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ORIGINAL ARTICLE

REDUCING PMTCT ATTRITION: PERSPECTIVES OF HIV+ WOMEN ON THE PREVENTION OF MOTHER-TO-CHILD HIV SERVICES IN ADDIS ABABA, ETHIOPIA

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ABSTRACT

Background: Only 41% of eligible Ethiopian women completed (PMTCT) therapy in 2012, with MTCT rate of 20%.

Objective: This study elicited the perspectives of HIV positive mothers on the situation and the unique beliefs, attitudes, cultural norms and individuals who have influence over them during their pregnancy.

Methods: The mixed-methods parent study included community level surveys, focus groups and in-depth individual interviews of HIV positive women with a child at least one year of age in Addis Ababa, Ethiopia: only focus group and interview data are presented here. All tools were completed in Amharic with English translation.

Results: 23 women completed in-depth interviews; 27 participated within 4 focus groups. The greatest barriers to PMTCT completion were: feelings of hopelessness and carelessness, lack of understanding of the efficacy of ARV, and negative religious influences. The advice to improve PMTCT adherence most frequently offered included increasing PLWHIV peer support and improving and extending current HIV educational efforts. Participants recommended that PLWHIV mothers be utilized in all PMTCT planning and interventions in the future.

Conclusion: Maintaining the motivation to adhere to the entire PMTCT cascade requires that a PLWHIV mother understands the validity of the steps she is taking and receives support for the many challenges she faces. Engaging PLWHIV peers as active members of the health care workforce and expanding their use as educators and counselors is important. Health officials can consider these findings to develop innovative and effective PMTCT interventions.

Keywords: Sub-Saharan Africa, PMTCT, women's perspective

INTRODUCTION

Although HIV infections among children globally have declined by 52% in the last decade (Joint United Nations Programme on HIV/AIDS, 330,000 children were newly infected with HIV in 2012 [1]. Mother to Child Transmission (MTCT) accounted for 90% of these infections, despite the fact that highly effective prophylactic medication for Prevention of Mother to Child Transmission of HIV (PMTCT) is available [2]. MTCT risk is less than 2% [3] if a mother fully adheres to the "PMTCT Cascade," a process that involves maternal HIV testing and counseling, accessing anti-retroviral (ARV)

medications at the time of diagnosis, adhering to medication usage through the completion of breast-feeding, following nutritional and delivery advice, and testing the infant for HIV [4]. Although each individual step may be straightforward, trying to successfully navigate all the steps in the PMTCT continuum can seem complex and overwhelming to an HIV-infected mother. As a result, only 62% of women were estimated to have achieved successful completion of the entire PMTCT cascade globally in 2012 [1].

Failure to follow this complex system through to completion (attrition) is a documented challenge in Ethiopia, where an estimated 9,500 infants acquired HIV in 2012. Only 41% of HIV positive pregnant

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women/children pairs received the most efficacious regimens of (ARVs) required for PMTCT in 2012 [1], and only 10% followed through to early infant diagnosis. Ethiopia's 2012 MTCT rate was 20% [5], and the government has recognized the critical need for a significant improvement in PMTCT uptake and adherence. Reducing the MTCT rate to less than 5% and the number of new childhood HIV infections by 90% by 2015, are stated goals under the national "Elimination of MTCT" (eMTCT) 2013-2015 plan. The plan also highlights a target to have 85% of mother-child pairs on ARVs by 2015 [6].

The focus of the Ethiopian government thus far has been primarily in increasing the availability of services, and the number of facilities offering PMTCT services has increased rapidly over the last few years [5]. HIV testing among pregnant women has also risen significantly in recent years [7,8]. The number of those identified as HIV positive eligible for ARVs has expanded dramatically since the roll out of the simplified "Option B+" regimen in 2013. Despite these gains, efforts to improve the MTCT rate have been relatively ineffective [9], and attrition from PMTCT must be addressed [10]. Many factors can positively or negatively influence a woman's ability to follow the PMTCT system through to completion, including systemic issues, social, cultural, and religious norms, peer and family relationships, and personal knowledge and beliefs [11-14]. Those unique socio-contextual factors which most powerfully affect HIV+ Ethiopian women must be considered if PMTCT interventions targeting high attrition rates are to be made culturally and socially acceptable [15].

