Gender and Participation in Option B+ Programs to Prevent Mother-to-Child Transmission of HIV in Malawi and Uganda

Study Overview

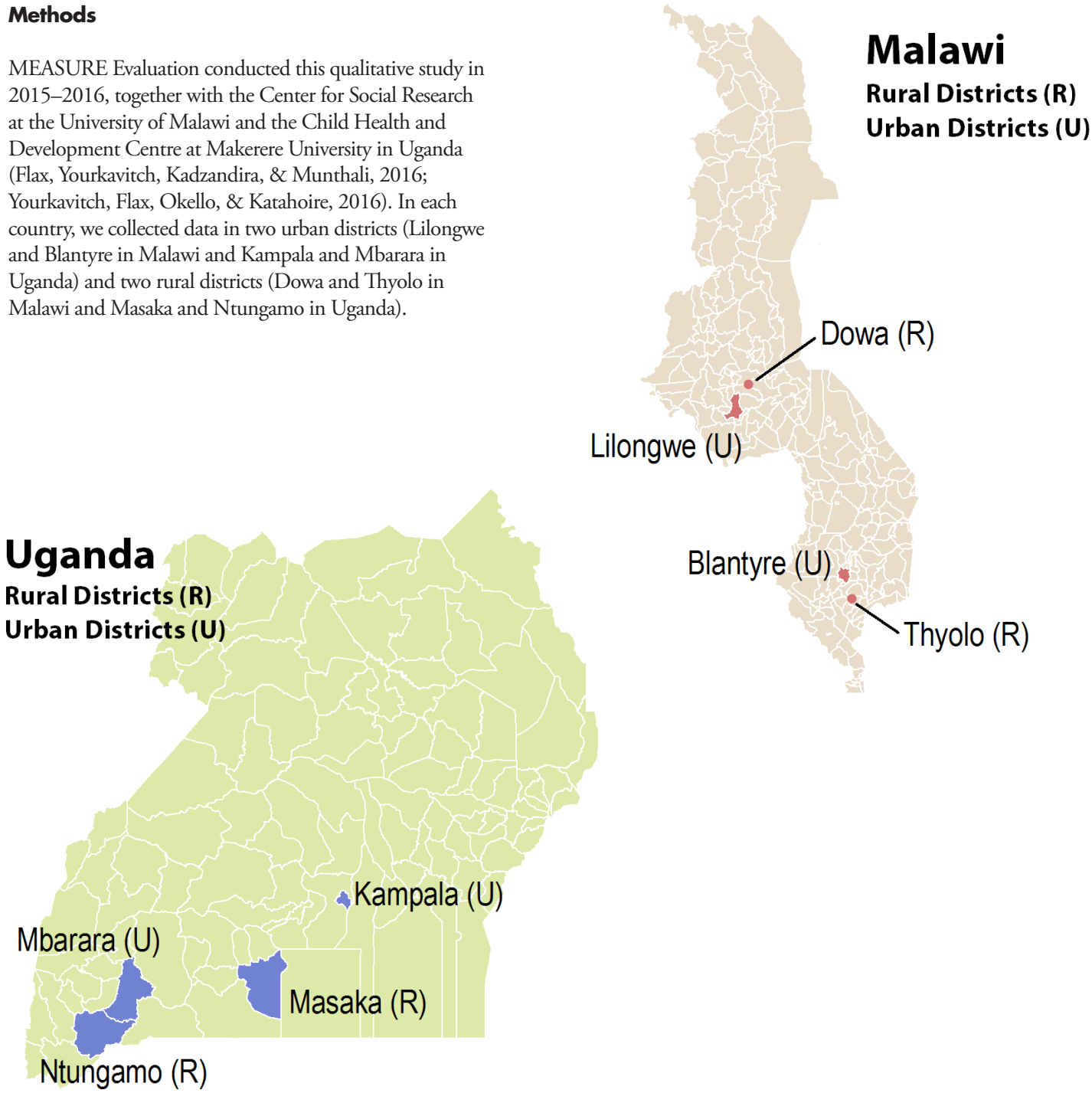
In Malawi and Uganda, women's roles center on marriage and motherhood, household duties, and caring for family members and the sick (Kyomuhendo & McIntosh, 2006; Chinkonde, Sundby, & Martinson, 2009). Women are supposed to consult their husbands and accept their decisions about household and health-related issues (Gipson, et al., 2010). Men's roles are to lead and represent the family and to earn income for household expenses (Gipson, et al., 2010; Otiso, 2006). Men frequently have more than one wife or girlfriend, which is considered a sign of masculinity, whereas women are expected to be monogamous (Fleming, DiClemente, & Barrington, 2016). These gender roles may constrain women's access to health services, including participation in programs to prevent (Malawi) or eliminate (Uganda) mother-to-child transmission of HIV (Njunga & Blystad, 2010). (For simplicity, we will use the term prevention of mother-to-child transmission [PMTCT] for the programs in both countries.)

