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Jennifer Yourkavitch, MPH, MEASURE Evaluation
Valerie L. Flax, PhD, MEASURE Evaluation
Elialilia S. Okello, PhD, Child Health and Development Centre, Makerere University
Anne Ruhweza Katahoire, PhD, Child Health and Development Centre, Makerere University

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MEASURE Evaluation
University of North Carolina at Chapel Hill
400 Meadowmont Village Circle, 3rd Floor
Chapel Hill, North Carolina 27517
Phone: +1 919-445-9350
measure@unc.edu
www.measureevaluation.org

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Cover photo: A health worker in Uganda helps a pregnant woman fill out a birth plan.
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FIGURE

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ABBREVIATIONS

ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral
EMTCT	elimination of mother-to-child transmission of HIV
FGD	focus group discussion
LTFU	lost to follow-up
PEPFAR	United States President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission of HIV
USAID	United States Agency for International Development

EXECUTIVE SUMMARY

"But then even the idea of going with your wife for antenatal, people might even think you were bewitched."

—Male participant in a focus group discussion for this study

In Uganda and other sub-Saharan African countries, women's gender roles center on marriage and motherhood. According to these roles, women's duties include caring for other members of the household, tending to household chores, and caring for the sick. Women are expected to consult with their husbands and obey their husbands' decisions in all matters. A man's primary role is to be the head of the family. Men are expected to bring in income to pay for shelter, food, and school, and they are expected to represent the family. Unlike women, who are expected to be faithful or monogamous, men are expected to have multiple partners (wives or girlfriends), thus signaling their masculinity. As other investigators have observed, these gender roles interfere with HIV prevention efforts. Gender roles may also constrain women's access to health services, including those for the prevention of mother-to-child transmission of HIV (PMTCT).

Globally, all countries are working toward achieving the goal of having 90 percent of people diagnosed with HIV on sustained antiretroviral therapy (ART) by 2020. PMTCT programs in sub-Saharan Africa have had difficulty pursuing this goal, owing to countries' weak health 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, side effects of ART, lack of funds for transport to the clinic, negative interactions with health workers, and lack of male involvement. Most studies of barriers to PMTCT were conducted prior to the implementation of Option B+, which places HIV-positive pregnant or breastfeeding women on lifelong ART at diagnosis. By examining how gender interacts with individual, interpersonal, health system, and community factors that cause people to discontinue PMTCT, this study fills an important gap in knowledge about Option B+ programs.

In partnership with the Child Health and Development Centre at Makerere University, MEASURE Evaluation—funded by the United States Agency for International Development (USAID) and the United States President's Emergency Fund for AIDS Relief (PEPFAR)—conducted qualitative research at eight health facilities (four urban and four rural) and their surrounding communities from 2015 to 2016. The purpose of this study was to describe gender-related factors at the individual, interpersonal, and programmatic or systemic levels that influence women's participation in the elimination of mother-to-child transmission of HIV (EMTCT) program in Uganda. We used in-depth interviews and focus group discussions (FGDs) to obtain data from women participating in EMTCT (n=32), women who were lost to follow-up (LTFU) (n=16), health workers involved in providing EMTCT services (n=8), stakeholders in organizations supporting EMTCT services (n=8), and men in the community (8 focus group discussions (FGDs), n=73 participants).

The interview guides for EMTCT women and LTFU women explored potential factors related to adherence, such as HIV disclosure, stigma and violence, distance to 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 EMTCT programs. We probed LTFU women about the factors that had led them to drop out of the program. Health workers and stakeholders told us their perceptions of the facilitators, barriers to EMTCT participation, and experiences with male involvement in EMTCT. Questions in the FGD guide explored HIV disclosure, stigma and violence related to HIV, gender roles within families, male support for and involvement in EMTCT participation, ways of improving male participation and involvement in EMTCT, and community perceptions about HIV.

Trained research assistants conducted in-depth interviews and FGDs in Runyankole and Luganda, which were digitally recorded. They transcribed the recordings verbatim, translated them into English, and uploaded them to Dedoose for analysis. Two University of North Carolina research assistants and the MEASURE Evaluation investigators developed codebooks for each type of participant. The initial codebooks included deductive codes based on the question guides. We independently coded one or two transcripts of 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 type of participant and which codes fit within those themes. The research assistants developed data matrices with the key themes in columns and participant identification numbers in rows, and inserted quotes or summaries in each cell to facilitate analysis and selection of quotes. We examined similarities and differences across types of participants and by rural or urban location.

When examined in the context of traditional gender norms in Uganda, our findings illustrate how the EMTCT program can unfairly burden women and interact with social norms to discourage women's continued participation. The major factors reported to negatively influence women's participation in EMTCT were similar across all types of study participants (i.e., women, men, health workers, and stakeholders). These factors are fear of HIV disclosure, HIV stigma, lack of support (material and practical), and poverty. Additionally, participants commented on the role of health workers and male involvement, and made suggestions for improving health services. There were some differences between the themes in rural versus urban settings. Participants in rural facilities emphasized fear of stigma, lack of transportation, discouragement by religious groups, illness, workload, not disclosing to husbands, peer influence, mistreatment by health workers, long wait times at health facilities, low self-esteem, and poverty. Participants in urban facilities emphasized barriers related to distance, fatalism (due to the lack of a cure), and low self-esteem, but did not say much about poverty. Several LTFU women identified their husbands' lack of financial support for transportation and food as reasons they had dropped out of the program. Others indicated that they wanted to keep their status secret from their husbands, or that the ART side effects were uncomfortable, or that they had traveled for family or school and had forgotten their medication or could not get the prescription refilled in the other location. Still others said that they felt healthy and did not want to take medication or that they had too much work to do.

Fear of disclosure—universally mentioned in our study as a major factor in ceasing EMTCT participation—is a pervasive part of women's experiences with EMTCT services and living with HIV, in general. Most men thought that women generally disclosed their HIV status to their husbands, but maybe not to their family members, although men acknowledged that a woman may be scared to tell her husband if she knows that he is HIV-negative or that she has not been faithful. Health workers believed that discordant status was a major problem for women but not men.

Although some respondents indicated that stigma is no longer a problem, the majority said that it remains a major problem, one expressed in different forms of exclusion: gossip, avoidance, and even violence. Stigma affects men and women differently, according to their prescribed gender roles. Men are protective of their reputations and demand respect within their homes; they are most troubled by loss of face. Women worry about loss of respect, too, but also about loss of economic support, their homes, and—in some cases—their children. Stigma affects a woman's desire and ability to disclose her HIV-positive status. In general, urban participants in EMTCT programs did not want neighbors or family members to know that they were HIV-positive; rural respondents emphasized hiding status more from neighbors than from family members. Fatalism contributed to stigma; men in urban areas confirmed that people will disregard what a person with HIV says, because she or he is considered already dead.

