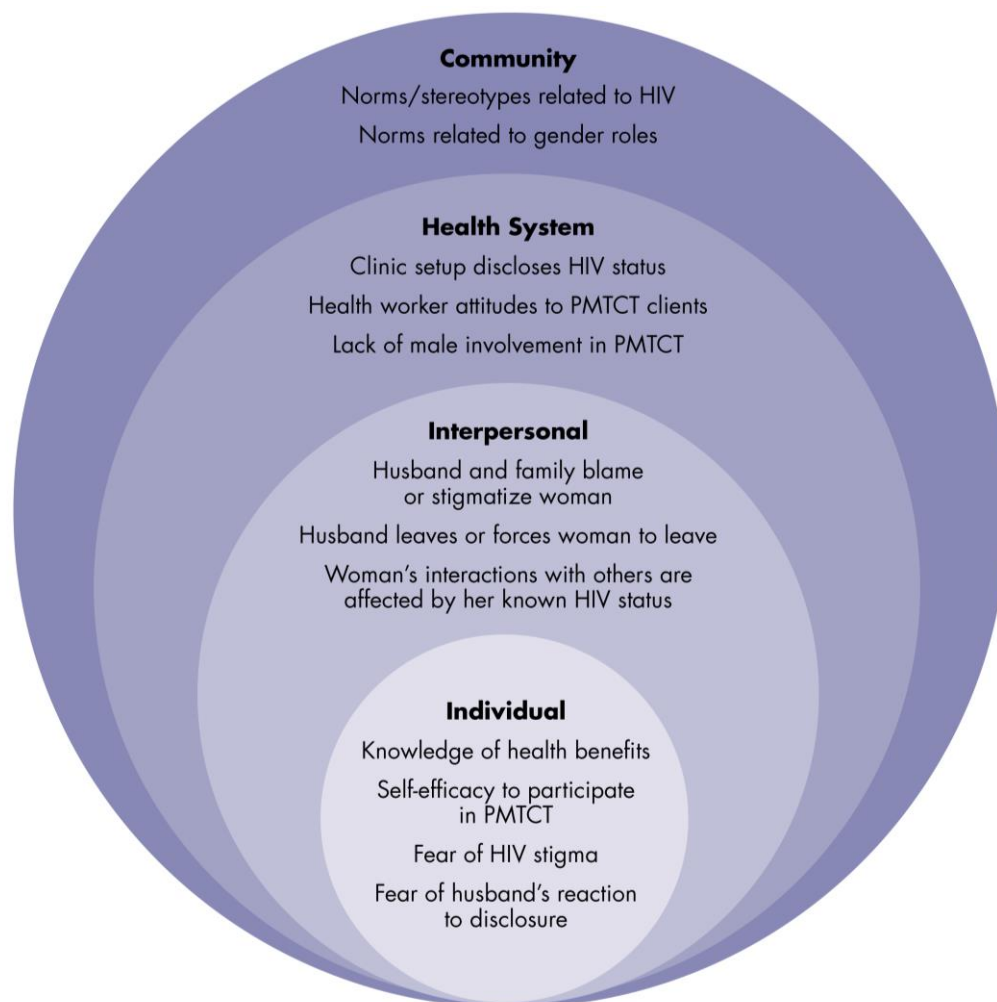
One important gap in knowledge about Option B+ programs is related to how gender, specifically, interplays with known individual, interpersonal, health system, and community factors that contribute to discontinuing PMTCT participation. In addition, national and global discussions largely omit men's views of Option B+. This project is one of the first to use qualitative research to assess gender-related factors related to PMTCT participation under Option B+. The findings will inform program implementation and related support for women in PMTCT care. Topically and thematically, this study focuses on facilitators of and barriers to PMTCT participation, with particular attention to gender and power dimensions. As countries scale up Option B+, data are needed to systematically identify and describe the gender-related factors that inhibit women's continued participation in PMTCT programs so that appropriate services can be designed to mediate these effects and thereby improve maternal and child health.

METHODS

Study Overview

The USAID- and PEPFAR-funded MEASURE Evaluation project conducted this study from August 2015 to April 2016 in partnership with the Centre for Social Research, Chancellor College, University of Malawi. The study's main aim was to describe how gender issues at the individual, interpersonal, health system, and community levels influence HIV-positive women's participation in Malawi's Option B+ PMTCT program. Our study design was guided by the socioecological model, to ensure that we examined gender-related factors that influence women's PMTCT participation at multiple levels (Figure 1) (McLeroy, Bibeau, Steckler, & Glanz, 1988). We used in-depth interviews and FGDs to obtain data from women in PMTCT, women who were LTFU, health workers involved in providing PMTCT services, stakeholders in organizations supporting those services, and men in the community.

Figure 1. Socioecological model of gender-related factors that influence women's participation in PMTCT based on existing literature



Study Sites

The study took place at nine government health facilities that provide comprehensive PMTCT services and in the surrounding communities in the central and southern regions of Malawi. Five urban facilities were located in Lilongwe (Bwaila, Area 25, Kawale—LTFU women only) and Blantyre (Limbe and Chilomoni), and four rural facilities were located in Dowa (Thonje and Bowe) and Thyolo (Mikolongwe and Khonjeni) districts. Study districts and health facilities were selected on the basis of HIV prevalence, urban or rural location, and history of PMTCT service delivery. We initially intended to collect data at eight health facilities, but one clinic in Lilongwe District was added owing to challenges with contacting LTFU women at another clinic in that district.

Sample and Eligibility

Our sample was purposively selected and consisted of 32 women in PMTCT (4 per clinic), 32 women LTFU from the program (4 per clinic), 16 health workers (2 per clinic), 6 stakeholders (1–2 per district), and 77 men (who participated in 8 FGDs) in the communities surrounding the clinics. Eligibility criteria for each type of participant is shown in Table 1. We chose our sample sizes in advance, to ensure that we

had enough participants to attain saturation in subgroups we might want to compare. Saturation is the point at which no new information or themes are observed in the data collected. A minimum of six interviews is needed to achieve saturation in qualitative research (Guest, Bunce, & Johnson, 2006). The types of participants included in this study were chosen to allow us to understand gender-related and other facilitators of and barriers to Option B+ participation at the individual, household, health facility, and community levels of the socioecological model.

Table 1. Respondents, eligibility criteria, and data collection methods

| Type of study participant | Number | Eligibility criteria | Data collection methods |
|------------------------------|------------------------------|--|-------------------------|
| Women participating in PMTCT | 32 | <ul style="list-style-type: none"> • ≥ 18 years of age • HIV-positive • Current PMTCT participant • Pregnant or has child < 24 months of age | In-depth interviews |
| Women who were LTFU | 32 | <ul style="list-style-type: none"> • ≥ 18 years of age • HIV-positive • Has not been to the clinic to collect ART for > 60 days (Ministry of Health definition of LTFU) • Pregnant or has child < 24 months of age | In-depth interviews |
| Health workers | 16 | <ul style="list-style-type: none"> • ≥ 18 years of age • Provides PMTCT services at one of the study clinics | In-depth interviews |
| Stakeholders | 6 | <ul style="list-style-type: none"> • ≥ 18 years of age • Works for an organization that supports or provides PMTCT services | In-depth interviews |
| Men | 8 groups, 77 participants | <ul style="list-style-type: none"> • 20–45 years of age • Lives in the catchment area of one of the study clinics | Focus group discussions |

Data Collection

Ten trained Malawian research assistants divided into two teams collected data simultaneously in different districts. They used several strategies to recruit and enroll participants. They approached PMTCT women during clinic visits, assessed their eligibility, and invited them to enroll in the study. If they consented, they were interviewed at the end of their clinic visit.

Clinic staff helped to identify LTFU women using records indicating that the women had not returned to the clinic to collect ART for at least 60 days, which is the Malawi Ministry of Health’s definition of LTFU. Research assistants contacted LTFU women by cell phone or through community health workers and interviewed them at the location of their choice (in the community or at the clinic). If they met the eligibility criteria, they participated in an in-depth interview.