Recognition of the value of obtaining the insight of PLWHIV (people living with HIV) is increasing across all spheres of the global HIV epidemic, and their advice is being widely sought in program development [16-18]. PLWHIV mothers can help to identify the critical factors which may be either beneficial or detrimental to their adherence to PMTCT, and their advice about how to increase maternal adherence to PMTCT can offer insight [19]. In Addis Ababa alone, 70,000 pregnant women were eligible for PMTCT in 2012 [7], providing access to a wealth of opinions and experiences from which to learn. However, most attrition research in Ethiopia has been focused with mothers at antenatal centers, excluding the large number of women who fail to access medical care during pregnancy. Insight from women who were lost to follow up in the PMTCT system in Ethiopia has also been notably under assessed [10]. While researchers have suggested a need

for formative qualitative research to understand the low uptake of PMTCT services and high attrition rates [2,20], much of the research to date has been quantitative in nature. To fill these gaps and inform the development of innovative program designs aimed at addressing PMTCT attrition, an exploratory mixed methods study with PLWHIV mothers in the community was implemented. The overall parent study focused on gaining a generalized understanding of the beliefs, attitudes, and socio-cultural factors which affect PLWHIV women during their pregnancies. The qualitative elements reported in this paper explore the primary influences that result in PMTCT attrition and explore, through the lived experiences of PLWHIV+ women, how best to overcome these factors.

MATERIALS AND METHODS

In order to explore and fully identify the reasons for the high rate of attrition from PMTCT in Addis Ababa, an inductive, mixed methods study was conducted. Qualitative methods included in-depth interviews, which allowed for broad elicitation of issues affecting PMTCT adherence, and focus groups, which facilitated the exchange of ideas between PLWHIV mothers. A quantitative survey provided additional information, and all methods were triangulated in data analysis. This paper addresses the methods and results only from the qualitative research. The research project took place over a two-month period in Addis Ababa, Ethiopia.

A variation of women representative of the demographics of the female PLWHIV population in Addis Ababa was recruited for the study using mixed purposeful sampling [21]. Staff from two local PLWHIV support programs identified women of varying ages, ethnicities, religions, educational and economic levels, and communities to recruit. PLWHIV women who had a child at least one year of age at the time of the study were eligible and mothers of both children infected with HIV and those with healthy children were chosen. Women who were aware of having HIV during their pregnancy and those who did not know they were infected were each sampled, and PLWHIV mothers who were not involved in a support program were also identified to participate. These variations in sampling were chosen in order to minimize bias.

Interview and focus group guides were developed by the PI in consultation with Ethiopian colleagues. These study tools were translated into Amharic by two native speakers then back translated by two other native speakers to ensure accuracy. The tools were pilot tested with five women in the population of interest and revised as necessary before data collection began. A trained research assistant conducted four focus groups in the local language of Amharic, and each group was digitally audio recorded. The PI observed and debriefed each session with the research assistant. Two focus groups included mothers of HIV positive children, and two groups included mothers whose children are not infected. A total of 27 women participated in the focus groups, each of which consisted of six to eight participants.

In-depth interviews were conducted in English by the PI; the research assistant translated to Amharic during the sessions. Interviews took place at PLWHIV program office and lasted between 45 minutes and one hour and half each. In total, 23 interviews were completed before the point of theoretical saturation was reached.

Inductive analysis of qualitative data using the constant comparative method was performed concurrently with ongoing data collection. Audio tapes of all sessions were translated and transcribed verbatim and uploaded into NVivo software [22]. Structural coding of the transcripts was first done according to questions asked of the participants. Key themes which emerged as transcripts were reviewed were then written into a codebook before additional levels of coding were completed. Three reflexive sessions were held with PLWHIV participants to check the accuracy of findings [23], and the research assistant periodically checked the analysis for agreement with local culture and customs. Four transcripts were re-coded to check accuracy once analysis was complete, and a data audit trail was maintained throughout the process.

Ethical Issues: Approval and oversight for this project was granted by the University of South Florida's IRB, the Ethics Review Board of Addis Ababa University, and the Federal Ministry of Health of Ethiopia. Written informed consent was gained from all study participants before data collection took place.

RESULTS

Description of the study participants: The results presented in this paper reflect the advice offered by participants for improving PMTCT retention and the barriers to PMTCT adherence that they find to be most significant. Fifty women in total participated in the qualitative element of the study: twenty-seven took part in focus groups and 23 participated in in-depth interviews. No significant differences in demographic characteristics were reported between groups. The average age of participants was 32.5 years old. Ethnicity was divided among Amhara (78%), Oromo (16%), and other (6%) groups. The religion of participants was mixed between Orthodox (46%), Protestant (46%), and Muslim (8%). Less than half of the women (42%) were married, with the remainder divorced, widowed, or otherwise single. Half of the women (50%) had no education; 20% had basic (1-5 years) education; 22% had secondary (7-9 years) education; and 8% had over 10 years of schooling. Women with higher levels of income (defined as having 1-2 people living per room in the home) made up 36% of the sample; 50% had mid-level income (3-4 people per room); 14% had lower level income (5 or more people per room). The sample included women involved in HIV support groups (56%) along with those not involved in support groups (44%).