Health workers' positive attitudes can facilitate a woman's participation, and negative attitudes can hinder it. Long wait times and mothers' travel to care for sick relatives or to work also discouraged continuous participation. The EMTCT program itself imposes differential treatment: It requires women who are becoming mothers, which is critical to their social role and value, to be tested for HIV. It does not require men who are becoming fathers to be tested for HIV. Thus, more women than men know their HIV status and bear the burden of the decision to disclose their status. That burden is intensified by the potentially more severe consequences for women than for their husbands. This uneven burden puts HIV-positive women who know that they have not been promiscuous in the awkward position of experiencing guilt and shame nevertheless.

Nearly all respondents considered supportive male involvement in EMTCT to be an important way to protect children from HIV transmission. Some women commented that they would like their husbands to accompany them to the facility. However, some men were clear about not wanting to go to the clinic with their wives. These men were not comfortable being at antenatal care (ANC) or EMTCT facilities, which are female spaces, and they were concerned about damage to their reputations if they were to be seen at the clinic or, as a result, thought to be HIV-positive. Several types of participants thought that men should be sensitized to EMTCT through community-based outreach.

It is clear that the Option B+ policy, as it is currently implemented, puts women at risk for negative consequences from an HIV-positive diagnosis, because it involves an "opt-out" strategy through which women coming for ANC are routinely tested for HIV unless they "opt-out." This approach disproportionately burdens HIV-positive women with the task either of hiding their HIV status or disclosing it. HIV-positive status interacts with another primary gender norm for women—being married and attending to one's family—because disclosure of HIV status threatens a woman's relationships with her spouse and family. HIV-positive status calls a woman's behavior into question. In doing so, it also calls into question her ability to be a wife and mother and to care for her family.

Our research builds upon the growing body of evidence about the differential impacts of HIV on men and women. Based on our findings, we recommend that Uganda review the Option B+ policy and related HIV programs in light of gender norms; recognize the EMTCT program's impact on men and women separately and on couples; and restructure services to provide effective care that eliminates negative impacts on women.

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

INTRODUCTION

Background

Gender equality is an important development goal, given its relevance to health and human rights, and the United Nations has included it in the Sustainable Development Goals (Goal 5): "Achieve gender equality and empower all women and girls" [1]. Gender is key in understanding and addressing HIV and AIDS. In many African societies where patriarchy remains strong, gender roles continue to structure and legitimize women's subordination. Gender roles also foster models of masculinity that justify and reproduce men's dominance over women [2]. The resulting gender dynamic permeates all spheres of life, including how health services are accessed. Gender norms and their impacts must be examined in a specific local context, before gender inequalities in health programs may be addressed [3]. In Uganda, as in many other countries, women face challenges particular to their normative gender roles. Their role as caretakers of the family, their deference to men, and the gender inequality they experience at home and in the public sphere [4] constrain their participation in EMTCT programs.

In resource-limited settings, strong evidence indicates that use of ART and adherence to infant feeding guidelines are key methods for reducing vertical HIV transmission [5]. Implementation of the World Health Organization's latest PMTCT guidelines in sub-Saharan African countries is limited by weak health systems and a variety of maternal, interpersonal, and cultural factors. Incomplete uptake and poor adherence to the recommendations further constrain the full realization of health benefits for mothers and children. To streamline the process of getting HIV-positive women into EMTCT care, nearly all high-HIV-burden countries have adopted a strategy known as Option B+ [6], under which HIV-positive women who are pregnant or breastfeeding start triple ART when diagnosed and continue lifelong treatment, regardless of their CD4 count. Uganda began Option B+ in 2012 and has now scaled up the program nationally. The most recent HIV prevalence and ART coverage data for Uganda are from 2011, prior to Option B+ implementation [7]. At that time, HIV prevalence was 8.2 percent for women and 6.1 percent for men. There was an estimated 53 percent antiretroviral (ARV) coverage for Ugandan women. While 69.6 percent of pregnant women reported receiving HIV counseling during ANC, only 60 percent reported receiving pretest counseling, having an HIV test, and receiving their results. Women who are LTFU from the EMTCT 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 for HIV infection.

The current literature documents several constraints to women's participation in EMTCT programs across the socioecological framework, at the individual, interpersonal, health system, and community levels [8]. Specifically, constraints **at the individual level** include: fear of stigma, domestic violence, divorce, and abandonment associated with disclosure [9–16]; lack of PMTCT knowledge [17]; a perception that PMTCT is more for a child's health than the mother's health [14, 18]; unpleasant side effects [18, 19]; hesitancy to start lifelong daily medications, given their potential for side effects, prior to disease progression [9, 17]; and challenges associated with taking daily medication for the rest of one's life [18]. Participation in EMTCT programs can be motivated by the opportunity to have HIV-negative babies [13,16], but several studies have noted mothers' intentions to stop taking ART when the fear of vertical transmission has passed [9, 18, 21].

Interpersonal factors affecting EMTCT participation are mainly related to the lack of male partners' involvement in EMTCT and general community norms. Women reported the following interpersonal barriers: They worried they could lose their husbands' economic support if they were to disclose their HIV status [12, 15]. They might stop taking ART to avoid disclosure [22]. They feel unable to negotiate safe sex regardless of disclosure [12, 15]. And they cannot convince their husbands to get tested or disclose HIV status [9, 15, 16]. Focus group discussions conducted in Uganda and Malawi revealed an increased concern about partner conflicts and domestic violence due to lifelong ART provision for mothers only under the Option B+ policy [9]. Although pregnant women in Uganda and Malawi have been required or encouraged to attend ANC with their partners [9], and one study found that male partner involvement was associated with improved ART acceptance [23], other studies found that men feel uncomfortable in the maternal and child health clinic setting [24] and may not prioritize attendance at ANC services for lack of transport or to spend their time earning money [25]. In addition, poverty may interrupt treatment adherence and optimal infant feeding practices due to food insecurity [24] and it limits the ability to pay transport fees to access healthcare services [12, 13, 19]. Some married men believe that women who have their own source of income may feel more empowered to initiate ART, regardless of their husbands' views [25]. Women in Uganda and Malawi specified that income-generating activities could help them attain proper nutrition and pay for related care [9].

Programmatic/systemic factors affecting EMTCT participation include staff shortages at facilities, leading to low-quality counseling and long waiting times [14, 17]; poor staff-client interactions related to stigma, scolding, and lack of confidentiality [9, 12, 13, 15, 19]; and lack of privacy [11]. Higher rates of LTFU have been noted at urban, rather than rural, clinics [26, 27], but poor tracking systems [17] and mobile populations [27] may result in self transfers appearing lost [19]. Travel for work or to assist relatives can also disrupt drug adherence schedules [19]. High dropout rates were documented when ART was initiated during pregnancy rather than while breastfeeding—due to women's own health needs [19, 27]—and when ART was begun on the day of testing, rather than anytime thereafter [27]. One possible 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 [14, 15]. So, they may accept the drugs without using them, and they may fail to return for follow-up care [24]. Distance to health facilities has also been cited as a barrier [17], and it has yet to be determined whether decentralization of services alleviates this challenge [13]. Gender-related factors affecting the quality of healthcare staff interactions with women in EMTCT programs could also inhibit women's continued participation.