The interview guides for both these groups explored factors potentially related to adherence, such as HIV disclosure, stigma and violence, distance from the clinic, side effects of treatment, experiences at the clinic, workload, psychosocial and instrumental support from family members, community perceptions of HIV-positive women, and male involvement in PMTCT programs. If they had a child younger than 24 months, we asked about their feeding practices to date. When women were LTFU, we probed about the factors that caused them to drop out of the program.

The officer in charge at each clinic helped to select health workers involved in providing PMTCT services, and research assistants conducted those interviews at the facility. The district health office referred us to stakeholders in each district. Research assistants interviewed stakeholders either at the health facility or at their project offices. The in-depth interviews with health workers and stakeholders included similar questions and focused on their perceptions of the facilitators of and barriers to PMTCT participation and their experiences with male involvement in PMTCT.

Village chiefs and local leaders in the selected communities helped to recruit men for the FGDs. We sampled men in general and did not require that they have a certain HIV status or be in a relationship with an HIV-positive woman, because we wanted to learn about social norms in perceptions of HIV-positive women and PMTCT. The FGD question guide explored HIV disclosure, stigma and violence related to HIV, gender roles within families, male support for and involvement in PMTCT participation, ways of improving male involvement, and community perceptions of HIV.

We field-tested data collection tools during interviewer training. We developed all consent and data collection forms in English and translated them into Chichewa. Research assistants digitally recorded in-depth interviews and FGDs, transcribed them verbatim, and subsequently translated them into English. The research team at MEASURE Evaluation checked English transcripts for completeness and then uploaded them to Dedoose for analysis. Research assistants obtained signed or thumb-printed informed consent from all participants. The Institutional Review Board at UNC-CH and the Malawi Ministry of Health's National Health Services Research Committee provided ethical approval for this study.

Data Analysis

Two UNC-CH research assistants and the MEASURE Evaluation investigators worked together to develop the codebooks for each participant group, which initially included deductive codes based on the question guides. We independently coded one or two transcripts from each participant group and compared our codes to help ensure consistency in code application. We also used this process to revise and finalize the codebooks. Thereafter, the research assistants coded the rest of the transcripts.

We then met to discuss key themes that emerged from each participant group and which codes fit within the themes. The research assistants developed data matrices, following the method proposed by Miles & Huberman (1994). They generated tables with the key themes in columns and participant ID numbers in rows and inserted quotations or summaries in each cell to facilitate analysis and the selection of quotations.

RESULTS

Participant Characteristics

Several characteristics of PMTCT women and LTFU women differed (Table 2). The LTFU women had more years of education, on average; more of them were working; and they had more household items than did PMTCT women. A greater number of LTFU women reported frequent household food insecurity than PMTCT women did. More LTFU women did not know their husband's HIV status or had husbands who had not been tested for HIV. The time on ART ranged widely for LTFU women: three never started the treatment; 14 took it for less than one year (usually for only a few months); 9 took it for one to two years, and 6 took it for three or more years.

Table 2. Characteristics of PMTCT participants and women lost to follow-up

| Characteristics | PMTCT women (n=32) | LTFU women (n=32) |
|--|-------------------------|-------------------------|
| Age (years) | 30.1 ± 5.5 | 29.9 ± 4.8 |
| Years in PMTCT | 3.5 ± 2.9 | 1.3 ± 1.6 |
| Parity | 3.6 ± 1.5 | 3.7 ± 1.6 |
| Youngest child's age (months) | 11.7 ± 7.2 ^a | 11.8 ± 6.7 ^b |
| Education (years) | 5.1 ± 3.4 | 7.5 ± 3.7 |
| Household items (max 10) | 2.4 ± 2.4 | 3.1 ± 2.7 |
| Marital status | % (n) | % (n) |
| Married | 84 (27) | 72 (23) |
| Separated/divorced | 9 (3) | 9 (3) |
| Widowed | 6 (2) | 9 (3) |
| Single/never married | 0 (0) | 9 (3) |
| Employment | % (n) | % (n) |
| Housewife | 34 (11) | 13 (4) |
| Agricultural worker | 31 (10) | 31 (10) |
| Petty trader | 22 (7) | 31 (10) |
| Salaried worker | 3 (1) | 6 (2) |
| Other | 9 (3) | 19 (6) |
| Husband/partner is HIV-positive | % (n) | % (n) |
| Yes, on ART | 15 (5) | 17 (5) |
| Yes, not on ART | 47 (15) | 14 (4) |
| No | 19 (6) | 10 (3) |
| Not tested/don't know | 19 (6) | 59 (17) |
| Presence of household food insecurity | 72% (23) | 69% (22) |
| Frequency of food insecurity | % (n=23) | % (n=22) |
| At least one day per week | 26 (6) | 54 (12) |
| A few days per month | 61 (14) | 32 (7) |
| Irregularly | 13 (3) | 14 (3) |

^aThe sample for child's age is (n=27), because 5 women were pregnant. ^bThe sample for child's age is (n=30), because 2 women were pregnant. ^cThree LTFU women were single, so the sample is n=29.

Health workers interviewed for the study either were nurses or nurse/midwives (n=13) or health surveillance assistants (HSAs) (n=3). They had been working in PMTCT for an average of 4.6 ± 3.1 years. Stakeholders worked for Mothers to Mothers (n=3), Baylor College of Medicine (n=2), or Management Sciences for Health (n=1). They had worked in their organizations for an average of 3.8 ± 2.3 years. Men participating in FGDs were 33.2 ± 9.7 years of age, on average, and had 7.5 ± 3.3 years of education; 90 percent (n=69) were married. They reported that they worked in the following occupations: farmer (n=33); business/petty trade (n=17); or other, such as guard, driver, bricklayer, carpenter, or community leader (n=27).

Factors Influencing PMTCT Participation

Although we used the socioecological model as a framework to guide data collection, we found that many of the themes cut across the levels of the model. Therefore, in the remainder of this section, we describe the results by theme and explain how the themes are interrelated. The key themes describing facilitators of and barriers to PMTCT participation were knowledge of health benefits, self-efficacy and agency, HIV disclosure and stigma, social support, and male involvement. Themes from the various types of

participants in this study were largely congruent. Throughout the results, we highlight discrepancies in the perspectives of participant groups where they were apparent, and also differences by residence (urban versus rural). Quotations from respondents are labeled with their type and identification number to differentiate the speakers. Identification numbers are consecutive for all respondents, not by respondent type.

Knowledge of Health Benefits

At the individual level, one of the main factors facilitating PMTCT participation was women's knowledge that by following the PMTCT guidelines (taking ART and exclusively breastfeeding up to six months) they were protecting their own health and that of the child. Participants in every group in the study mentioned the health benefits. Some direct quotations supporting this point follow:

Health of the Child

"The benefit is that your child grows stronger and healthier. You might have the infection but your child will not get it from you. And when the child grows, he feels proud that you cared for him."
(PMTCT Woman #2)

"The benefit is that the child will be [HIV] negative and healthy... if the mother is participating in the PMTCT program." (LTFU Woman #36)

Health of the Mother

"Since the time I came to the clinic... I am healthy and able to work, washing and everything. I work [in paid employment] and I will start [again] when my child is four months, because I am healthy and I adhere to the drugs." (PMTCT Woman #22)

"[When you are on ART], you stay healthy and live like any other person. No one knows that you are HIV-positive." (LTFU Woman #52)

Not only knowledge but also experience of the health benefits of ART could encourage women to continue participating. For example, one health worker (#68) explained, "They get encouraged, because they stay healthy and don't get sick after taking ART, giving birth to uninfected children if they adhere to medication and advice. And even an HIV-negative test result for the child after a number of tests encourages them."

Maintaining maternal and child health is also important, because motherhood and caring for the family are important gender roles assigned to women. A healthy child is seen as a sign of a good mother. Women need to stay healthy themselves so that they can continue in their role as caregivers. Thus participation reinforces their gender roles. A few respondents mentioned that the health benefits for the child are also benefits for the mother, because Malawian gender norms dictate that mothers are responsible for child care, and it is easier for them to care for a child who is not ill. One LTFU woman explained, "Women benefit more because of the gender roles assigned to women. Because everything that happens [to the children] is the responsibility of women."