Approximately one third of the women (34%) had children infected with HIV. Of the total pregnancies for the participants, 46% had not been involved the use of PMTCT. Five women who did not utilize PMTCT and delivered HIV+ children had subsequent pregnancies during which they utilized PMTCT and delivered HIV- infants. Complete demographics of participants are shown in Table 1.

Table 1. Distribution of demographic characteristics of study participants

Characteristics	Interviews N=23	Focus groups N=27	Total N=50
Age			
Under 30	26.1	37.0	32.0
30-40	60.9	55.6	58.0
Over 40	13.0	7.4	10.0
Religion			
Orthodox	34.8	55.6	46.0
Protestant	52.2	40.7	46.0
Muslim	13.0	3.7	8.0
Education			
No education	34.7	63.0	50.0
Basic (1-5)	34.7	7.4	20.0
Secondary (6-9)	21.7	22.2	22.0
Advanced(10+)	8.9	7.4	8.0
Income			
Low	17.4	11.1	14.0
Medium	47.8	51.9	50.0
High	34.8	37.0	36.0
Marital status			
Married	52.2	33.3	42.0
Single (unmarried, divorced, separated or widowed)	47.8	66.7	58.0
Ethnicity			
Amhara	73.9	81.5	78.0
Oromo	26.1	7.4	16.0
Other	0.0	11.1	6.0
Completed PMTCT			
Yes	60.0	52.0	53.0
No	40.0	48.0	47.0
HIV status of children			
HIV+	26.1	48.1	34.0
HIV-	73.9	51.9	66.0

Barriers to PMTCT Adherence: Women in the study were asked to share their views about existing or potential barriers or facilitators to PMTCT adherence, either from their own experiences or from that of other PLWHIV women with whom they interact. A comprehensive list of these influences was generated from their responses and is reported as part of the parent study (Klaus, in process). In order to inform the advice given by participants for improving PMTCT adherence, only those barriers which were most frequently reported and generated the most discussion are addressed in this paper.

Hopelessness: Hopelessness was the most frequently mentioned barrier to PMTCT adherence reported by women in the study: it was cited by 22 different women. Hopelessness was expressed as directly giving up hope and was reported as women shared stories of how they personally felt “despair” and had thoughts of “giving up.” Some women even expressed “I desire not to live.” This theme was directly linked to the concept that HIV is a death sentence for all who contract it. Although this perception is changing slowly, it was reported to still be fairly widespread and to affect adherence to PMTCT. For example, one woman stated, *“the biggest thing is being hopeless. They have doubt about being able to recover from the disease.”* Another shared, *“It’s because they give up hope they don’t think they can live like people and make it.”* While some women shared stories of others, others reported personally experiencing this hopelessness. One woman explained her feelings the first year after her HIV diagnosis by saying: *“I lost my hope and I did not consider that I can live. I even lost my hope about my kid, also, and did not consider that I can live.”* Actual suicidal attempts were reported by four participants at the time of their HIV diagnosis. Feelings of hopelessness also extended to a fear of death for the women’s children. One participant explained that *“an HIV+ neighbor threw out her child’s ARV medication because ‘She has a mind that the baby is going to die, is not going to survive.’”*

Concern about medication: Concern over the use of ARV medication was reported as a barrier of equal importance to that of hopelessness. Participants reported that women frequently tire of taking a chronic medication, and they often doubt its efficacy since it is not completely curative. One woman explained the loss to follow up in PMTCT by saying *“Another reason they are not taking the medicine is it is too much. They are exhausted with it.”* Another woman explained that *“People are stopping the medicine because one, they give up on the medicine. . . . They*

say, ‘since we are dying, why do we take this medicine? For how long will we take it? It is not going to cure us, so why are we taking it forever?’” One woman admitted that she frequently misses her own medication doses and stated: *“I will tell you for myself. I was also hopeless one time. I still think sometimes the medicine is not appropriate, it is from the devil. I sometimes skip the medicine because of the hopelessness and I am an example of why people are not taking their medicine. A big thing is the medication does not cure.”*

Several participants explained that ARVs are frequently thrown in the trash by pregnant women because “they doubt that the medication will work for them or either for the baby or the mother.” Participants also expressed that many women have concerns about side effects of ARVs and how they must be taken. One woman succinctly stated, *“People are just misinformed about the medication.”* Other women reported a widespread teaching that ARVs must be taken with food and how this hinders the compliance of those who live with food insecurity. Some women believe that taking the medicine without food would simply be ineffective, while others expressed concerns over side effects being enhanced without food. One participant said: *“People are not taking the medication because of balanced diet. The medication has burning characteristics in our body. In order to avoid that burn we need to eat good food. Most people don’t have foods in their house, but so they will avoid taking the medication.”*