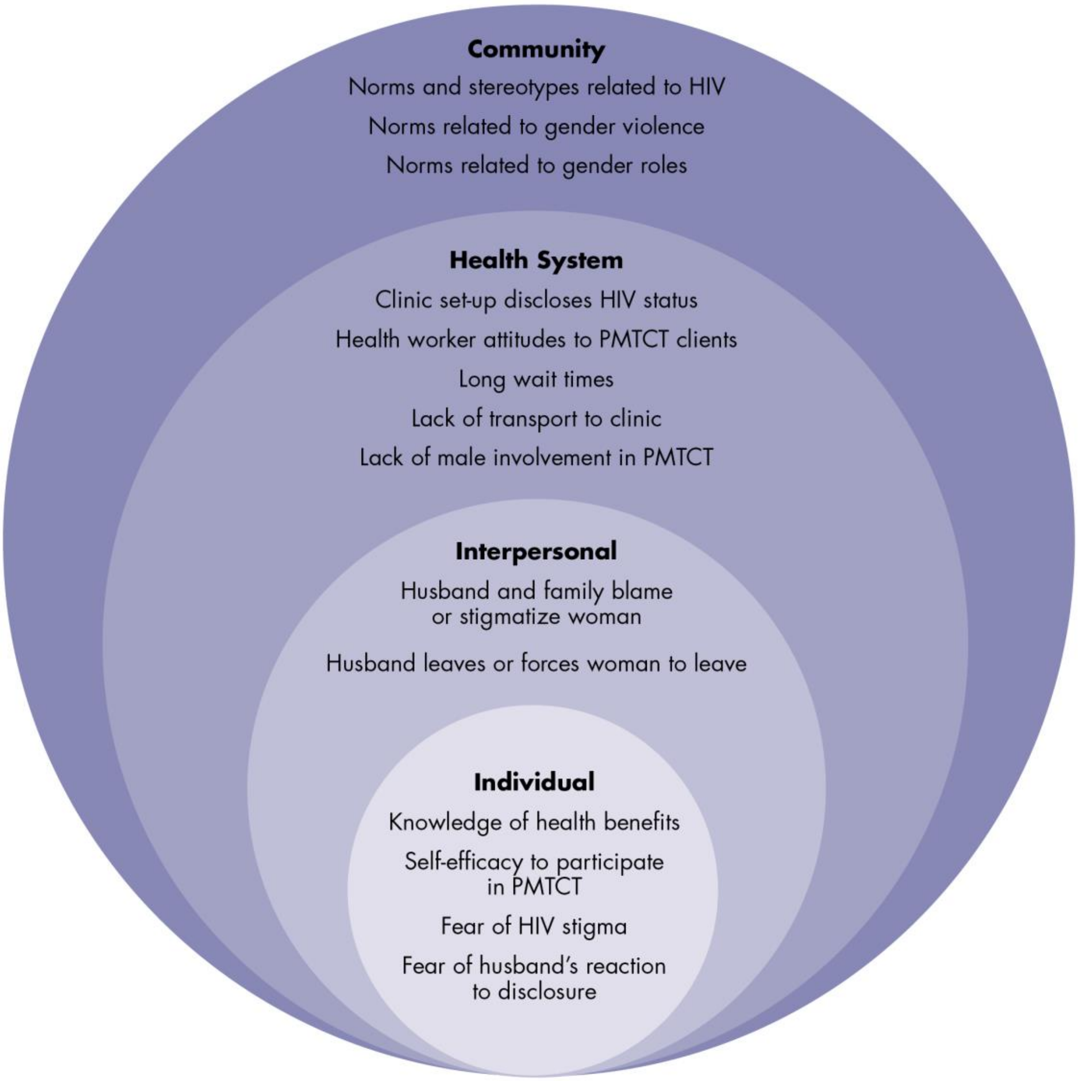
The literature on facilitators and barriers to Option B+ implementation and participation is growing. Women have concerns about disclosure, stigma, breastfeeding, distance to facilities, and side effects of treatment, as well as the belief that the Option B+ program is more for an infant's health than for a mother's health [9]. In addition, men's perspectives of Option B+ are largely absent from national and global discussions. **There are global concerns about Option B+, some of which are related to gender** [10]. There are gaps related to the understanding of how gender interacts with known individual, interpersonal, health system, and community factors that may facilitate nonadherence to, or dropping out of, EMTCT programs; and it is appropriate and timely to document gender-related factors influencing adherence and participation in EMTCT programs under Option B+. This research is one of the first qualitative assessments of gender factors related to EMTCT participation under Option B+ programs. These findings will inform program implementation and related support for women in EMTCT care. Topically and thematically, this qualitative study will focus on reasons for treatment default and program LTFU, with particular attention to gender and power dimensions. As more countries adopt Option B+ policies, data are needed to systematically characterize the gender-related factors that inhibit women's continued participation in EMTCT programs, so that appropriate services can be designed and delivered to effectively meet the needs of women and their families, thereby improving maternal and child health.

METHODS

Study Overview

The USAID- and PEPFAR-funded MEASURE Evaluation conducted this study, in partnership with the Child Health and Development Centre, at Makerere University, from 2015–2016. 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 Uganda's Option B+ EMTCT program. We used the socioecological model to guide our study design (see Figure 1) [8]. In developing the model, we considered both gender-related and non-gender-related factors that could influence PMTCT participation. We used in-depth interviews and FGDs to obtain data from women participating in EMTCT, women who were LTFU, health workers involved in providing EMTCT services, stakeholders in organizations supporting EMTCT services, and men in the community. The findings of this study could inform program implementation and related support for women in EMTCT programs under Option B+ policies.

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



Study Sites

We conducted this study in eight government health facilities that provide comprehensive EMTCT services and the surrounding communities in the Central 1 and Southwestern regions of Uganda. Four facilities were located in the urban areas of Kampala and Mbarara, and four rural facilities were located in the Masaka and Ntungamo districts. We selected the study districts and health facilities based on area HIV prevalence, location (urban or rural), and history of EMTCT service delivery.

Sample and Eligibility

We purposively selected our sample, which consisted of 32 women in the EMTCT program (four per clinic), 16 women who were LTFU from the EMTCT program, 17 health workers (roughly two per clinic), 8 stakeholders (two per district), and 73 men (divided among eight FGDs) in the communities surrounding the clinics. Table 1 shows the eligibility criteria for each type of participant. We chose our sample sizes in advance, to ensure that we had enough participants to attain saturation in the subgroups we might want to compare. Saturation is the point at which no new information or themes are observed in the data collected. Achieving saturation in qualitative research requires a minimum of six interviews [28]. We chose the different types of participants for this study in order to understand gender-related and other facilitators and barriers to Option B+ participation at the individual, interpersonal, and health-system levels.