Countries worldwide are working to achieve the goal of having 90 percent of people diagnosed with HIV on sustained antiretroviral therapy (ART) by 2020 (Joint United Nations Programme on HIV/AIDS, 2014). Maintaining 90 percent of HIV-positive women initiated on lifelong ART under the Option B+ PMTCT program has been challenging. Other studies have documented barriers to PMTCT (for example, Bwirire, et al., 2008; Duff, et al., 2010; Iroezi, et al., 2013; Webb & Cullel, 2013; Kim, et al., 2016), but few of these were conducted under Option B+, and they did not specifically consider how gender influences PMTCT program participation. This study fills the gap, by examining the interplay of gender and individual, interpersonal, health system, and community factors related to participation in PMTCT programs.

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

Methods

MEASURE Evaluation conducted this qualitative study in 2015–2016, together with the Center for Social Research at the University of Malawi and the Child Health and Development Centre at Makerere University in Uganda (Flax, Yourkavitch, Kadzandira, & Munthali, 2016; Yourkavitch, Flax, Okello, & Katahoire, 2016). In each country, we collected data in two urban districts (Lilongwe and Blantyre in Malawi and Kampala and Mbarara in Uganda) and two rural districts (Dowa and Thyolo in Malawi and Masaka and Ntungamo in Uganda).



Maps of Malawi and Uganda showing the rural and urban districts where data were collected for this study.

Source: MEASURE Evaluation

Table 1 describes the methods, types of participants, and issues explored in this study. We analyzed the data using qualitative content analysis methods and developed data matrices to facilitate cross-group analysis in this study (Miles & Huberman, 1994).

Table 1. Research methods

Method/type of participant	Number of participants	Types of issues explored
In-depth interviews		
Women participating in PMTCT	32 Malawi 32 Uganda	HIV disclosure experiences, HIV stigma and violence, distance to clinic, antiretroviral therapy (ART) side effects, women's workload, social support, community perceptions of HIV-positive women, male involvement in PMTCT
Women who were lost to follow-up (LTFU)	32 Malawi 16 Uganda	Same as women in PMTCT plus factors that led them to stop participating in the program
Health workers	16 Malawi 17 Uganda	Facilitators and barriers to PMTCT participation, experiences with male involvement in PMTCT
Stakeholders working in organizations supporting HIV services	6 Malawi 8 Uganda	
Focus group discussions (FGDs)		
Men in the community	8 groups Malawi 8 groups Uganda	HIV disclosure, stigma and violence related to HIV, gender roles within families, male involvement in PMTCT and ways to improve it, community perceptions of HIV

Findings

When examined in the context of traditional gender norms, our findings illustrate how PMTCT programs interact with social norms to encourage some women to participate, but more often to discourage women's continued participation. The most common facilitators of PMTCT participation that emerged from the data were knowledge of the health benefits of ART, social support, and self-efficacy (Table 2).