Another woman explained that: *“People are giving up on their medication, because they just give up. They say it’s too much. It causes irritation and heartburn, and needs to have foods with it. As you know people are poor they don’t have foods to eat, so if they don’t have anything to eat, they also stop taking the medication.”*

Even without food insecurity, fear of the potential side effects of taking the medication was commonly expressed. One woman said: *“I am thinking ‘for how long will I take this medicine?’ I know that I will take it forever. But I am thinking whenever I take the medicine it will go inside me and stay there. So ‘how long, how long, how long?’ It makes me worried to take the medicine the rest of my life.”*

Other concerns: Other important barriers to PMTCT, which emerged less frequently in discussions, included carelessness, a fear of stigma, the use of holy water, and poverty. Several women stated that the HIV education available on media, through clinics,

and through non-governmental-organizations (NGOs) in the communities is sufficient for PMTCT, but that carelessness is causing many PLWHIV women not to listen to it. One woman expressed her viewpoint by saying “People are passing the virus to kids because they are careless of listening to the media and doctors.” Another explained, “The teachers are there, but the listeners aren’t.” Another woman explained that “women practice carelessness when they go against medical advice.” One woman stated: “They get pregnant and only go to clinic to deliver the baby. Just carelessness, they only go to clinic to deliver the baby and then go home. They are just careless, even [if they would] tell the provider they are HIV+ and then they would be protected but they don’t tell them. This is carelessness.”

Several other participants explained that pregnant women are careless when they are “lazy,” don’t take responsibility for taking care of themselves, or are “selfish” when they do not act responsibly in the care of their children.

Stigma in communities was frequently mentioned as a possible barrier to PMTCT use. Several women reported having been forced by landlords to leave rented homes when their diagnosis was discovered, and others explained that neighbors often gossip about them. A few participants also expressed that a fear of discrimination from family members may hinder women from taking ARVs. Overall, however, several women reported that the level of HIV stigma has been decreasing in the last few years.

Almost half of the women interviewed directly referred to the practice of taking “holy water” for healing as a common reason that women do not adhere to HIV medication or PMTCT services. They reported that many women are encouraged by Orthodox neighbors and religious communities to discontinue their ARVs when they drink holy water as a sign of faith. One woman explained: *“If they need the healing, they have to leave the medication behind. When people are going to get the holy water they have to leave the medication. They are not allowed to take it.”* Although they reported that the necessity of discontinuing medicine is not officially taught by Orthodox priests, many participants either had done so personally at one time or knew others who had. Several women described having seen women die as a result of this practice.

Although ARVs are available without charge to pregnant Ethiopian women, several participants expressed that stark poverty is a significant limitation

to PMTCT adherence. Not only does food insecurity hinder the ability of women to take ARVs, but several women reported having been forced to beg at times for food. Some women expressed concerns over difficulty finding shelter, while others stated that having to work long hours for others hindered their ability to follow through with medical care. Some women noted a search for employment took away the time they could use for medical care, while others noted that being impoverished limited the strength they had to care for their children well.

Advice to Improve PMTCT: As participants were asked about barriers to adherence to PMTCT, they were also asked their thoughts about what could be done to increase PMTCT retention. Through sharing opinions and advice that developed out of their own experiences, participants expressed the need for enhanced education and the implementation of government level interventions. Further, they stressed the importance of including PLWHIV in all efforts to enhance knowledge of HIV and adherence to protocols.

Enhancing education: Enhancing educational and counseling efforts was reported as vital to increasing adherence to PMTCT protocols. One woman expressed that *“without knowledge and education, no one will take HIV medication.”* Women stated that much more information is needed about the importance of taking ARVs and how to manage medication side effects if they occur. One participant addressed this by saying:

At the clinic, the clinic workers should tell the patients to understand the medicine. To discuss deeply to understand the medicine. If you tell the person the importance of the medicine, they will take it, but the most important thing is for them to understand, the teaching. One woman shared her own personal story of how education had changed her thoughts and behaviors in regards to stigma and taking medication adherence. She described her experience by saying: *“My view is at the beginning that HIV can be transmitted by sharing somebody’s food and I was so afraid and I was disappointed and so I was afraid of going to the people or telling people about this stuff. But at the end from the media I learned a lot and taking the medicine is important even if I am at work. So I do this, take the medication during work when it is time to take it.”*

Many women expressed having had positive interactions with health care workers and their high level of confidence in educational messages when they are

offered by a clinician. Women also suggested that effective education could come through several different avenues, in addition to the teaching offered by health care workers in clinical settings. One possible method of education, which was controversial among participants, was that of media. Two women said that media is the next best vehicle for education after listening to medical providers; a few said that television (TV) and radio programs are helpful for generating overall awareness of HIV and PMTCT. Several said that TV should absolutely be used for “such important things” as teaching about HIV and PMTCT, rather than just as “mindless entertainment.” Yet, other participants argued that education through media is already available but is not sufficient. Some said that many women do not listen to the media messages, and another said that education from the media is not taken seriously.