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

Type of study participant	Number	Eligibility criteria	Data collection methods
Women participating in EMTCT	32	• ≥ 18 years of age • HIV-positive • Current PMTCT participant • Pregnant or has child < 24 months of age	In-depth interviews
Women who were LTFU	16	• ≥ 18 years of age • HIV-positive • Has not been to the clinic to collect ART for > 56 days • Pregnant or has child < 24 months of age	In-depth interviews
Health workers	17 (1 male)	• ≥ 18 years of age • Provides PMTCT services at one of the study clinics	In-depth interviews
Stakeholders	8 (5 male)	• ≥ 18 years of age • Works for an organization that supports or provides PMTCT services	In-depth interviews
Men	8 groups; 73 participants	• ≥ 20 years of age • Lives in the catchment area of one of the study clinics	FGDs

Data Collection

Nine trained Ugandan research assistants, who were divided into two teams, collected data simultaneously in the different districts. In order to take care of the language variations between the two regions, the teams included Runyankole and Luganda speakers. They used several strategies to recruit and enroll different types of participants. They approached **EMTCT participants** during clinic visits, assessed them for eligibility, and invited them to participate in the study. If EMTCT participants consented, they first participated in an observation, where the research assistant followed them through their entire EMTCT clinic visit and recorded the types and quality of the counseling and services they received on a structured observation form. At the end of the observation, the women participated in an in-depth interview.

Clinic staff helped to identify **LTFU** women using clinic records indicating that the woman had not returned to the clinic to collect ART for at least 60 days. 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 EMTCT participants and LTFU women explored potential individual factors related to adherence, such as HIV disclosure, stigma and violence, distance to 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 EMTCT programs. We also asked about their infant and child feeding practices to date. For LTFU women, we probed to discern the factors that had led them to stop participating in the program.

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

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

We field-tested data collection tools during interviewer training, and adjusted translations for clarity. We developed all consent and data collection forms in English and translated them into Luganda and Runyankole. Research assistants obtained signed or thumb-printed informed consent from all participants. The Institutional Review Board at the University of North Carolina, the Makerere University School of Medicine Research and Ethics Committee, and the Uganda National Council for Science and Technology provided ethical approval for this study.

Data Analysis

Research assistants digitally recorded in-depth interviews and FGDs, transcribed them verbatim, and then translated them into English. The MEASURE Evaluation team checked English transcripts for completeness and then uploaded them to Dedoose (v. 6.1.18) for analysis. Two UNC research assistants and the MEASURE Evaluation investigators worked together to develop the codebooks for each type of participant. The initial codebooks included deductive codes based on the question guides. We all coded one or two transcripts of each type of participant and compared our codes to help ensure consistency in code application. We also used this process to make revisions to and finalize the codebooks. Following this process, the research assistants coded the rest of the transcripts.

We then met to discuss key themes that emerged from each type of participant and which codes fit within the themes. The research assistants developed data matrices, with the key themes in columns and participant identification numbers in rows, and inserted quotes or summaries in each cell to facilitate analysis and selection of quotes [29].

We labeled quotes from respondents with their type and identification numbers in order to differentiate among the speakers.

RESULTS

Participant Characteristics

Table 2 shows the characteristics of EMTCT participants and women LTFU. We originally planned to conduct interviews with 32 women who were LTFU but did not attain this sample size due to the low numbers of dropouts in some clinics. Health workers interviewed for the study were mainly nurses and or midwives (n=15), along with one clinical officer and one peer mother. They had been working in EMTCT for an average of 5.6 years. Stakeholders worked for health facilities (n=2), nongovernmental organizations (n=3), Makerere University Joint AIDS Program (n=2), and the Infectious Disease Institute (n=1). They had worked in their organization on average for 3.8 years. Men participating in FGDs were 37.6 years of age, on average and had an average of 9.8 years of education; all but five were married. They reported working in the following occupations: farmer (n=17); business (n=9); other (n=50), such as guard, community health worker, mechanic, electrician, or teacher.

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

Characteristics	**Women in EMTCT** (n=32)	**Women who were LTFU** (n=16)
Woman's age (years)	26.8	26.9
Parity	2.3	2.9
Youngest child's age (months)	7.8	9.9
Marital status		
Married	25 (78%)	12 (75%)
Separated/Divorced	6 (19%)	2 (13%)
Widowed	1 (3%)	1 (6%)
Missing	0 (0%)	1 (6%)
Education (years)	7.4	6.8
Employment		
Housewife	7 (22%)	3 (19%)
Agricultural worker	8 (25%)	8 (50%)
Petty trader	2 (6%)	0
Salaried worker	7 (22%)	2 (13%)
Other	8 (25%)	3 (19%)
Household items (max 10)	5.5	4.3
Presence of household food insecurity	12 (38%)	10 (63%)
Frequency of food insecurity (n=22)		
At least one day per week	3 (25%)	2 (20%)
A few days per month	2 (17%)	3 (30%)
Irregularly	7 (58%)	5 (50%)

Characteristics	**Women in EMTCT** (n=32)	**Women who were LTFU** (n=16)
Husband/partner is HIV-positive		
Yes, on ART	12 (38%)	4 (25%)
Yes, not on ART	4 (13%)	3 (19%)
No	9 (28%)	4 (25%)
Don't know	7 (22%)	5 (31%)
Years on ART (average)	2.76	1.59

Factors Influencing EMTCT Participation

While we used the socioecological model as a framework to guide data collection, we found that many of the key themes cut across the levels of the socioecological model. Therefore, we have decided to present the results by theme. The factors that encourage and discourage EMTCT participation are described in detail, by theme, in this section.

What Encourages Women to Participate in the EMTCT Program

In general, support from health workers, family, and friends encouraged women to participate in the EMTCT program.

> "The benefits are that 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. Personally, I did not know that when you are HIV-positive, you are not supposed to have unprotected sex with your partner, that it affects my health and well-being. . . It gives me pleasure and comfort when I sit with my health workers and chat." (EMTCT Participant #5)

> "What encourages me is that whenever I come to collect drugs, they are always available. Another thing is that I used to think I was the only HIV-positive victim in the whole world, but when I came here, I found others; and they shared what they have gone through, and you feel encouraged without losing hope. At first I thought I was going to die, but now I am encouraged and used to the situation." (EMTCT Participant #16)

> "Sometimes when I don't have money, he [husband] gives me transport and lunch. . . If he didn't have money, I wouldn't be participating in this program. Because he has money, so I help myself and love myself." (EMTCT Participant #18)

Women were aware of the health benefits and were particularly encouraged by their infants' HIV-negative status. They wanted to stay healthy to take care of their children.

> "Also the fact that HIV-positive women can have HIV-negative babies encourages women to participate." (Health Worker #78).

Both urban and rural participants mentioned supporting themselves. Some participants' comments indicated high levels of self-efficacy:

> "The drugs have helped me gain energy; it is the drugs. I keep reminding myself and take the drugs, because I have nobody to remind me. I remind myself, because it is my life." (EMTCT Participant #14)

> "Even if they treat me badly, I can't fail to get medication." (EMTCT Participant #24)

There were some differences between respondents in urban and rural settings. Health workers in urban areas mentioned health benefits as facilitating factors: the child is HIV-free, and the mother looks, and is, healthy. Health workers in rural areas mentioned programmatic and contextual factors: clear guidelines for treatment under Option B+ and better peer support, counseling, and health worker attitudes. They also believed that patients experiencing less HIV-related stigma than they did previously, along with women having money for transportation and continued good health for mothers and children also facilitated participation in the EMTCT program.