Table 2. Facilitators of PMTCT participation in Malawi and Uganda

Facilitators	Illustrative quotations
Women's knowledge of the health benefits for themselves and their children	• "The benefit is that your child grows stronger and healthier. You might have the infection, but your child will not get it from you."—Malawian PMTCT Woman #2 • "Women benefit more, because of the gender roles assigned to women. Because everything that happens [to the children] is the responsibility of women." —Malawian Lost-to-Follow-Up Woman #39 • "I have good health and I look after my children…This program is life…[by stopping participation] you are looking for death."— Ugandan PMTCT Woman #24
Social support	• "He [my husband] reminds me to take my medication and to go to the clinic on time."—Malawian PMTCT Woman #1 • "The health workers continue encouraging you to adhere to treatment and advise you on how to live positively, and they share with you some important information that you may not know…It gives me pleasure and comfort when I sit with my health workers and chat."—Ugandan PMTCT Woman #5
Self-efficacy: belief in one's ability to engage in a behavior	• "The feeling or the will to stay healthy is the one which enables me to participate in this program."—Malawian PMTCT Woman #2 • "I keep reminding myself to take the drugs, because I have nobody to remind me. I remind myself, because it is my life."—Ugandan PMTCT Woman #14

The main barriers to participation were fear of HIV disclosure, HIV stigma, lack of social support and male involvement, and lack of self-efficacy and agency (Table 3). The themes that emerged were largely congruent across participant groups and countries. We found more differences between urban and rural responses in Uganda than in Malawi.

Table 3. Barriers to PMTCT participation in Malawi and Uganda

Barriers	Illustrative quotations
Fear of HIV disclosure	• "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."—Malawian Health Worker #65 • "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."—Malawian Health Worker #71
HIV stigma	• "Of course, women are more stigmatized than men. Because we have this mentality that it is okay for [men] to do whatever they want, like they can have many women and it is okay. But if you are a…discordant woman, your husband is negative and you are positive, the whole village will think that you are a slut or something like that. And if it's the other way round, and it's the man who is HIV-positive and you are not, they will actually be telling you, please support your husband, take care of him, make sure this and that. But if you are a woman, most probably they will throw you out of the house. It affects women more than it would men."—Ugandan Stakeholder #84
Lack of social support and male involvement	• "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."—Malawian FGD #107 • "Most men think that when a man accompanies his wife to the clinic, it means that the man is being controlled by his wife."—Ugandan FGD #91
Lack of self-efficacy and agency	• "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."— Malawian Stakeholder #86 • "One of the gender issues is that men take the decisions in the homes, so they decide whether you go to the hospital or not. It is the men who control the finances, so if they don't give the money to go to the clinic, then how are you going? It is the men who determine where you get your treatment from."—Ugandan Stakeholder #88
Other barriers	• Women miss clinic appointments when traveling to take care of family members • Health facility issues: lack of privacy, negative interactions with health workers, fear of inadvertent HIV disclosure • Food insecurity: lack of food to eat when taking ART • Violence in the household • Fatalistic attitudes about HIV

Conclusion

Our findings show that gender norms in Malawi and Uganda have a strong influence on pregnant and breastfeeding women's experiences of HIV diagnosis, disclosure, and PMTCT participation. The way PMTCT programs are implemented—testing women during the first antenatal visit and starting treatment immediately—means that many women are the first in their families to be tested. This puts them in a difficult position, because an HIV diagnosis runs counter to gender norms, which dictate that women should be deferential to their husbands and "good" wives and mothers. Women risk abandonment, loss of economic support, and loss of social status when they disclose their HIV-positive status to their husbands.

Our findings indicate that many HIV-positive women feel they are more stigmatized then men. 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, because of their decision-making power. We found little evidence of male involvement in PMTCT, even though PMTCT clinics make services for couples a priority.

Based on our findings, we recommend that ministries of health use evidence-informed strategies to strengthen or scale up facility and community efforts to address issues such as women's fear of stigma and disclosure; lack of social support, male involvement, and self-efficacy; and gender inequality.