Participants noted a need to offer educational messages which focus on the benefit of PMTCT to their children. They suggested that ensuring women understand that children of an HIV+ mother can truly grow up and live healthy lives offers hope to adhere to PMTCT therapy. Ten women also suggested that issues of faith should also be presented in educational messages. Six of these women noted that having hope in God can facilitate medication adherence and should be encouraged within education. One stated that her desire for the future is to tell all PLWHIV women: There is hope. People can live with HIV if they take medication appropriately. The first thing we should do is trust in God and then to take the medication. The medicine does not hurt at all. To take the medicine as prescribed and to have hope are useful. Tell the people there is hope always.

Two participants wanted to advise women that they can take holy water, but that they must also be responsible for their children by taking ARVs. One expressed this idea when she stated her advice to PLWHIV peers: *“I think God gave us [a] way out of perishing and we should use it. Faith has nothing to do with taking medicine or not, [you] need to be educated about importance of medication. Since [you] have faith [you] should take both medicine and holy water. That's why people die.”*

Several women from each of the three predominant faiths (Orthodox, Protestant, and Muslim) suggested that it would be helpful to have more HIV education in their religious communities, particularly if taught by a leader. One explained that if a religious leader would teach about PMTCT, the people would be likely to “open their ears and listen.” Some women

expressed personally having found it helpful to attend the HIV educational gatherings that are held in a few large Protestant churches in the city. They reported that the education is not being brought before the larger congregations, however, and none of the Muslim or Orthodox participants had experience with HIV education within their religious communities. *“It is good if a pastor talks about HIV,” said one Protestant participant.* A Muslim participant stated that *“having any sort of HIV education in the mosque would be helpful”*, and several Orthodox women expressed the need for teaching explicitly about ARVs and holy water. One participant summarized her advice by saying *“I would just tell them to accept it [PMTCT] according to each faith. Every single religious institution should educate the people.”*

Implementation of government sponsored interventions: Women in focus groups were asked specifically what they wanted to tell the government about how to better control the transmission of HIV to children. Several women expressed their belief that it is ultimately the government's responsibility to provide more widely distributed education about HIV and PMTCT, especially to impoverished communities. Stronger legal action against discrimination was mentioned by several, and one said that they should be responsible for educating the public that PLWHIV are equal members of society. Assistance in overcoming poverty was requested by several participants: they suggested that the government create job opportunities for women with HIV, offer food subsidies, and provide them with housing. While a few women made the optimistic suggestion of “finding a vaccine and distributing it nationwide,” others simply requested stronger support and encouragement for medical adherence. Many who asked for this support and increased education explicitly suggested that it should come through PLWHIV counselors.

Involving PLWHIV peers: The recommendation to involve PLWHIV in PMTCT interventions was given by 24 different participants; this was over twice the number of times that any other idea was suggested. Expressing the common thought that PLWHIV should be more effectively utilized, one woman advised that: *“The government should assign trainer mothers who are living with HIV already.”* It was suggested that PLWHIV women can function well as peer models and volunteer social workers, and they can also function as links to community and religious engagement in HIV care. Their role in education was also described by several participants as vital.

Many of the women attested to having personally benefitted from interactions with other PLWHIV women, stating their peers had encouraged them, offered them hope, set good examples, and taught each other well. When asked who supported her during her pregnancy, one woman said, *“I have a friend also diagnosed with HIV who is the one who encourages me to go to clinic and take care of myself. She is the one.”* Several said PLWHIV peers are those who provide the critical emotional support needed to cope with the challenges of chronic medication use. Three participants stated that they had given up hope in taking their medicine in the past, but a PLWHIV peer had actually helped them to change their minds and start taking the medicine again. A woman explained, *“During this pregnancy, I had almost given up on medicine and almost stopped. But my friend says ‘see I am taking the medicine, why will you stop? Please keep taking the medicine! That is what she always tells me.’”* Others expressed that PLWHIV peers are helpful in the practical challenges of taking ARVS, as well: a few said that a PLWHIV peer keeps them accountable to taking their medication each day by calling, texting a reminder, or visiting their home.