What Discourages Participation in the EMTCT Program

Several factors emerged that discouraged women's participation in EMTCT. These factors cross levels of the socioecological model and interact with each other. LTFU women mentioned the following specific themes around discontinuing program participation: husbands' lack of financial support for transportation and food; wanting to keep their status secret from their husbands; experiencing unpleasant ART side effects; travelling for family or school and forgetting their medication or not being able to get it refilled in the other location; feeling healthy and not wanting to take medication; and having too much work to do.

The major factors that negatively influence women's participation in EMTCT were similar across the types of respondents (women, men, health workers, and stakeholders), and those are discussed below. There were some differences between rural and urban areas in the themes. Participants in rural facilities emphasized fear of stigma, lack of transportation, discouragement from religious groups, illness, workload, not disclosing to husbands, peer influence, mistreatment by health workers, long wait times at health facilities, low self-esteem, and poverty. Participants in urban facilities emphasized barriers related to distance and to fatalism (because of the lack of a cure). More urban than rural participants talked about low self-esteem. Urban participants did not say much about poverty. Here we should note that some rural residents travel to urban health facilities for EMTCT services; because women were interviewed at clinics, the responses of some women who reside in rural areas may be included in the "urban" category.

Fear of Disclosure

Fear of disclosure was a major factor mentioned by all respondents that contributes to interrupted EMTCT participation and to women's experiences with EMTCT services and living with HIV, in general. For example, one LTFU woman had not disclosed her results to anyone and feared that her marriage would end if her husband discovered that she was HIV-positive. He refused to go to clinic with her. She explained,

> "The fact that he doesn't know that I am HIV-positive is what stops me from participating in the EMTCT program." (LTFU Woman #49)

Some EMTCT participants also do not disclose to their husbands. It is difficult to discern if they could be at higher risk of LTFU than their counterparts who disclose their status to their husbands or if, perhaps, they have personal attributes (e.g., self-efficacy) that will enable them to maintain participation. This participant was concerned about maintaining her participation:

> "I don't know how I am going to tell my husband, because I am supposed to take the drugs every day, and he does not know. I am worried about that." (EMTCT Participant #16)

Some participants disclosed to their husbands even though they were fearful and were surprised that there was no problem. For example, one participant said,

> "[I didn't want to tell my husband…], because, when we would talk about it, he would say, 'I will kill you.' If I find that it is [HIV] that I will kill you. Around that time is when I got pregnant and came to be tested. When I tested, I decided to tell him the truth and if he is to kill me, let him kill me. When I told him, he said that there was no problem." (EMTCT Participant #31)

Most men thought that women disclosed their HIV status to their husbands but maybe not to their family members. Although they acknowledged that a woman may be scared to tell her husband if she knows that he is HIV-negative or that she has not been faithful. The following quotes from male FGD members explain why some women find it difficult to disclose and how a man might react to disclosure.

> "A woman finds it difficult to disclose to her husband because he can yell at her, talk to her rudely, [saying] that she is the one who gave him HIV." (FGD #89)

> "It would be easier for a woman to disclose to her husband when she is sure that she has never had sex with anyone else, and the only person responsible is her husband. In that case, she can easily disclose to you, but if that is not the case, she gets scared to tell you." (FGD #94)

> "Obviously, some caning [beating] happens, because [she] has to tell me who infected [her]. She has to tell me everything, and that is why we beat them." (FGD #94)

Men in rural areas believed that women disclosed to their husbands, but acknowledged that it can be difficult. They said that a woman would tell her mother first, but would not tell her mother-in-law. They also said that men fear to know their status; having HIV could indicate that a man was not faithful and he would have to explain that to his wife. Men in urban areas did not think that women disclosed to their parents or neighbors. They said that a woman would tell her husband, depending on their relationship; they also said that a woman *should* tell her husband.

Health workers from both urban and rural areas agreed that women feared disclosure to husbands, although some health workers said that women might disclose to husbands. Health workers in the rural area stated that women would disclose to mother and relatives. Those in the urban area indicated that women would disclose to female friends. One health worker (#68) stated that men also feared disclosure: "They also fear the woman would say he is the one who brought the disease."

Health workers believed that discordant status is a major problem for women, but not for men. A health worker (#73) stated, "If there is discordance and [the] woman is HIV-positive, then she is in trouble [from the husband], but if he is HIV-positive, then he may keep it a secret and continue his life." Health workers believed that discordance causes domestic violence and forces women to leave the home. Anticipation of a husband's reaction, together with the belief that he is HIV-negative, contributes to fear of disclosure. A health worker explained what she thought happened to women in discordant couples:

> "Because when you look at it, where the man is the one who is negative and the woman is positive, this woman is going to be isolated. She is going to be depressed. The man will come in and say you are the one who is infected. I can't have sex with you. He is going to bring in another woman, and he will start looking after the new woman; and she [the wife] is going to suffer all the consequences of stress, the depression and everything; then she will deteriorate into a bad state." (Health Worker #76)

Stigma

In general, urban participants did not want neighbors or family members to know that they were HIV-positive, but rural respondents emphasized hiding status more from neighbors than from family members. One factor affecting a woman's desire and ability to disclose her HIV-positive status is stigma. There is a strong undercurrent of fatalism attached to an HIV-diagnosis, which fuels stigma:

> "They [community members] minimize you, and you find yourself not fitting in their company. Once in a while, when we would be seated there, someone would say that so-and-so's family is dead [meaning, they have HIV]. . . So you have no peace in the community, and you have no rest; and you become the topic [of conversation]." (LTFU Woman #35)

Fatalism and stigma can also affect adherence:

> "[T]hey may tend to discourage me. For instance, if they say you will not be cured and you [think] that at one time I have to die, and. . . maybe I should default taking medication. And if it means I die, let me die, so that I can get rid of worrying. Because a community member may tell you that even if you take medication, you will still die. This can at times make you think of stopping to take medication." (EMTCT Participant #20)

In response to a question about differential stigmatization by gender, one man illustrated how stigma cut across gender lines:

> "I don't think it is about women only. It is about every person infected with HIV. When someone knows that you are infected with HIV, they do not respect you. They know that you are dying [at] any moment and whatever you are doing is useless. They look at you as a dead person." (FGD #93)

Men in urban areas confirmed that people will disregard what a person with HIV says, and also commented that a child with HIV will not be cared for as well as a child without HIV.