Self-Efficacy and Agency

"Laziness" was cited by different types of respondents as a factor that influences PMTCT participation. We have interpreted "laziness" as meaning a lack of will or self-efficacy, defined as people's beliefs about their ability to engage in certain behaviors and to exert control over their own motivation and social environment (Bandura, 1977). Here are two explanations showing how lack of self-efficacy impacts PMTCT participation:

“Some people are lazy. They are even lazy to take the drugs. Even in the fields, some people are lazy. If you are lazy, you are lazy. Some are lazy to take the drugs daily, so they take drugs today and skip tomorrow.” (PMTCT Woman #13)

“To be frank, the medical personnel at our clinic really try their best. They always encourage us to adhere to medication, but it’s just us people are not willing to accept our status and follow the right procedures.” (LTFU Woman #57)

Some women were not motivated to go to the clinic to collect ART or to take the medicine on a regular basis, whereas others were motivated by the health benefits. For example, a PMTCT woman (#2) explained, “The feeling or the will to stay healthy is the one which enables me to participate in this program.” In general, there was no difference in motivation or self-efficacy between urban and rural LTFU women. LTFU women residing in both areas mentioned laziness as a reason for nonparticipation. Among PMTCT women, however, a stronger sense of self-efficacy emerged from rural residents than from urban residents.

Some respondents attributed lack of self-efficacy as related to women’s failure to accept their HIV status or to internalized stigma. Here are two examples:

“Some women stop [taking ART] because they give up, lack faith. They consider themselves dead.” (FGD #117)

“It all depends on individuals and how they have accepted their results. There are others who are in denial. Even if they have been put on medication, still they have not accepted it.” (FGD #135)

In Malawi, married women frequently have limited decision-making power and often lack control over decisions related to their own health. Their lack of agency has an impact on their self-efficacy. Here’s an example of husbands taking over decisions about their wives’ PMTCT participation:

“We have some women who were told by their husbands that if you want to start taking that ART, you should leave my house. That means the woman has no say, though she wanted to start taking the medication. There was this other incident where the man reached a point of throwing the woman’s ART into the toilet because he didn’t want his wife to be taking it.” (Stakeholder #86)

Women who appear to be “lazy” or to lack motivation to participate in PMTCT may have no control over decisions about their health or may be depressed, because depression is more common in people living with HIV and in postpartum women.

In addition to being constrained by their husbands’ decisions, many women feel they have little control over whether their husbands have other wives or relationships with other women. Gender roles for men dictate that they show their masculinity by having multiple sex partners, often including those outside marriage. Although this behavior is expected, it obviously has an impact on their wives and other female partners. An LTFU woman (#48) explained, “Sometimes it happens that maybe your husband doesn’t live right and that can make you get [HIV].” Women’s lack of agency in relationships is linked to their denial of their HIV status, which may make it difficult for them to participate in PMTCT.

HIV Disclosure and Stigma

HIV disclosure and stigma were themes mentioned by nearly all respondents. The two are interrelated and also connected with many other themes that emerged from the data.

HIV Disclosure

All the PMTCT women in this study had disclosed their status to at least one person. Among LTFU women, 10 out of 32 had not disclosed to their husbands or had not disclosed to anyone. Of the PMTCT women and LTFU women who had disclosed to one or a few others, most had done so reluctantly, because they feared being stigmatized and gossiped about. A few women said that because they wanted others to learn from their experience, they had disclosed more widely.

Among LTFU women, some urban and rural respondents reported disclosure to husbands, mothers, and friends and others did not. Urban respondents talked more about the effort needed to hide one's status and how it led to nonparticipation. Among PMTCT women, both urban and rural dwellers mentioned disclosure to husbands, sisters, and mothers and agreed about not disclosing to neighbors. We noted some differences in opinions on disclosure between urban and rural men's groups. Some men in an urban FGD said that women would disclose to their husbands, and some said that they would not, for fear of divorce. However, men in rural FGDs generally believed that women disclose to their husbands and their mothers. Men in both locations agreed that, to avoid gossip, women would not disclose to their neighbors.

Within the topic of HIV disclosure, the following issues emerged: in PMTCT, the burden of HIV disclosure is on women; women fear disclosing to their husbands, because of economic dependence and possible abuse; most women worry about disclosing to friends and some family members owing to fear of stigma; women who do not disclose to their husbands or the people they live with find it difficult to stay in PMTCT; the operational setup at PMTCT clinics inadvertently makes women's status public; and many women disclose their HIV status, with some gaining social support and personal strength. We explore each of these subtopics below.

The current operational setup of Option B+, whereby women are tested for HIV during their first antenatal care visit, places the burden on the woman to disclose her status to her husband or partner. As we describe in more detail below, very few husbands accompany their wives to antenatal care or PMTCT visits. In most cases, the wife learns her status alone and then must decide whether, when, and to whom to disclose. If she discloses and her family is not accepting, it is hard for her to stay in the program.

Women especially fear disclosing to their husbands, because they are afraid they will be blamed for bringing HIV into the relationship. For example, an LTFU woman (#56) stated, "I was afraid he would say that you are the one who was found [HIV] positive; where did you get it from?" In addition, most Malawian women are economically dependent on their husbands and afraid that they will be abandoned if their husbands find out they are HIV-positive. Wife and mother are their most important roles as women, and an HIV diagnosis threatens those roles with the risk of separation or divorce. Study respondents in various groups made this point:

"Most women don't disclose to their husbands, because they fear that they could be divorced if the husband doesn't agree or accept the results." (PMTCT Woman #1)

"I can't tell my husband I am on treatment—that's suicide. If I tell my husband I am on treatment, he will leave me." (LTFU Woman #52)

"Men usually don't just accept the results... It's true that when a woman is found positive, she may not be sure if her partner will accept the news or not. Sometimes they fear they may lose their relationship and they just keep it to themselves." (FGD #127)

"When a woman is found positive, they hide sometimes, because usually they are not sure how their husbands would react to the news. 'If I tell him, is he not going to leave me?'" (FGD #155)

“It’s the men who are breadwinners, so [women] are afraid to tell them their status, because they fear being chased from the house or that their husband would leave them for another woman.” (Health Worker #65)

Some women in our sample decided not to disclose their HIV status to their husbands in order to protect themselves from verbal and possible physical abuse. One LTFU woman (#34) explained,

“I made the decision to just keep quiet. That’s how I was protecting myself... There are some men who insult and mistreat their wives, especially when the husband is HIV-negative and the wife is HIV-positive. And this behavior can disappoint the woman, so instead of continuing with the program she just stops.”

Women also worried about disclosing their HIV status to other members of their families and communities, mainly because they did not want to be stigmatized. Two examples:

“I was afraid they [my friends] would be gossiping about me behind my back.” PMTCT Woman #15

“I did not want them [my friends] to know, because some of them are too talkative. So I was afraid they would be mocking me or even talking bad about me behind my back.” LTFU Woman #40

Various groups of respondents described the difficulties that women who decide not to disclose their HIV status face in staying in the PMTCT program. It is hard for non-disclosers to take their ART regularly without having others find out, and problematic for them to go to the clinic regularly to collect more ART. Here are some illustrative quotations:

“They [women who have not disclosed] are afraid of their husbands or the ones they are staying with. It becomes a challenge to take their medication, because they are afraid that they may get caught.” (Health Worker #71)

“I did not disclose to my husband, and it’s very difficult for me to participate in the PMTCT program without him noticing.” (LTFU Woman #45)

“What happened is that when I noted that I was HIV-positive, I didn’t tell my mother, because I was afraid... At the hospital when they gave me the drugs, I started taking them. When I came back during evening, because our rooms are close to each other, that’s when my mother was surprised to hear some noise each day. The noise was happening when I was opening the drugs. So that made me stop, because I was afraid.” (LTFU Woman #51)

For many women in this study—whether they had not disclosed or had disclosed to only a few people—the setup at most of the health facilities made them worry about inadvertent disclosure to others in the community. This may occur because women in PMTCT are asked to go to a certain part of the facility or because the PMTCT clinic is on a specific day. They may see people they know, and those people might figure out that a woman is HIV-positive. In other cases, a woman’s status may be disclosed through lack of privacy at the clinic or when health workers call out patients’ names in a public space. For example:

“Yes, because this is the time people get to know the status of people around them [when they are waiting at the clinic], so this discourages most people to attend PMTCT.” (PMTCT Woman #17)

“Some of them don’t want to be known to others. In other words, they are ashamed. They hide when they are coming here [to the clinic].” (PMTCT Woman #27)

“People I know go to the same hospital to receive their medication, so I am shy to go and receive ART, because I might run into them. Nobody knows about my HIV status.” (LTFU Woman #46)

“I have always wanted to continue with the treatment, but I don’t like the long queues and the arrangement itself whereby they give you one date for receiving ART and you are put in a separate queue from other patients with general illnesses. If it were in one queue, then it would be much better rather than calling out names of people going to receive ART. That is a burden to me.” (LTFU Woman #53)

“But for PMTCT, they set specific days for the clinic, every Thursday, so I decided not to attend such a clinic.” (LTFU Woman #54)

A few women were afraid of inadvertent disclosure through outreach programs that target HIV-positive individuals. One LTFU woman (#46) explained how the health surveillance assistants (HSAs) or community health workers visiting her made a family member suspicious about her status, so she stopped participating in the program. She stated, “I stopped taking ART, because I was being visited at home by some people...who came to give me support, so it was raising some suspicions among my relatives. They were asking me why I am being visited by those HSAs.”

Despite all the issues related to HIV disclosure, many women in this study were able to disclose to someone close to them, and a few felt that it was important to disclose their status widely. According to the health workers and women in our study, women are advised to disclose to a relative or a close friend in case anything happens and they need someone to go to the clinic to collect ART or for other reasons. Women themselves know to whom they feel comfortable disclosing. A health worker (#68) explained, “Everyone knows who can be trusted with such issues without humiliating them about their status.” Some women took courage from the counseling they received at the clinic. One PMTCT woman (#5) said, “Through counseling... from the health workers I felt strength and the need to disclose this to my husband, mum, relatives, and people close to me. And I am happy, because they showed me love, support, and care.” A few women wanted to use themselves as examples or believed that so many people were HIV-positive that they did not worry about negative consequences if they disclosed. For example:

“Aaah, I can’t hide my status. HIV is not new. Everyone knows there is this pandemic, so I can’t hide it from anyone.” (PMTCT Woman #30)

“I wanted my family members to learn from me. In case in the future something like this happens to them, they should not waste time hiding their status.” (PMTCT Woman #10)

HIV Stigma

As noted above, many respondents described the interrelationship of HIV disclosure and stigma. Women who were worried about stigma were also worried about disclosure, and some respondents clearly thought that stigma still existed in their families and communities. Both urban and rural women spoke of hurtful, fatalistic attitudes toward HIV-positive people, characterized by comments such as “Look at her. She is already dead.” More LTFU women in rural than in urban areas spoke about gossip, avoidance, and mocking. However, some women, especially those participating in PMTCT, did not experience stigma, and other respondents thought that it was less common than in earlier times. Subthemes related to stigma that we explore in this section are differences in experiences of stigma, community perceptions of HIV-positive men and women, and the need for outreach and sensitization about HIV stigma.

Some respondents, especially PMTCT women and health workers both in urban and rural areas, felt that there was no stigma in their communities or that it was significantly less than in earlier phases of the HIV pandemic. For instance:

“In our community there is no stigma, because now, everybody knows that it’s an epidemic.” (PMTCT Woman #2)

“[Discrimination] happened in the past, but now almost everyone is either infected or affected, so people have accepted it.” (PMTCT Woman #13)

“These days, people are used to the pandemic, which is why it is like that, but long ago it would have been different.” (Health Worker #72)

Some PMTCT women felt that stigma should not influence their participation. This feeling was linked to their self-efficacy to be in the program and their knowledge of and desire to attain the health benefits of PMTCT. One PMTCT woman (#18) explained, “I have never experienced any violence or stigma, maybe because I disclosed my status just after I was told. And even if they had a different opinion of me, it would not affect me participating in the PMTCT program.”

Other PMTCT women, however, along with many LTFU women and men in FGDs, described the continued existence of HIV stigma. Some women were able to ignore it:

“It hurts and you become disappointed and worried that how could she be talking about my [HIV] status to a group of people? Sometimes you just ignore whatever they are saying and focus on the advice you receive at the hospital. The important thing is protecting yourself and your child so that you don’t easily get sick.” (PMTCT Woman #7)

“They [HIV-positive women] cannot be worried because they are being gossiped about. They have to participate in the PMTCT program, because they want to shape their future as well as that of their child.” (PMTCT Woman #16)

Some women who were hurt by the stigmatizing gossip in their communities stopped participating in the PMTCT program. Women also experienced self-stigmatization and were embarrassed or ashamed of their HIV status. The following quotations illustrate this:

Interviewer (I): “What makes it difficult for women to stay in the PMTCT program?”

Respondent (R): “They feel ashamed of their status, especially if people know that they are HIV-positive.”

I: “What else, apart from feeling ashamed?”

R: “They just fear being stigmatized by people who are ignorant and unaware, because they talk a lot and consider you to be useless when you are in this situation. They deliberately do things that annoy you, which puts you in a dilemma. So people [women] see no need to continue with the treatment.” (LTFU Woman #53)

“Some of my relatives were discriminating me. I don’t know where they heard about my HIV status...they were talking a lot of bad things behind my back...That I am on ART so I shouldn’t be with them or touch their things.” (LTFU Woman #55)

“When they [women] face stigma in the communities, they find it hard to come to the hospital. And even here at the hospital, if we show that we don’t want to help them because of their status, then they feel the stigma and just decide to drop out.” (Health Worker #75)

HIV stigma in our sample was related, in part, to community perceptions of HIV-positive women. HIV-positive women and FGD participants we interviewed talked about people who assume that women with HIV are promiscuous, are prostitutes, or are “already dead,” and, therefore, cannot fulfil their role as good and faithful wives, as prescribed by Malawian gender norms. Some examples:

“If a woman is HIV-positive, people think that she was a prostitute...and then these [women] are discriminated...when they are known to be on ART. As such, women are ashamed to participate in PMTCT or HIV testing, for fear of being shamed.” (FGD #97)

“They [HIV-positive women] are perceived in different ways. First of all, people perceive them as being promiscuous and that has resulted in them being found [HIV] positive.” (PMTCT woman #22)

“People think when you are HIV-positive, you are dead...When women feel discriminated, they choose not to adhere to PMTCT.” (LTFU woman #39)

Several respondents said that there were no differences in how HIV-positive men and women were viewed in the community. A few felt that women simply reacted differently to the stigma and gossip than men. One PMTCT woman (#6) explained this point of view:

“There is no difference. It’s just that women react differently as compared to men. Usually men are stronger in handling issues. For example, if women heard that someone was talking about them, they would react in a certain way, whilst men would just brush it off. [It’s] not necessarily that women are facing different treatment than men.”

In contrast, other respondents thought that HIV-positive women face more discrimination than HIV-positive men. A PMTCT woman (#31) said, “HIV-positive women are more victimized and discriminated than men.” Several respondents said that women experienced more discrimination about their HIV status, because they are not as tough as men. For example:

“Women face discrimination, unlike men, because men are tough. Women often stop participating in PMTCT as a result [of discrimination].” (LTFU Woman #44)

“Women face discrimination, unlike men, because men are usually difficult people and easily get angry, so people are afraid to discriminate against them.” (LTFU Woman #58)

Several LTFU women and men in FGDs encouraged community sensitization to reduce HIV stigma. For example, an LTFU woman (#59) said, “Awareness in the community should be raised so that we could participate in PMTCT freely and fully without getting scared of being mocked.” A participant in FGD #148 said,

“I would say all those parties concerned, mainly the health sector, if they could have outreach programs going round with megaphones spreading the messages. You know, when you use the PA system, most people pay attention to what you have to say. If it was once a month, people would have interest in the program.”