In addition to offering advice and hope through personal interactions, participants expressed that PLWHIV women can be helpful in official capacities as clinic workers, educators, and counselors. One participant recommended that PLWHIV women should be hired in every clinic to track all PLWHIV pregnant women through their pregnancies. Others agreed that PLWHIV women should be prioritized to be hired as part of the healthcare workforce.

The majority of women who expressed a need for increased PMTCT education agreed that PLWHIV women would be the best teachers in any context and preferable to community leaders, religious leaders, or NGO workers. They explained the importance of using PLWHIV educators by noting how they can add elements of personal modeling and peer encouragement to education. One woman stated, *“Someone who lives with the virus should teach, because that person can be good example to others.”* *“If a patient tells them about it, people would be more willing to learn about it,”* said another participant. Another stated that *“[an educator] should be a person with HIV to be a good counselor also.”*

Many said that PLWHIV should teach in both antenatal and general health care clinics, explaining that peer educators are capable of offering more clearly understood education than health care workers. Some

women suggested sending PLWHIV educators to religious communities to hold classes, while many suggested using PLWHIV educators in communities to teach classes or hold coffee ceremonies.

Holding coffee ceremonies in communities or in individual homes is a very common Ethiopian custom, the women explained, and they are occasions in which “you can invite everyone and raise awareness.” One woman expressed that: *“TV and radio are ok, but it [education] is better in the community. Like a coffee talk. We go door to door in a culture, and ask people for coffee. If we live here, we make coffee and ask people to come. We do not tell them it is for HIV, just coffee, then we talk.”*

Several participants suggested that those who gather for coffee ceremonies would take educational messages from that experience more seriously than they will from media messages, and a few referenced having personally learned a lot from attending coffee ceremonies offered by NGO programs. Two women stated that they are actively engaged in organizing coffee ceremonies in their own communities for the purpose of teaching about HIV and that the gatherings are always very beneficial to those who attend.

Some women suggested that coffee ceremonies should take place as small gatherings in individual homes, in which case participation is encouraged, personal support is offered and education can be more extensive. Other women affirmed the value of having larger coffee ceremony sessions in the communities, even extending invitations to individuals who are not HIV+. One participant noted that this method will raise interest: *“Most [women] will come out for coffee then will go home with awareness of the [HIV] virus. I think this is the best way to reach.”*

Frequent suggestions were also made that women are effective as peer mentors and counselors who make home visits to other PLWHIV. Several women who are currently engaged in the practice of making home visits reported receiving great satisfaction from their roles. They stated that they like having the opportunity to offer counsel and “give a model example.” One counselor expressed what she enjoys about her volunteer work by saying, *“I like going house to house serving people, visiting people, seeing the people hopeless in bed and encouraging them. This is what I like the most.”* Another peer counselor said she enjoys her work because *“by making them a kind of service, bringing it to them, it is possible to help them.”* Another woman who previously volunteered worked as a home based counselor explained from

her experience the impact such visits can have: *"I am one of the examples to the people to go to clinic and get medicine every 3 months. I tell them my life and my story. The people, now, they always tell me because of you we are living today. . . There are 10 or 11 people now who are taking their medicine."*

Women who were not personally engaged in peer counseling also affirmed the value of PLWHIV women making home based visits. They suggested that such visits offer opportunities to provide in-depth education, to model how to take ARVs properly, and to check on medication adherence. Several women expressed that home visits can offer great personal emotional encouragement to PLWHIV peers. One participant who did not utilize PMTCT has a child who was infected with HIV during pregnancy. When she was asked what may have helped her to obtain PMTCT services if she had a second chance, she said: *"I may have [taken medicine] if someone would have come and visited me about this [and showed] caring. And I would have gotten tested earlier."*

Many women expressed a desire that home-based PLWHIV counseling and education programs be greatly expanded. They noted that a few NGOs currently offer programs which include home visits, but that they are limited in scope and reach very few women overall. Almost all of the women in the study expressed a personal desire to help their peers, and many of them said that they would be happy to personally be more actively engaged in offering PLWHIV support as educators or peer counselors.

DISCUSSION

While attrition from the PMTCT system in Ethiopia is a well-documented issue, the exact significance of each influence that affects a woman's ability to complete the PMTCT cascade is not well understood. To better understand how the most significant barriers leading to attrition can be overcome, this study explored the lived experiences of PLWHIV mothers in Addis Ababa. It also sought to bridge the gap between knowledge and practice, empowering PLWHIV women to guide future implementation efforts by allowing their voices and opinions to be heard.