> ". . . [I]t is very sad to give birth to an HIV-infected child with no future. So they do not [care] for him properly, thinking that he would not live for long. Even when they provide school fees, they think the child might not study well, because of being sickly, like any other person infected with HIV." (FGD #93)

EMTCT participants both in urban and rural areas cited gossip as a form of stigma they experienced, although some participants in both areas claimed there was no stigma. The main difference between urban and rural areas was that more EMTCT participants in urban areas than in rural areas mentioned experiencing violence. All LTFU women commented on stigma, in contrast to only some of the EMTCT participants. Regarding gossip, one EMTCT participant said:

> "When you have just started, you find people talking about you a lot, but when you are used [to it], there is no problem. . . It also annoys us; we don't [want] everybody to know that we are sick. . . They can even call you a lousy person, and it annoys, so you hate yourself and don't want to be around people. . . because if you find people talking about you, you fear to be amidst them. You feel distant. . . They don't respect you, they say now like this one!. . . They fear you and avoid you and they isolate you." [Interviewer: How?] "Like having a neighbor, and you help each other. . . if she wants something, like a shoe, the way people lend each other, talk to each other; but you find the person doesn't want to associate with you, and you find her gossiping about you that you are sick." (EMTCT Participant #11)

Some participants get drugs from facilities outside of their community to avoid stigma:

> "You may want to go to a health facility. . . nearby to get ART, but fear that they would see you and know about your HIV status. So you go to a health facility, which is far, to seek medication where people would not recognize you. If you go to a nearby health facility, they would start saying this is your day, and you have gone to collect your drugs. Some time back, TASO [a local project] vehicles used to come and visit people in their homes. The whole village could know that there is an HIV victim in that home, but it has helped us now that we have to go to a health facility." (EMTCT Participant #15)

Study respondents generally believed that women face more stigma than men. This stakeholder's quote illustrates the gender differences, emphasizing a woman's enduring role and worth as a caregiver, regardless of the circumstances:

> "Of course, women are more stigmatized than men. Because we have this mentality that it is ok for [men] to do whatever they want, like they can have many women and it's ok. But if you are a woman and 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." (Stakeholder #84)

Women noticed the inequality:

> "They [community members] can't gossip about a man the way they gossip about the woman. They don't despise men with HIV the way they despise women with HIV. They fear men." (LTFU Woman #37)

Men acknowledged the gender difference, too:

> "I think the way they look at a man who is HIV-positive is very different from the way they look at a woman who is HIV-positive. In most cases, people think it's the woman who brings the disease; they point fingers at them more than they do to men." (FGD #96)

Men in rural areas said that stigma is still a problem and manifested in terms of avoidance and gossip, and people believed that the woman brought the disease into her family. Men in urban areas say that while being HIV-positive is more "normal" now, there is still fear. In-laws could force a woman to leave her home, if they knew that she was HIV-positive:

> "They will mistreat us; and I won't remain in the home, and yet my husband doesn't want me to leave and I go home." (LTFU Woman #44)

Health workers agree that most women will not disclose their HIV-positive status to their mothers-in-law, because they want to avoid rumormongering.

One stakeholder (#88) summarized the gender issues related to stigma:

> ". . . If a woman is [HIV] positive, the society thinks about them as being promiscuous. Yet with men, the Luganda saying is that *omusajja assajalata.* Men can have as many women as they want. So they do not blame them so much. They will always point to this woman that she was loose; she was reckless; she got HIV. The men are not blamed like the women are blamed."

One woman feared a loss of livelihood if she disclosed her status:

> "So if you are running a restaurant business [refers to it as a hotel] and some of your customers learn about that you are HIV-positive, they cease eating at your place. So there are several people you can't disclose your HIV status to." (EMTCT Participant #10)

EMTCT participants, more so than LTFU women, talked about low self-esteem, worsened by stigma:

> "And you find people busy talking about you, and you also find yourself having low self-esteem." (EMTCT Participant #6)

> "Somebody can hate oneself and decide to leave the medicine." (EMTCT Participant #19)

A stakeholder provided a broader context:

> "Yeah, they might feel that they are unworthy to keep on living; after all, they are positive. They might think, 'we're the cause of the problem,' even if they are not the ones. They may not come to pick the drugs, because they do not have money; it's the spouse to convey that money, and they are not providing the money; they are just abusing them." (Stakeholder #88)

Lack of Support

Support was primarily mentioned as coming from a husband or family. A husband's support could be monetary (money for transport to clinic and food for children) or practical (reminder to take medicine and use condoms). Lack of family support, particularly when a woman does not disclose to her husband, can negatively affect her:

> "It's my aunt who helps me out, but sometimes she doesn't like to do it, because she thinks that I can infect her with the HIV virus." (LTFU #47)

Conversely, family support can help women whose husbands have left them, e.g., brothers and grandmothers taking care of them. Some families are more supportive than others.

Poverty and Reliance on Husband for Financial Support and Decision Making

Many women rely on their husbands for financial support, including funds to pay for transportation for clinic visits to pick up ART and for food for the woman to eat before taking ART daily. Some women felt that transportation was not a major issue, especially since they received the drugs for free. According to EMTCT Participant #11, "If the medicine is for free, then really transport is not a big issue." However, other women could not get money for transportation from their husbands or were not able to raise the money themselves. One LTFU woman (#45) explained, "I would have continued taking my drugs, but I could no longer afford transport costs to the clinic."

In addition to relying on their husbands for funds for transportation, women are often constrained by the decisions about their own care-seeking made by their husbands. A stakeholder summarized this in terms of women's gender disadvantage:

> "One of the gender issues is it's the men who 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. There are also other gender issues related to culture. The women will always respect so much the in-laws. So there are some in-laws who might not want their children to be born from the health centers and they want them to be born from the local traditional birth attendants. So gender really affects a lot in the way that women do not control resources. That's another problem, so she can't have her own money to bring her in the EMTCT. The other issue is that sometimes the man might think that this woman, if she goes alone, would get other men and yet he is so busy or he does not feel like escorting her to the clinic." (Stakeholder #88)

According to health workers, women may not adhere to infant feeding guidelines because of poverty (they cannot afford the recommended foods) and stigma resulting from indirect disclosure of HIV status through not breastfeeding to two years. (WHO's recommendation at the time of the study was for HIV-positive women to breastfeed for one year, rather than the two-year recommendation for the general population). Poverty also contributed to women not having food to eat when they take their ART medication.

Health Workers: Service and Attitudes

Some women had good experiences interacting with health workers. For example, one EMTCT participant (#5) explained how she found the health workers to be helpful: "The benefits are that 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." However, other women described negative interactions or rude behavior by health workers, which made some of them stop participating in the EMTCT program. The following two quotes are examples of these negative experiences:

> "For sure, [health workers] are rude. . . They should change. They should stop barking at us." (EMTCT Participant #22)

> "At the hospital, if you [live] far [away] and you don't come for medication, then you come later and they treat you bad, although at times it is because they [the health workers] want good health for you. Giving you that medication becomes war. They send you back to the counselor so that they teach you afresh, because you missed a lot. You hate everything when they make you move here and there and yet you never wanted it to happen." (EMTCT Participant #13)

> "She would change the tone of [her] voice if one takes long to answer." (LTFU Woman #44)

Some health workers were aware of the criticism of their behavior; one acknowledged her role in affecting participation. She said, "I think there is a lot of change in health workers, as well. We are now approachable. We are a bit friendlier. We listen, which was not there before; we listen." (Health Worker #78)

Suggestions to Improve EMTCT Services

Overall, rural EMTCT participants suggested changes related to the place of service: providing lunch, transportation, and a secure place to store belongings. They also suggested bringing services to women. Urban participants requested changes related to medication: a smaller tablet size, providing more tablets at a time, and changing the protocol, so that medication could be taken when a woman has time rather than at a certain time each day. There were also suggestions to ensure privacy at the clinic and improve health worker treatment of patients. Participants from both areas mentioned decreasing wait times.