Two FGD participants mentioned stigma-reduction policies in their communities, whereby the village chiefs had created bylaws making it illegal to stigmatize community members with HIV.

Social Support

Both PMTCT women and LTFU women described the types of social support they received and the importance of support in encouraging PMTCT participation. Nearly all of the PMTCT women and about two-thirds of the LTFU women said that family members, friends, health workers, or religious leaders supported their participation in PMTCT. Women described social support in the form of expressions of empathy, tangible aid, or advice and suggestions. Here are some examples:

“My husband gives me transport and he reminds me about medications.” (PMTCT Woman #1)

“He [my husband] tells me to go to collect drugs because he appreciates the changes at home, how happy we are because I don’t feel any pain anymore. I am healthy and I can do work.” (PMTCT Woman #26)

“My sister encouraged me to start taking my medication, and my husband always reminds me about taking my medication. Besides, I don’t want my child to get infected.” (PMTCT Woman #15)

“They [my relatives] accepted the results and encouraged me not to lose hope or faith. They gave words of encouragement about taking medication regularly and following all hospital procedures.” (LTFU Woman #40)

It was common for relatives to remind women to take their ART or to go to the clinic for scheduled appointments. They also offered moral support, and some husbands provided their wives with money for transport to the clinic.

Not all PMTCT or LTFU women in this study felt they had enough support, and some LTFU women either had no support or had family members, especially husbands, who were either negligent or actively unsupportive. If the husband was angry or threatening, the woman had difficulty continuing with PMTCT. The words of an FGD member and a health worker illustrate this point:

“If the husband is angry at the woman, it would be hard for the woman to participate in the program.” (FGD #117)

“They [husbands] threaten them [their wives] because they don’t want their wives to come here [to the health facility]. They know that if their wives are seen coming here at PMTCT, then they will know that they are receiving ART. And they are ashamed that people would also think that they too are taking ART.” (Health Worker #72)

According to one LTFU woman (#50), her husband not only told her not to go to the clinic but also “just told me to stop taking my medication.” Husbands with multiple wives or partners were sometimes either not supportive or not around. In other cases, husbands withdrew support by leaving the marriage. We explore these issues in more detail in the next section.

Spousal Relationship

Some PMTCT and LTFU women described having a good relationship with their husband or partner and being able to discuss issues openly. One PMTCT woman (#13) explained, “He [my husband] encourages me, because now everyone is affected by HIV. We don’t fight and we live in harmony.” An FGD participant described how love could help a couple continue to live together with HIV:

“It all depends on the level of love that the two have for each other. If one is found to be positive, they easily understand the situation and follow advice from the health workers. If you love one another, it’s very easy to go together for the HIV test where you can also be counseled together on how you need to stay together without problems.” (FGD #135)

But more commonly, both PMTCT and LTFU women talked about instability in their relationships with their husbands and partners and the lack of trust and communication within couples. In some cases, the relationship was already unstable, and when the woman disclosed her HIV status, it became worse. In other cases, it was the disclosure that brought on instability and led the relationship to break up. Some examples:

“My husband, as I already said, he doesn’t stay long at home [because he has other wives]. At first, he encouraged me to go for VCT [voluntary HIV counseling and testing], but now we quarrel a lot. That’s all I can say.” (LTFU Woman #58)

“I told my husband about my status and that he should also go for testing, but he left me after that.” (PMTCT Woman #25)

A lack of trust in relationships makes it difficult for women to disclose, which makes it hard for them to continue participating in the PMTCT program. Many men, too, are fearful of disclosing their HIV status to a spouse; often a woman learns her husband's HIV status only after disclosing her status to him. A PMTCT woman (#35) said that when she disclosed to her husband, he was not surprised. He “expected” her to be HIV-positive, because he already knew that he was, but he had not told her.

Some women were worried that their husbands don't respect their lives, meaning that they continue to engage in extramarital affairs or have other partners, and a few LTFU women specifically said they had dropped out of the program for that reason:

“I am worried, because he goes out to work and comes back and I am afraid he engages in extramarital sexual affairs and comes back to me with more virus.” (PMTCT Woman #30)

“The other reason I stopped taking my medication was that he was still coming here to sleep with me. I was taking my medication and protecting myself, but he wasn't. So I felt like I wasn't doing anything [by taking the drugs].” (LTFU Woman #56)

These quotations once again evoke women's lack of agency and decision-making power in their relationships with their husbands. Owing to a power imbalance between the sexes and the economic dependence of women on men in both urban and rural areas, husbands could choose their own extramarital sexual behavior, while wives felt they had to accept that behavior in order to protect their status as wives and mothers. For example, an LTFU woman (#35) said, “You know men, right, you just hear that he has partners...”

Similarly, husbands might refuse to be tested for HIV or not accept their wives' HIV status, whereas wives felt compelled to accept their husbands' HIV status in order to maintain the marriage and ensure a source of support for themselves and their children. Two FGD #135 participants made this point:

Participant #7: “Most women, if their husband overreacts or refuses to go for [an HIV] test, don't force it, because they think about their situation. ‘If I let him go, who will take care of the unborn child? What about the other children that we have?’ So because of this, the women just let their partners be. If he refuses to go for a test, they just let it go, for fear of losing him.”

Participant #4: “The thing is, usually it's the men who are difficult here. So women find it difficult to say, ‘I am leaving him because he is positive.’ They usually think about how they would survive. As such, they find it easier to stick to their husbands despite their [HIV] status.”

And a PMTCT woman (#7) explained, “When the wife is tested positive while the husband is negative, the husband ends the marriage. When it's the other way round, the woman still stays.”

Respondents from several groups explained that men are allowed to make independent decisions but women are not, particularly when it comes to ending the marriage because their partner is HIV-positive. These words from a health worker are illustrative:

“If we differentiate between a woman and a man who are HIV-positive, it is the man who makes independent decisions. But for women, they don't usually make independent decisions; other people have a say, too. For instance, if the man is HIV-positive, he can just decide to get out of the marriage and go elsewhere. It is possible. But for women to make a similar decision, it's not possible. So women experience different things from men despite both of them being HIV-positive. They still receive different treatment.” (Health Worker #77)

Unstable spousal relationships and male control over decision-making also have implications for male involvement in PMTCT, the topic of our next section.

Male Involvement

Except for some men in the FGDs, all respondents considered involvement in PMTCT to be an important way that husbands could support their wives in protecting their children from HIV transmission. Both urban and rural LTFU women commented that they would like their husbands to accompany them to clinic visits. PMTCT women discussed how male involvement at the time of HIV testing helped them accept their status and took the burden of HIV disclosure off them. Some examples:

“It was easier for me to accept my status because we encouraged one another than would have been the case if I was here [at the health center] alone. Overall my reaction was better because I had my husband by my side.” (PMTCT Woman #4)

“When you are here [at the health center] and get tested with your husband, if the test results are positive, the doctors inform you together. So it is easier for the husband to accept the test results than coming here alone, then going back home to inform you are HIV-positive. It is difficult for the husband to accept you. When you are together, the husband accepts the results and you encourage one another.” (PMTCT Woman #13)

Women in our sample also talked about the importance of husbands’ getting information about PMTCT directly from the health staff. An LTFU woman (#36) explained,

“Husbands should be accompanying their wives to antenatal. That’s where they can hear a lot of things that can encourage them to be involved in PMTCT program. But if you tell them about PMTCT at home, they will simply say that it’s women’s stuff.”

PMTCT women both in urban and rural areas had experiences in which their husbands did not believe the information that they relayed from the health facility or simply saw women providing them with information as being impertinent:

“But for the wife to explain to her husband, he [the husband] thinks it’s not useful... I explained to my husband everything that the doctor told me, but my husband was still denying and that was the reason he died.” (PMTCT Woman #24)

“When I am explaining to him, it’s like I am disobeying him, so most of the time I just stay quiet.” (PMTCT Woman #29)

Stakeholders and health workers both in urban and rural areas talked about the limited participation of men in the PMTCT program and the need to get them more involved. One stakeholder (#81) explained,

“It [PMTCT] is a good program, but the problem is we should also get the male to be involved. Most of the women are accepting...but now the problem is when they go back home. You know what we do, we test them now, and if they are positive we start treatment immediately, before even they have time to discuss with their families. So if the family is not accepting it, then it becomes difficult for this woman, who has made the decision to take treatment. But because the family is not accepting it, then she has to stop taking treatment.”