Results from this study suggest that overcoming hopelessness among PLWHIV women and providing better education about vital factors affecting the use

of ARVs must be addressed if more women are to effectively complete the PMTCT cascade. The study also demonstrated that these concerns, along with issues of carelessness, stigma, and poverty, could be addressed by the use of PLWHIV women as educators and peer counselors and thereby facilitate PMTCT adherence.

The eMTCT plan for Ethiopia for 2013-2015 contains goals targeted to improving PMTCT services at multiple levels, yet findings from this study suggest that a different focus may be necessary [6]. Although the plan recognizes the key demand-side challenges of missed opportunities for service and the high attrition rate from PMTCT care, the majority of the plan's goals and objectives are focused on improving the PMTCT system from within. However, in contrast to many studies which document low quality health care services or poor interactions with HCWs as common reasons for PMTCT attrition [13-14, 24-25], most women in this study described having very positive, encouraging experiences within the health care system and a high degree of trust in the advice they had received from HCW.

Participants expressed the need for increasing community awareness and understanding of PMTCT services as a greater concern; although not prioritized, the eMTCT plan does also recognize this need. National strategies to improve awareness include increasing media messages, male involvement, and the use of Health Extension Workers (HEW) and the Health Development Army (HDA) [6]. Some study participants agreed that increased media education may promote awareness, but none of the women suggested that engaging males would improve PMTCT retention. Considering other studies which strongly indicate male support to be a key facilitator to PMTCT use [14,26], the omission of this suggestion by the participants is notable and should be more explicitly explored. Further, although they did not refute the use of HEW and HDA, women advised that engaging PLWHIV mothers in promoting awareness and education would be more valuable. Expectations that health workers alone can increase awareness and provide consistent support to PLWHIV women are optimistic at best when considering their already heavy workloads.

Results from this study suggest that the PLWHIV mothers are very interested in becoming involved in helping to reduce MTCT of HIV. Specifically, women desire to be voices of hope and encouragement to their peers through counsel, to serve as models for medication adherence and healthy lifestyles,

and to share what they have learned with others as educators. The value of involving PLWHIV in peer support groups and actively engaging PLWHIV as peer educators and counselors is being increasingly recognized in other sub-Saharan African countries, with successful interventions documenting increased PMTCT adherence, improved infant health outcomes, and up to 95% HIV- delivery rates [11, 27-29]. These successes and our study findings suggest that the involvement of PLWHIV mothers should be much greater than what is currently being recommended.

Previously several successful Mother Support Groups were started in Ethiopia [30] and PLWHIV peer counselor programs were run through local NGOs. However, due to financial constraints, these programs have been sporadically sustained, with most no longer active: this further supports the critical need to capitalize upon the high level of motivation for involvement expressed among PLWHIV mothers in Ethiopia. PLWHIV peer educators and counselors can effectively address the most influential barriers to PMTCT adherence highlighted in the study.

The potential impact of this peer support is widely supported in the chronic disease literature prevalent in the US and other developed nations [31-32]. These same peer support principles also have the implication for effect in low resource areas, allowing women to provide hope and positive reinforcement that can translate to behavior change [31,33]. Particularly, PLWHIV models who are adhering to a medication regimen and living a healthy lifestyle can be sources of encouragement who help women to overcome hopelessness and to be more attentive to caring for themselves. Further, women in the study expressed that focusing on their children inspired hope and gave them strength to continue taking their medication. Thus, PLWHIV peers with healthy children can serve as living reminders of the possibility for delivering babies born free of HIV.

Results from this study suggest that a general failure to understand the benefit of ARV treatment either for a mother or her child remains a significant concern. Thus, while educational campaigns in Ethiopia have succeeded in promoting a high level of awareness of HIV and MTCT among the female population [13,34], it appears that a comprehensive understanding of the value of PMTCT services has not been reached. As the country rolls out Option B+, a more simplistic regimen hoped to promote higher levels of adherence; it may be an ideal time to incorporate

PLWHIV as peer educators in health clinics, communities, religious institutions, and the media. By targeting their messages to an understanding of how ARVs can both prevent infant HIV infection and also benefit a woman's health, the teaching and support of PLWHIV peers can help women to overcome the confusion about ARVs that prevents PMTCT adherence.

The concern over the use of holy water expressed in this study is significant, and it is clear that education encouraging medication adherence along with faith practices is needed within the Orthodox Church. Interviews with PLWHIV elsewhere have indicated that engaging faith leaders in HIV issues can have significant positive impacts [35]; religious leaders have also been proven able to positively affect maternal health [6,36]. Priests should play an important role in providing teaching about holy water, but their ability to reach women individually may be limited by time constraints. Orthodox PLWHIV peer counselors could provide important additional personal support and enhance the education given in the church.