Specific comments included recommendations to reduce stigma in families and communities:

> "I think. . . family counseling [should be] done, because they [family members] are fond of verbally discriminating and minimizing fellow family members who are HIV-positive." (EMTCT Participant #4)

One participant suggested reducing the size of tablets and commented that it is difficult to take medication at the same time each day. Another suggested that the health system provide transportation for those who come from far away and a secure place to store belongings while receiving services. Regarding transportation, one woman acknowledged the challenge and felt personal responsibility for it:

> "What can be done in my thinking is transport. . . That one is on my side, because there is no way they can solve it." (EMTCT Participant #1)

Many women complained about the time they spent waiting for services:

> "The health workers don't attend to us in time, and this causes women to get fed up with this program." (LTFU Woman #46)

There was a suggestion to employ more health workers, so that wait times are not so long. Some women suggested providing food and water, given the long wait times:

> "The way [the program] has been operating, you come with your baby and spend here the whole day without having lunch. You spend the whole day with the child crying. Along the way you feel dizzy and fall down. You have come without eating anything, because you want to reach here on time." (Participant #8)

Having too few health workers for the patient load contributes to long wait times. One stakeholder commented on the inadequate number of health workers available to implement Option B+ and other infrastructure challenges:

> "The moment you bring Option B+ plus you want all mothers to be tested and then you enroll them immediately. It means at least you must have enough space. You need a pharmacy, a counseling room, and a consultation room for the clients so that they are attended to in one building, but the infrastructure hasn't yet changed. Secondly, it needed human resources, but human resources in some settings haven't yet changed. Ever since they rolled out the Option B+ program, mothers who are being initiated on treatment are many, but the number of health workers is constant." (Stakeholder #83)

Some recommended adding related services, including family planning services. ARVs are free but treatment for opportunistic infections is not, and women cannot always find that treatment at the clinic:

> "I usually want medicine for syphilis and they don't give it to me. They tell me that it is finished [and] I should go and buy it." (EMTCT Participant #17)

Another issue complicating women's participation is the amount of medicine (ARVs) dispensed, coupled with the fact that women travel to visit and care for family members:

> "They should give us medication that exceeds at least one week from the time you are supposed to come back for more, because sometimes you may go somewhere and become too sick and fail to make it and that causes a problem. And yet where you are, they don't know that you are sick. So they should give us a lot of medication." (EMTCT Participant #13)

Male Involvement

Although clinics have policies to allow women who come to the health facility with their husbands to go to the front of the queue, few men reportedly came to EMTCT services with their wives, regardless of urban or rural residence. According to one LTFU woman (#48):

> "[Men] are not involved; they don't want it. . . they don't want to be tested. He says, 'Leave me alone. I will eat my food. When it makes me ill, I will die.'"

This woman recommended male sensitization and door-to-door HIV testing. EMTCT participants in rural areas noted that men could provide material and emotional support, and use condoms. More urban participants than rural participants stated flatly that men don't participate, and that there is nothing men could do: "There is nothing much they do, maybe just encouraging you." (EMTCT Participant #3)

Some men viewed the clinic as women's space and don't see the benefit of going there, as noted in these quotes:

> "Most men think that when a man accompanies his wife to the clinic, it means that the man is being controlled by his wife. I have children, but I only accompanied my wife once to the clinic in my entire life, because I viewed it as wastage of time when I reached there." (FGD #91)

> "But then even the idea of going with your wife for antenatal, people might even think you were bewitched." (FGD #94)

Urban men commented specifically that the antenatal clinic is a space for women. They also said that pride may keep men away. For example, if a woman does not have nice clothing, then that indicates that a man is not providing well for his wife.

Transportation and money for transportation are also barriers keeping men from accompanying their wives, because, if a man accompanies his wife, he needs to provide transportation for two people rather than one. Both health workers and men suggested community outreach to sensitize men. Men also suggested incentives (e.g., a T-shirt or gift) and money to encourage them to attend. Some men could not accompany their wives to the health center because they were working.

DISCUSSION

Our findings reflect many of those previously reported, including (fear of) disclosure, spousal involvement in EMTCT, HIV stigma, access to services, and health worker attitudes [30]. However, we added a thorough investigation of gender-specific factors influencing both women's and men's participation in EMTCT, and we also presented urban and rural differences among study respondents. Our findings support the notion that the lower status of women in society (compared to men) contributes to the multifactorial challenges they experience in relation to EMTCT participation, across the levels of the socioecological framework.

Underlying women's participation in EMTCT are gender norms that ascribe respect and recognition to women who are married and who have children. This "model of domestic virtue" has persisted through the past century and emphasizes women's household duties, contributions to family, and deference to men [4]. These norms permeate Ugandan society, to the extent that women perceive themselves as incomplete without a male partner, regardless of the nature of the relationship; having children gives them more status while cementing their relationships. EMTCT preserves the motherhood role, but because participants in this program are seen as burdening their family with the knowledge that someone in the family is HIV-positive, they have breached their main role of attending to the family. This affects relationships within which women live and work. Thus, in a context in which motherhood and being in a relationship are important to women's status, and women believe that it is important to stay in their relationships, the EMTCT program threatens a woman's status by challenging the gender norms of being a good wife and mother. This leads to stress and fear surrounding disclosure of HIV status. This program could also create stress for women and men who come to the facility together. A woman could come to a health center with her husband expecting simply to confirm her pregnancy, only to find out that she is HIV-positive and her husband is not. She could then leave with medicine for HIV and, possibly, a broken relationship, if her husband does not accept her status. Personal accounts indicate that EMTCT programs implemented without consideration for gender norms have unintended negative consequences for women. A local moniker for the PMTCT program in Malawi, as well as in other countries, is "the divorce program" [31].

Male gender norms, too, can be detrimental to women's and men's health. Men are expected to have multiple sex partners as a sign of their masculinity. When a man learns that his wife is HIV-positive, his masculinity is threatened. That masculine norm contributes to a woman's disclosure dilemma and can exacerbate a husband's reaction.

Another example of the difficulties that the program creates for women comes from the initial ANC visit: A woman goes to ANC because she thinks that she is pregnant. During that initial visit, her pregnancy is confirmed, and then she receives HIV test results. Although it is difficult for her to process what she is experiencing, she is advised to begin lifelong medication immediately. At the same time, gender norms dictate that she has little autonomy and decision-making power; she is supposed to be deferential to her husband. That is the first barrier she encounters to initiating ART; she may simply need more time to think [20] or to consult with her husband, although that disclosure may upend her life. This situation is worsened by the brusque behavior of overextended health workers who have to attend to large numbers of mothers waiting for ANC.