Lack of male participation in PMTCT visits also means that most men do not take the opportunity to get tested for HIV. In fact, many PMTCT and LTFU women complained that their husbands refused to get tested even after learning that their wives were HIV-positive. A PMTCT woman (#32) said,

“I told him about my [HIV test] results and I also asked him to go and be tested so that he too should know about his status. Even though he learnt about my status, he has not made any effort to go to the clinic and get tested despite all my efforts encouraging him to go and get tested.”

Some participants in FGDs said that men definitely accompany their wives to PMTCT visits, but this seemed to be more theoretical than actual behavior. PMTCT and LTFU women and some FGD members talked about requiring women to bring their husbands to the clinic with them in order to receive PMTCT services. However, given the issues that men brought up, this does not seem feasible. Some men in the FGDs said that men going to the clinic with their wives would be laughed at. Participant #8 in FGD #107 said,

“I think it is very difficult for most men in this community to come out in the open and be involved in issues to do with HIV/AIDS... A lot of them are still quite fearful of being laughed at and they want to maintain a good reputation. I may say that I have never seen a man and his wife going to the clinic together under this program.”

Men in other FGDs explained that men are shy about going to the clinic with their wives. For example, participants in FGD #127 stated:

Participant #7: “Men are usually shy to stay in front or with a lot of pregnant women on antenatal care/PMTCT days.”

Participant #1: “Men are usually afraid that everyone would know that ‘this one is the one responsible for this pregnancy.’”

These opinions indicate that although it is a social norm for men to go to PMTCT with their wives, it is also one that men do not want people to know they are responsible for a specific pregnancy or that they may have HIV. Further, men see the antenatal care/PMTCT clinic as a female space, in which they are uncomfortable.

Respondents from all the groups in this study talked about the need to sensitize men on PMTCT. Two examples:

“There is need for sensitization [of men] in the communities, as well as in various companies where people work, so that if they get the message from their workplace, they will feel that it’s important rather than hearing it from their wives. Because if they hear it from workplaces, they may take it seriously. If they also hear it from the communities through chiefs, it could help, because whatever the chief says is taken seriously.” (Stakeholder #85)

“There is need to involve the men in the PMTCT program. There is a need to sensitize them so that they take an active role in PMTCT. That way, women would be encouraged to take part. They would

be encouraging the women to be taking part in PMTCT program or even help their women in drug adherence, following the right child feeding practices, among many other things.” (Health Worker #65)

Other Factors

In this section, we have grouped factors related to PMTCT participation that were mentioned by respondents but were not major themes and were not necessarily gender-related. These are important issues, but they did not affect all women.

ART Side Effects

Many PMTCT and LTFU women described experiencing side effects of ART when they first started taking the drugs. For most women, the side effects stopped after a short period. For a few LTFU women,

the side effects continued or were so debilitating that they decided to discontinue use. However, most of these women also had other reasons for ending participation in the program. LTFU woman #55 provides one example:

I: “Please tell me your experiences with taking ART. How did the drugs make you feel?”

R: “I was feeling nausea, dizziness, and I was vomiting a lot.”

I: “Did you go to the clinic to tell them about this?”

R: “Yes, but the doctor I was seeing was away, and the doctors I found at that time said my medical file was missing, so after that I didn’t go again.”

FGD participants also mentioned side effects as a reason some women dropped out of the program, but health workers and stakeholders did not consider this to be a major issue.

Health Facility Issues

Several health facility issues were mentioned by PMTCT and LTFU women, including distance from the clinic, length of waiting time at the clinic, negative interactions with health workers, and the need for transfer documents when traveling or moving.

Only a few respondents mentioned distance from the clinic as a problem, but urban dwellers mentioned it more often than rural dwellers. For example, an LTFU woman (#51) said, “The hospital is far away. If it is possible for the government to consider having the medication at the health center that is close, it would be better.”

Some PMTCT and LTFU women complained about the amount of time they spent at the clinic when they went to collect ART, and most said they arrived at the clinic very early to get in the queue before the facility was even open. Two examples:

“The only thing we get worried with is time. They [the health workers] could have been treating us faster so we go back home faster as well.” (PMTCT Woman #7)

“It was taking a lot of time [at the clinic], because there were a lot of people. Maybe four to five hours before going back home... It’s only the issue of time. They take time to serve us, but otherwise everything is okay.” (LTFU Woman #50)

In general, most PMTCT and LTFU women were happy with the treatment they received from the health workers at the clinics. This statement from a PMTCT woman (#4) is typical: “They [the health workers] welcome us and treat us well.” However, a few respondents talked about health workers insulting clients. One PMTCT woman (#1) said, “Health workers should be helping them properly, not insulting them, and they should remind them when to go to the clinic.” A few LTFU women had dropped out because of a lack of respect from health workers. An LTFU woman (#52) explained, “I left XXX health center because it lacks discipline and I wanted some respect. The community workers always move around searching for us; in the end everyone around here will know I am HIV-positive.”

Several PMTCT and LTFU women talked about issues related to missed appointments and either not being welcomed back into the system or being refused a transfer to another clinic. An LTFU woman (#48) traveled to take care of a sick relative and asked for a transfer upon her return, but did not receive it. She said,

“When I went to Blantyre, it was difficult for me to continue taking the pills because I didn’t have any idea where to get them. After two months I came back, so I went to the hospital and I asked them to give me referral/transfer to start getting the drugs at [another] hospital, but they refused... Since then up to now I haven’t gone back to get the drugs.”

Another LTFU woman (#41) refused to take ART and found that the clinic would not provide her with cotrimoxazole preventive therapy for her child. She explained, “I was told that since I myself have rejected taking ART, then the clinic cannot continue helping me to protect the child from HIV. So I decided to leave things as they were.”

A third LTFU woman (#34) realized she had made a mistake when she dropped out of PMTCT and tried to return to care, but the clinic lacked the necessary materials to test her child for HIV on two subsequent visits. She explained,

“I myself realized that I did the wrong thing [when I dropped out of PMTCT]. I was found HIV-positive when I was pregnant with this child, and that’s when I got into the program. But after delivery, when I went to the under-five clinic at the health center for check-up, there was a plan that the child would be tested for HIV, and that was after six weeks. When I went there, they didn’t have testing materials and the health worker who was supposed to do the test did not come. When I went there the second time, it was the same story. So I just thought that maybe I am pushing this thing too much on them, so I decided to just continue with the usual under-five visits, but the child took Bactrim for just one month.”

Clearly, some women do not feel they have the agency to change how they are served at the clinic, and they are afraid to push too hard when services they need are not readily offered.

Faith Beliefs

A few LTFU women dropped out of PMTCT specifically because of faith beliefs. Either they had revelations or someone in a faith group told them to stop taking ART and they would be cured through prayer. An LTFU woman (#49) explained,

“I was feeling dizzy after taking them [ART pills]. I was feeling weak and sometimes I would be hallucinating. I would imagine animals attacking me. It was feeling bad generally. So once I started hallucinating, I would just pray; then they would stop. That’s the reason I stopped taking them [the drugs]. I joined a fellowship group, not just at the Seventh Day Adventists. I have been praying for some time now... That’s why I just put my trust in God, because I know that there is no problem that is bigger than God.”

Some of the men participating in FGDs and some of the health workers also talked about women who dropped out of PMTCT because of faith beliefs. For example, a participant in FGD #107 said, “Yes, a lot of women stop adhering to medication because of two reasons. Firstly, is because of faith beliefs. A lot of churches are misleading their church members. They tell their members to always pray and they will be healed.”