The difficulties expressed in the study of living jointly with HIV and in poverty are consistent with other studies completed in sub-Saharan Africa [12,14]. Poverty and poor health are often linked; poverty both directly limits access to health care and indirectly limits access to prevention education [37]. Direct provision of food, housing, and other material aid must be addressed at a government level, but PLWHIV can play a role in addressing poverty, as well. Through starting and managing self-help groups, utilizing micro-loan models, and engaging with innovative new methods they design, PLWHIV mentors may be able to provide economic empowerment for their peers [38]. These strategies have been recommended as an important part of global HIV prevention (Interagency Task Team [39].

Existing national anti-discrimination laws are intended to promote equitable access to treatment and support for PLWHIV, but stronger enforcement and better legal retribution for discrimination is needed from the government [10]. PLWHIV can also play a role in fighting discrimination. Engaging more PLWHIV women as community educators and members of community planning committees may promote increased HIV awareness and help to mitigate the effects of stigma in these locations. PLWHIV women who were previously involved in mother support groups also reported that their own fear of social stigma decreased with participation [30].

PLWHIV women are being effectively utilized in the PMTCT healthcare workforce in order to prevent attrition in a number of countries [40]. Not only can they provide individual and group counseling to PLWHIV mothers at the clinic level, but PLWHIV workers can promote linkages to health care systems through home based visits and provide default tracing for women who have dropped out of PMTCT care. The highly motivated PLWHIV mothers in this study could greatly extend the reach of the current PMTCT system if engaged as part of the workforce. In addition, although not expressly discussed in this study, PLWHIV peers may be effective in addressing issues beyond attrition that also affect the MTCT rate: encouraging the use of institutional delivery and advocating for exclusive breastfeeding are examples.

WHO's Global Health Sector Strategy 2011-2015 [41] recommends that engaging PLWHIV in planning interventions is essential for their success, and UNAIDS and PEPFAR support the incorporation of PLWHIV in developing HIV/AIDS care and prevention strategies [16,18,42]. In light of such strong international recommendations, the advice given by women in this study to engage PLWHIV mothers should not be overlooked. Current efforts to improve the quality of PMTCT services and the utilization of HEW and HDA to promote awareness may improve uptake and retention in the PMTCT system. The potential impact of such programs, however, should be reconsidered in light of the significant findings of this study. Giving greater attention to the use of PLWHIV mothers at a system wide level, investing in their training as educators and counselors, and developing designated PLWHIV peer support programs may result in markedly greater improvement in PMTCT adherence and better infant health outcomes in the future.

Limitations: Cultural misunderstandings are inherent limitations to any international study, but the involvement of a multi-national research team and close communication with a local research assistant sought to minimize these barriers. The choice to have the primary investigator conduct interviews in English with translation expedited the study's completion, yet also presents the potential for inaccurate translation. However, training and consistent evaluative discussion with the local research assistant who translated each interview minimized this concern. Use of this local research assistant during both interviews and focus groups also enhanced the trust of participants, but the possibility remains that perceived power barriers between the research team and the participants may have limited their total transpar-

ency. Although study participants often recounted their own experiences, they also described the experiences of others. To minimize inaccuracies in such secondary data, the plausibility of findings was checked by reporting them back to participants, as well as using both focus groups and interviews in data collection. Confidentiality concerns were minimized by holding research sessions at the program offices rather than in the communities. Research bias during the design of the study, data collection, or data analysis was possible but limited by several collaborating researchers giving oversight in this area. Although the results of the study may inform future research efforts in other locations, they should only be interpreted for women in Addis Ababa and not be generalized to the rural population of Ethiopia nor other locations. Many factors affect the high rate of vertical HIV transmission in Ethiopia, and it must also be noted that this study only represents the opinions of PLWHIV mothers on the specific problem of lack of adherence to PMTCT care. It does not address issues such as low uptake of ANC services or low institutional delivery rates.

Conclusion: Maintaining the motivation required to adhere to the entire PMTCT cascade requires that a PLWHIV mother both understands the validity of the steps she is taking and receives support for the many challenges she faces. Making sure these requirements are met should be the primary target of any future interventions if the goal of reducing the MTCT to less than 5% in Ethiopia in 2015 is to be met. According to the advice of PLWHIV mothers given in this study, programs should target educational efforts toward better understanding of the benefit of ARVs and interventions should be designed that help PLWHIV mothers overcome a feeling of hopelessness. These difficulties and several others, could be mitigated by the use of PLWHIV peers. Strong consideration should be given to investing in training and engaging PLWHIV peers as active members of the health care workforce and significantly expanding their use in the communities as educators and counselors. Doing so will allow the expressed needs of the PLWHIV population to be met more effectively and result in a decrease of attrition from PMTCT care.

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