More information can be found in each country's report: https://www.measureevaluation.org/our-work/gender/gender-and-participation-in-option-b-programs-to-prevent-mother-to-child-transmission-of-hiv

A health worker in Uganda helps a pregnant woman fill out a birth plan.
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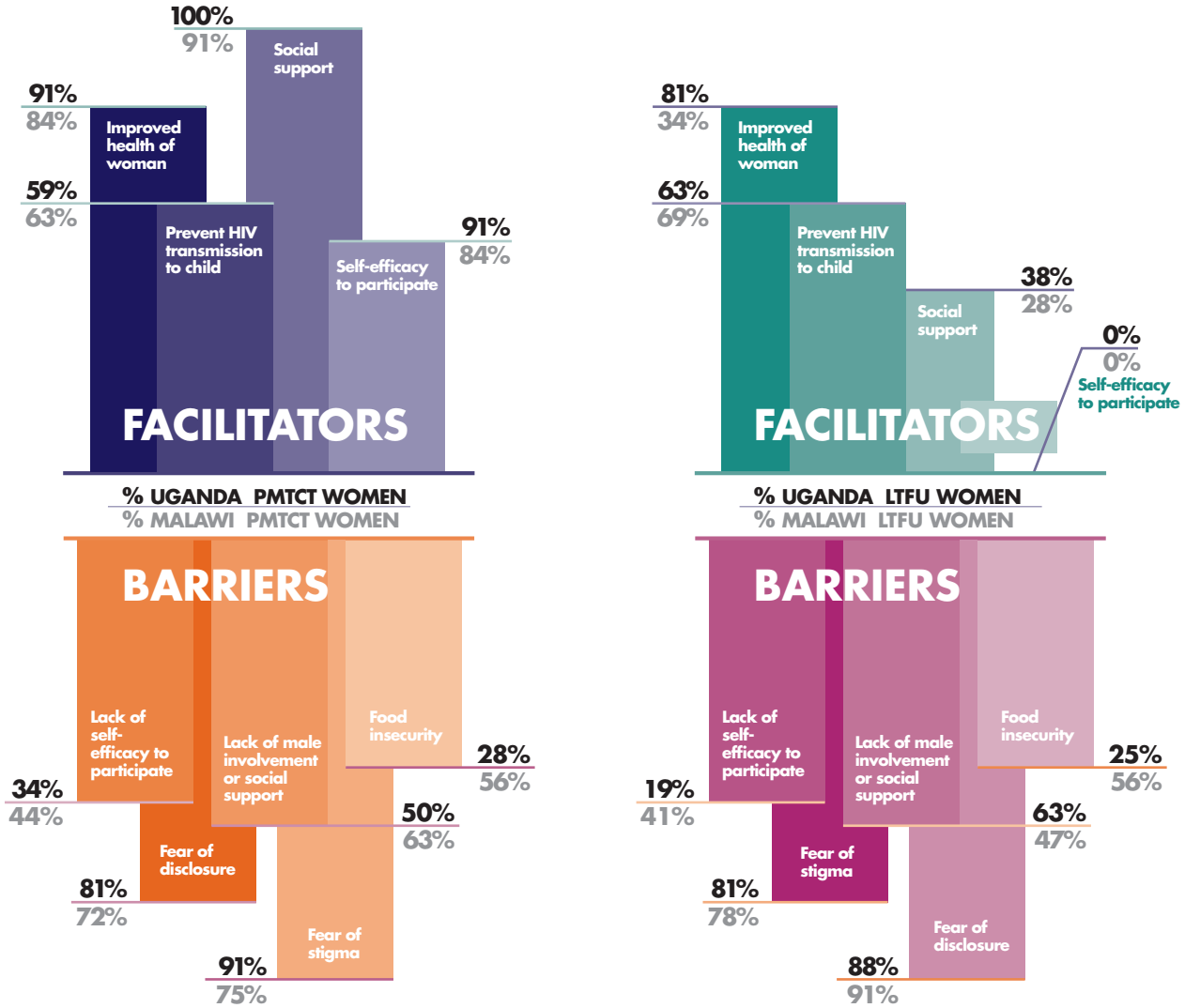
Facilitators of and barriers to participation in PMTCT in Malawi and Uganda



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