Too Busy to Participate in PMTCT

Three LTFU women said that the main reason they had stopped participating was that they were too busy with work and did not have time or were too tired to go to the clinic. For example:

“I am always busy with work, business, trying to find money to buy food for my household, so I don’t find time to participate in the PMTCT program.” (LTFU Woman #36)

“Sometimes I go to the field or garden so when I come back, I usually get tired, so that makes me not participate.” (LTFU Woman #58)

Some men in the FGDs also thought that women stop participating because they are too busy with household and other work, and rural respondents said that men should reduce women’s workload so that they have time for the PMTCT program.

Food Insecurity

Both PMTCT and LTFU women in urban and rural areas mentioned that poverty affects women's ability to consume the recommended food, and thus to adhere to PMTCT recommendations. Two LTFU women mentioned food insecurity in their households as the main reason or part of the reason they dropped out of the program. An LTFU woman (#40) said,

“You know, for one to focus on something, you need to eat well. There was a time when I couldn't go to the clinic, because we had no food in the house and I was very weak and could not walk to the clinic to collect my medication. Sometimes even when I had the medication, I couldn't take it without eating something, as it would make me feel very weak. As a result, I decided to stop taking the medication.”

The importance of food security to continued PMTCT participation was also underlined in a couple of FGDs. According to a participant in FGD #89,

“Mostly they [women] stop [participating in PMTCT] because they know they can be taking the drugs, but they do not have other support... For others, even when they are on drugs, they do not have enough food to eat, maybe just a 20-kwacha fritter. So they stop taking drugs because they do not have food.”

One way to address the problem of food insecurity was suggested by an LTFU woman (#64), who said, “The government should provide us loans so that we can start doing small businesses that can help us to sustain ourselves. So that we can be able to buy food and other basic necessities.”

In Malawi, it is considered a man's role to provide food and basic necessities for his family, but some men are not able to earn enough money, and women living on their own need a way to support themselves. Lack of food in the household affected women's PMTCT participation as well as their ability to follow the complementary feeding guidelines they received at the clinic. Many women said they could not afford to give their children the six Malawian food groups (grains and tubers, fruits, vegetables, beans and peas, fish/meat/dairy, and fats). A PMTCT woman (#16) explained, “The child has to be given six groups of food. So if there is a lack of money, the woman fails to adhere to infant feeding recommendations.”

DISCUSSION

Our findings reflect many of those factors previously reported as facilitators of and barriers to PMTCT, both prior to the implementation of Option B+ and in the few studies that have been conducted under Option B+. Like our study, other research documents the importance of having an HIV-negative baby as a major motivating factor for women to participate in the PMTCT program (Iroezi, et al., 2013; Murithi, et al., 2015; Webb & Cullel, 2013). Our findings are also consistent with other studies in terms of some of the barriers to PMTCT participation, including fear of HIV disclosure, lack of support from husbands, and fear of HIV stigma (Bwirire, et al., 2008; Chinkonde, et al., 2009; Clouse, et al., 2014; Duff, et al., 2010; Elwell, 2016; Hodgson, et al., 2014; Iroezi, et al., 2013; Kebaabetswe, 2007; Kim, et al., 2016; Webb & Cullel, 2013). Some issues that were highlighted in earlier research as major barriers to PMTCT participation, such as long waiting times at the clinic, negative treatment by health workers, costs of transport to the clinic, and side effects of ART (Bwirire, et al., 2008; Clouse, et al., 2014; Elwell, 2016; Gourlay, et al., 2014; Hodgson, et al., 2014; Iroezi, et al., 2013; Kebaabetswe, 2007; Kim, et al., 2016; Lubega, et al., 2013; Tweya, et al., 2014), were raised in our study but were not described as the main issues for most respondents. This study adds to the literature by including a thorough investigation of how gender and gender norms are related to the key facilitators of and barriers to PMTCT participation. We also present urban and rural differences when they were evident. Our findings support the notion that the lower status of women in society contributes to the multifactorial challenges at the individual,

interpersonal, health system, and community levels that they experience in relation to PMTCT participation.

Underlying women's participation in PMTCT are gender norms that provide respect and recognition to women who are married and have children. This "model of domestic virtue" persists and emphasizes women's household duties, contributions to family, and deference to men (Kyomuhendo & McIntosh, 2006). These norms permeate Malawian society to the extent that women perceive themselves as incomplete without a male partner, regardless of the nature of the relationship they are in; and having children gives them more status while cementing that relationship. PMTCT preserves women's motherhood role but threatens their relationships, because they have breached their role of caring for family members by afflicting them with the knowledge that they may be HIV-positive. Thus, in a context in which motherhood and marriage are important to women's status and women believe that they need to preserve their relationships, the PMTCT program is threatening, because it challenges the gender norms of being a good wife and mother. This leads to stress and fear surrounding disclosure of HIV status.

The way the PMTCT program is implemented combines with gender norms to magnify the negative impact on women. During the initial antenatal visit, women are tested for HIV unless they opt out, which very few women do. Under Option B+, they learn about their HIV status and are initiated on lifelong ART before they have had a chance to talk to their husbands/partners or other family members. Through the PMTCT program, women are often the first family members to be tested for HIV. This puts them in an awkward position, because gender norms dictate that women are deferential to their husbands and are "good" wives and mothers. When women are the first in the family to be tested for HIV and then disclose their status, they risk abandonment, loss of economic support, and "the social disgrace of a ruined family" (Njunga & Blystad, 2010). In some parts of Malawi, the PMTCT program is referred to as "the divorce program," owing to its frequently negative impact on social relations within the structure of prevailing gender norms.

The PMTCT program itself imposes differential treatment for men and women. It requires that women going through the process of motherhood, which is critical to their societal role and value, are tested for HIV, but it does not require that men going through the process of fatherhood are tested. Thus more women than men know their status and bear the burden of the decision to disclose it. That puts HIV-positive women in a position of guilt and shame even when they have not been promiscuous. Many of our respondents indicated that HIV is more stigmatizing for women than for men. The PMTCT program approach of "opt-out" for women but "opt-in" for men enables men to deny their status, thus furthering differential treatment by gender. Another way of putting this is that women have more to lose from an HIV diagnosis than men do. In this study, men were described as fearing loss of respect if they were known to be HIV-positive, but they were also able to go on with their lives after getting that diagnosis because of their decision-making power. Women had no such luxury and were at the mercy of male decisions following disclosure. This scenario indicates a particular problem for couples of discordant status, where the woman is HIV-positive and the man is HIV-negative.

Studies of HIV disclosure by pregnant and postpartum women report wide variations in the proportion of women who disclose (Tam, Amzel, & Phelps, 2015). Studies in Malawi and Uganda indicate that the majority of women in PMTCT disclose their status, most frequently to their husbands or partners rather than to other family members (Batte, Katahoire, Chimoyi, Ajambo, & Tibingana, et al., 2015; Bedell, van Lettow, & Landes, 2014). Women's decision to disclose is related to individual, partner, and household factors. Women find it easier to disclose when they have lower levels of internalized stigma, their partners have previously been tested, and they are financially independent (Tam, et al., 2015). A study in Uganda found that women did not disclose owing to their fear of abandonment and bringing HIV to the family (Rujumba, Neema, Byamugisha, Tylleskar, & Tumwine, et al., 2012). This aligns with our findings that many women have difficulty disclosing because they fear stigma or abandonment and are financially dependent on their husbands. These reasons for nondisclosure are linked to the power differentials and gender norms described above.

Although some respondents indicated that stigma is no longer a problem, the majority said that it is still a major problem, and that it takes different forms through gossip and avoidance. Stigma affects men and women differently, according to their prescribed gender roles. Women in our sample seemed to feel that they experience HIV stigma more strongly than men because of gender differences and their position in society. Men are protective of their reputations, do not want to lose face, and demand respect within their homes. For women, loss of economic support, home, and respect are at stake.