Although some respondents indicated that stigma is no longer a problem, the majority said that it is still a major problem, taking different forms of exclusion through gossip, avoidance, and even violence. Stigma affects men and women differently, according to their prescribed gender roles. Men are protective about their reputation and demand respect within their homes. For women, economic support, home, and the respect of their community, and (in some cases) their children are all at stake. In addition to those potential consequences, stigma is hurtful.

The EMTCT program itself also imposes differential treatment: it requires women going through the process of motherhood, which is critical to their societal role and value, to be tested for HIV, but it does not require men going through the process of fatherhood to be tested for HIV. Thus, more women than men know their status, and bear the burden of the decision to disclose their status. That creates guilt and shame for HIV-positive women—even those who know that they have not been promiscuous. Several of our respondents indicated that HIV stigmatizes women more than men; the EMTCT program approach of "opt-out" for women but "opt-in" for men enables men to deny their status, with negative consequences for women and men alike. From another perspective, women are not necessarily more stigmatized, but they have more to lose from an HIV diagnosis than men do. As we mentioned, men who are HIV-positive fear losing others' respect and having to take on their wives' responsibilities (child care, for example) if their wives are also HIV-positive. At the same time, men who learn that they are HIV-positive were described as being able to go on with their lives, because they hold decision-making power and can rely on their wives to care for them. HIV-positive women, in contrast, were described as having to submit to their husbands' decisions following disclosure. Women could potentially lose their status in society, their economic support, and even, in some cases, their children. This scenario indicates the depth of the problem for a woman who is HIV-positive, particularly when her husband is not, or is not willing to be tested.

A systematic review of disclosure among pregnant and postpartum women found that disclosure was related to individual, partner, and household factors [32]. One study in eastern Uganda found that most HIV-positive women did not disclose their status for fear of abandonment, violence, and being perceived as bringing HIV to the family [33]. We didn't specifically study the proportions of disclosure among EMTCT participants and LTFU women, but we found similar reasons for nondisclosure between both groups. Although a study in South Africa found similar experiences of stigma and disclosure among people in urban and rural areas [34], we found some differences as well as some overlap. For example, respondents in both areas talked about gossip as a form of stigma; and rural participants spoke more about avoidance, while urban participants spoke more about violence. We did not explore depression as a contributing factor to women's dropping out of the EMTCT program, although some women mentioned having low self-esteem. Because being HIV-positive and being in the perinatal period are both risk factors for depression, this is an important area for future research. Few studies to date have examined it [35].

We also found urban and rural differences in responses from health workers regarding facilitative factors for EMTCT program participation. Health workers in urban areas mentioned health benefits, while those in rural areas emphasized programmatic and contextual factors. The factors mentioned by rural health workers could indicate the effort to make EMTCT accessible to all, in contrast to other programs that may disproportionately advantage urban residents. In addition, barriers cited by rural respondents were more closely related to poverty than those cited by urban respondents, who instead described fatalism, low self-esteem, and excessive distance to services. (Long distances to services, however, may have been reported by rural residents traveling to urban areas for care.) The last main difference between urban and rural respondents can be seen in the different types of suggestions they made to improve the program: rural respondents made more suggestions about the location of services than urban respondents, who focused on changes in medication, such as the size of the pills.

Greater mobility was one of the reasons given for women defaulting from the program in urban areas. The mothers reportedly traveled elsewhere to do business and did not always return in time to pick up their medication. Others changed residence without notifying the health units or requesting referrals. The women in the rural areas reported less mobility.

One study found that male partner involvement was associated with completion of the PMTCT program in Malawi [36]. We found little evidence of male partner participation, despite EMTCT program encouragement and prioritizing services for couples rather than single women, a practice that may actually further stigmatize single women. Men acknowledged that antenatal clinics are women's spaces. 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 one's family, and work prevents men from having the time to accompany their wives to ANC. Therefore, a challenge remains to find a way to implement an EMTCT program in a way that preserves motherhood as well as relationships. Although there have been calls for a family-centered approach [23] and the EMTCT 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.

There are a few limitations to our study in both its content and implementation. EMTCT is a relatively new program, and we interviewed only those with young children, so we do not have information about long-term adherence. Even though most women interviewed were not pregnant for the first time, we cannot tell if they stopped participating between pregnancies. The average time on ART was low (<3 years) for both participants and LTFU women, although Option B+ had been in effect for less than five years at the time of this study. In addition, we could not find the number of LTFU women that we had hoped to enroll. The long-term effect of Option B+ in Uganda and the implications of long-term participation for women are unclear and need further investigation.

CONCLUSION

It is clear that an HIV diagnosis affects men and women differently and that the EMTCT program puts women at higher risk of negative consequences of HIV-positive status than men. This disparity is largely due to the fact that EMTCT programs use an "opt-out" strategy while interacting with the primary identity factor of motherhood. This approach disproportionately burdens HIV-positive women, forcing them either to disclose or hide their status. HIV-positive status also interacts with the primary gender norm for women that involves being married and attending to one's family. Disclosure of that status threatens a woman's relationships with her spouse and family, by calling into question her behavior and her identity as a good wife and mother. It is clear that depending on men for financial support and decision making can hinder women's participation in the EMTCT program.

Our research brought to light several important considerations for the EMTCT program in Uganda. There is a clear need do the following: review the program in light of gender norms, recognize its impact on men and women separately and as couples, and restructure services to provide effective care that limits negative impacts on women. Urban and rural respondents have different perceptions of and needs for services. Health authorities should adopt some contextual flexibility, in order to provide equitable services. For example, constraints related to poverty may be of greater consideration for rural areas. Our research builds upon the growing body of evidence about the differential impacts of HIV on men and women. In order for EMTCT programs to achieve universal and lifelong coverage, they will need to become both gender-friendly (carried out in a way that considers negative impacts on men and women) and gender-inclusive (addressing needs of men in the context of their role in the family, as well as women). In addition, future studies of EMTCT participation should be designed with knowledge of and consideration for the local gender norms, and they should be analyzed in a disaggregated fashion, to ensure that the differences between urban and rural areas are revealed.


"We just talk. We want men to be involved, but then there is nothing we give them..."
"Even if they treat me badly, I can't fail to get my medicine."
"The fact that [my husband] doesn't know that I am HIV positive is what stops me from participating in the EMTCT program."
"When someone cares, you don't feel stigmatized."
"If...your husband is negative and you are positive, the whole village will think that you are a slut...And if...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..."
"I think if your home is peaceful, and you don't mistreat your wife, she finds it easy to tell you immediately."
"...when a man accompanies his wife to the clinic it means that the man is being controlled by his wife...I only accompanied my wife once...because I viewed it as wastage of time when I reached there."

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MEASURE Evaluation
University of North Carolina at Chapel Hill
400 Meadowmont Village Circle, 3rd Floor
Chapel Hill, North Carolina 27517
Phone: +1 919-445-9350
measure@unc.edu
www.measureevaluation.org

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