Studies of male partner involvement in PMTCT in Malawi and elsewhere in sub-Saharan Africa indicate that it improves women's participation in the program (Kalembo, Zgambo, Mulaga, Yukai, & Ahmed, 2013; Morfaw, Mbuagbaw, Thabane, Rodrigues, & Wunderlich et al., 2013; Osoti, John-Stewart, Kiarie, Richardson, & Kinuthia, et al., 2014). However, we found little evidence of male partner participation in our study, despite the PMTCT program's encouragement and prioritizing services for couples over those for individual women. Men in our sample acknowledged that the PMTCT clinic is a woman's space. They would feel strange there and would be concerned about their reputations if seen going there. In addition, the male gender role is to provide for the family, and work prevents men from having the time to accompany their wives to antenatal care. Similar barriers have been reported in a review of male involvement in PMTCT programs (Dunlap, et al., 2014). Thus we are left with a challenge: How can we implement PMTCT programs in a way that preserves relationships as well as motherhood? Although there has been a call for a family-centered approach (Hsieh, et al., 2014), and the PMTCT program is trying to respond to that call with preferential treatment for male attendees, clearly a deeper understanding of local gender norms and practical barriers to male involvement should inform program adjustments.

Our study has a few limitations in both content and implementation. We chose to include men in the community to learn about gender norms related to HIV in general and male perceptions of PMTCT, HIV disclosure, and male involvement. It would have been helpful to specifically target men whose wives are HIV-positive in order to understand their experiences with their wives' HIV disclosure and PMTCT participation or lack thereof. We focused on pregnant women and women with children younger than 24 months, so we cannot reach conclusions about long-term or lifelong use of ART. Future studies might take a longitudinal approach, by following women who continue with ART after their children "graduate," to determine what factors influence their participation. A longitudinal study could also follow women who drop out of the program to see if or when they return to care and what their reasons are for returning. In terms of study implementation, we found it challenging to enroll enough LTFU women, and that required adding one health facility to the study. We learned that many women who are LTFU are actually transfers, so there is a need for a better transfer system and for comprehensive tracking of PMTCT participants.

CONCLUSION

It is clear that the PMTCT program puts women at risk for negative consequences of an HIV-positive diagnosis by implementing an "opt-out" strategy while interacting with a primary identity factor: motherhood. This approach disproportionately burdens HIV-positive women with the task of either hiding or disclosing their HIV status. In addition, HIV-positive status interacts with other primary gender norms for women—being married and attending to one's family—because the disclosure of that status threatens a woman's relationships with her spouse and family. It calls into question her behavior and her ability to be a wife, a mother, and a caregiver.

Our research identified important considerations for the PMTCT program in Malawi. There is a clear need to review Option B+ in light of gender norms, to recognize the program's impact on men and women separately and as couples, and to restructure services to provide care that limits negative impacts on women. The Ministry of Health should use evidence-based strategies to strengthen or scale up facility and community efforts to address issues such as women's lack of self-efficacy/agency, lack of

social support, fear of stigma, fear of disclosure, lack of male involvement in PMTCT, and gender inequality. Some key areas for consideration:

- Strengthening peer-to-peer programs to improve self-efficacy and increase social support, especially among HIV-positive women who are lacking in these areas (Futterman, Shea, Besser, Stafford, & Desmond, et al., 2010)
- Scaling up evidence-based HIV-stigma-reduction programs in communities (Prinsloo & Greeff, 2016; Pulerwitz, Oanh, Akinwolemiwa, Ashburn, & Nyblade, 2015; Turan & Nyblade, 2013)

Reducing stigma will make it easier for women to disclose their HIV status and to feel comfortable going to the clinic to participate in Option B+.

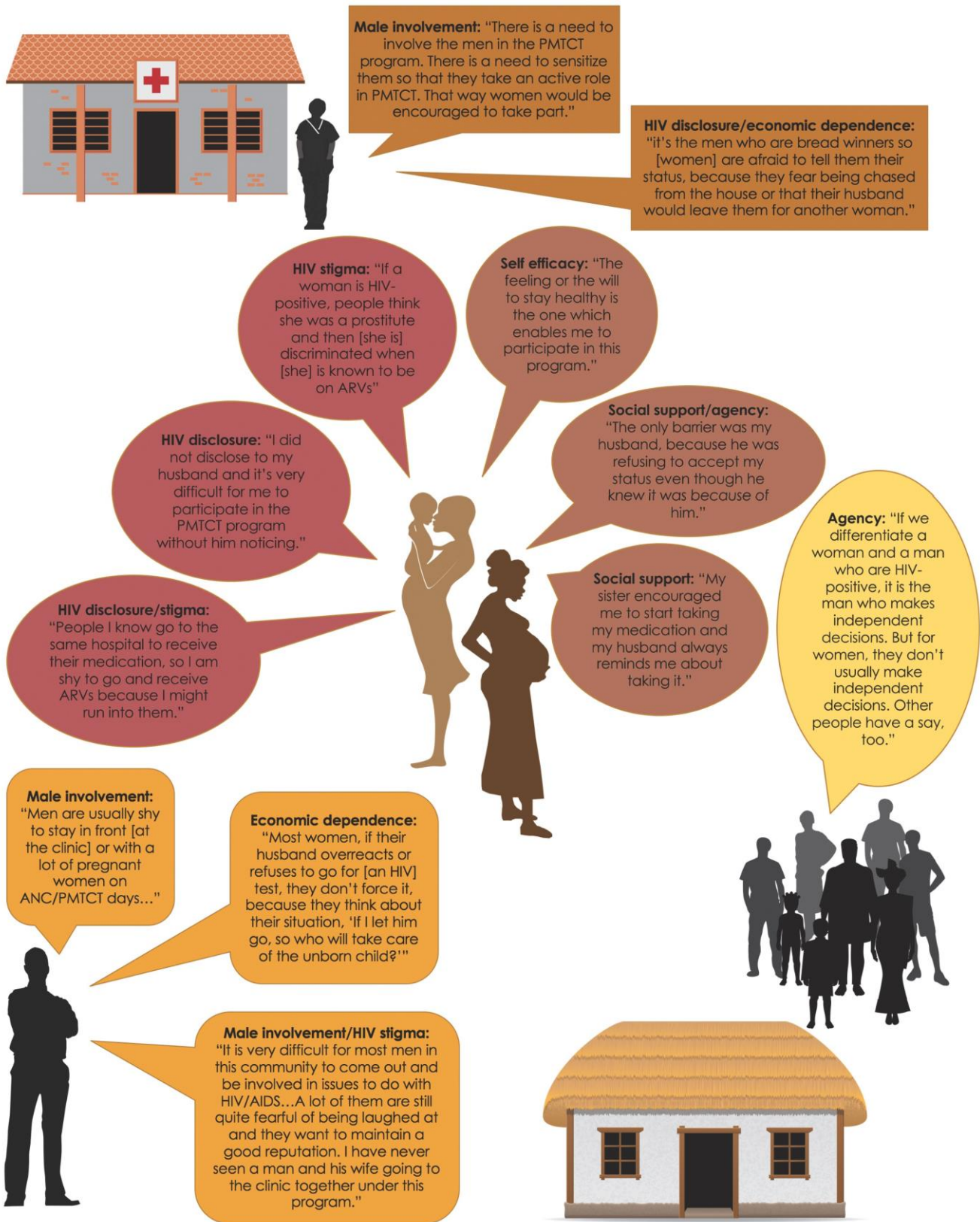
- Scaling up strategies to increase couples counseling and tracing and testing programs as ways of increasing male involvement in PMTCT (Osoti, et al., 2014; Rosenberg, Mtande, Saidi, Stanley, & Jere, et al., 2015)

Trying to involve men should not be limited to encouraging them to attend PMTCT clinic visits; it might also include community-based outreach, radio programs, and other interventions. Greater male involvement would facilitate disclosure and should improve men's support for women to regularly take ART and to follow the infant and young child feeding guidelines while participating in PMTCT.

- Developing programs that improve gender equality by increasing women's agency and access to credit or economic opportunities (The World Bank, 2016)

Such programs would help women take control over health-related decisions and make them less financially dependent on men.

For PMTCT programs to achieve universal and lifelong coverage, they need to become both gender-friendly (carried out in a way that considers negative impacts on women *and* men) and gender-inclusive (addressing the needs of men as well as women in the context of their roles in the family). In addition, future studies of PMTCT participation should be designed with knowledge of and consideration for local gender norms and should be analyzed in a disaggregated fashion to ensure that urban/rural differences are revealed.



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