

Sex inequality, high transport costs, and exposed clinic location: reasons for loss to follow-up of clients under prevention of mother-to-child HIV transmission in eastern Uganda – a qualitative study

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Background: In Iganga, Uganda, 45% of women who tested HIV-positive during antenatal care between 2007 and 2010 were lost to follow-up (LTFU). We explored reasons for LTFU during prevention of mother-to-child transmission (PMTCT) from a client perspective in eastern Uganda, where antiretroviral therapy (ART) awareness is presumably high.

Methods: Seven key informant interviews and 20 in-depth interviews, including both clients who had been retained under PMTCT care and those LTFU during PMTCT were held. Ten focus-group discussions involving a total of 112 participants were also conducted with caretakers/relatives of the PMTCT clients. Content analysis was performed to identify recurrent themes.

Results: Our findings indicate that LTFU during PMTCT in eastern Uganda was due to sex inequality, high transport costs to access the services, inadequate posttest counseling, lack of HIV status disclosure, and the isolated/exposed location of the ART clinic, which robs the clients of their privacy.

Conclusion: There is a need for approaches that empower women with social capital, knowledge, and skills to influence health-seeking practices. There is also a need to train low-ranking staff and take PMTCT services closer to the clients at the lower-level units to make them affordable and accessible to rural clients. Posttest counseling should be improved to enable PMTCT clients to appreciate the importance of PMTCT services through increasing the number of staff in antenatal care to match the client numbers for improved quality. The counseling should emphasize HIV status disclosure to partners and encourage partner escort for antenatal care visits for further counseling. The exposed and isolated ART clinic should be integrated with the other regular outpatient services to reduce the labeling stigma.

Keywords: mother-to-child transmission, HIV, Uganda, sex inequality

Introduction

Globally, HIV disproportionately affects women and children compared to men.¹ In sub-Saharan Africa, 57% of all people living with HIV/AIDS (PLHIV) are women.² In Uganda, of the 6% of adults aged 15–49 years infected with HIV, the prevalence among women is higher: 8% compared to 5% among men.³

The UN's sixth Millennium Development Goal aims at access of antiretroviral therapy (ART) to 50% of all those who need it, and to have halted and begun to reverse the spread of HIV/AIDS by 2015.^{4,5} A large part of the progress in reducing

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the incidence of HIV is the prevention of mother-to-child transmission (PMTCT) of HIV. From an estimated 30%–35% risk of transmission without intervention, the risk for an infant to become infected by the mother is today 1%–2% with antiretroviral prophylaxis and replacement feeding. These achievements in risk reduction come from optimal settings. In reality, many patients in resource-poor settings cannot practice exclusive breastfeeding and do not have access to enough information to follow all PMTCT recommendations. The global coverage of pregnant HIV-positive women being reached by PMTCT services has increased from 10% in 2004 to 45% in 2008.¹ PMTCT services are still insufficient, with low access to ART services for pregnant women and shortages of obstetric services and skilled personnel.¹

In 2010, the World Health Organization (WHO) issued new HIV and AIDS guidelines on PMTCT and HIV and breastfeeding. Under the 2010 guidelines, all HIV-positive mothers identified during pregnancy should receive a course of antiretroviral drugs from 14 weeks of gestation to prevent mother-to-child transmission. All infants born to HIV-positive mothers should also receive a course of antiretroviral drugs and should be exclusively breastfed for 6 months and complementarily fed for up to a year.⁶ In resource-poor settings, however, the WHO recommended that health providers continue using the 2006 guidelines.⁶

Unfortunately, even where PMTCT services are available, not all women receive the full benefit of the services. Some HIV-positive pregnant women do not access the drugs, either because they have not been offered an HIV test, they have refused to take an HIV test, do not adhere to self-medication, or do not return for follow-up visits.⁷

Studies in sub-Saharan Africa show that while approximately 90% of pregnant women accept voluntary counseling and testing (VCT) as part of the PMTCT program, only 45% of those who test positive at the clinic continue with follow-up care up to delivery.⁸

In Uganda, despite a presumably high ART awareness and a rapid increase in the number of accredited sites offering PMTCT – from 48 to 205 sites between 2003 and 2009 – studies show that up to 50% of either the HIV-positive mothers or their positive infants are lost to follow up during either the antenatal or postnatal period.⁹

In Iganga district, only 115 kilometers east of the capital, Kampala, 45% of women who tested HIV-positive during antenatal care (ANC) between 2007 and 2010 were lost to follow-up during either the antenatal or postnatal period.¹⁰ Approximately 40,000 (6.7%) adults out of a district population of 600,000 people currently live with HIV/AIDS, and

6000 of PLHIV in the district are presumed to have AIDS and would be eligible for ART.^{3,11}

The Iganga district PMTCT services are quite representative of rural Uganda, offering services at the general hospital and three other health centers every week from Monday to Friday. The clinic is part of the general antenatal/postnatal clinic and is often managed by at most four midwives every day. The average daily antenatal/postnatal attendance ranges between 100 and 200 mothers. On her first visit, every mother is taken through a mandatory health-counseling and optional testing session. Those that test HIV-positive are supposed to be initiated on ART at 14 weeks of gestation and routinely followed according to the WHO PMTCT guidelines.^{6,12} Other services offered at the clinic include obstetric examination, antenatal laboratory screening and examination, and clinical management of any illness. In addition, refills for antiretroviral drugs and cotrimoxazole for those that are eligible, adherence counseling, psychosocial support, and early infant-feeding education and nutritional support are also given.¹² There has been no active surveillance of PMTCT clients in the district, and it is not known whether those lost to follow-up are under other care, no care at all, or dead. Many PMTCT clients in the district are, however, diagnosed with AIDS very late, often with a very poor prognosis.

Loss to follow-up (LTFU) of PMTCT clients is a major concern for the district, when global efforts are being driven towards increased access to comprehensive HIV care. Little is known about the reasons for LTFU of PMTCT clients in a country like Uganda, where HIV and ART awareness are presumably high. This study aims at filling the knowledge gap in explaining barriers or motivators to regular PMTCT attendance for either the HIV-positive mothers or their infants in this resource-poor setting in sub-Saharan Africa.

Materials and methods

Between August and November 2010, we conducted this study in Iganga district in eastern Uganda, where the majority of the population is of the Basoga tribe. The main occupation is subsistence farming. The district offers ART services at the district hospital and two other health centers. Over 30 out of 400 of Iganga's health workers have been trained in comprehensive HIV/AIDS care, including PMTCT. Because the district has no CD4-count machine, the clinicians often use the WHO clinical staging system to determine eligibility for ART.¹³ Occasionally, however, when required, the clients have to pay an equivalent of US\$16 for a CD4 count at a facility 30 kilometers away, which is very expensive in Uganda, where the average per capita income is US\$2.4 per day.¹⁴

This qualitative study used key informant interviews (KIIs), in-depth interviews (IDIs), and focus-group discussions (FGDs) for data collection. Seven key informants, including the district health officer and the PMTCT focal persons and staff at the respective three PMTCT sites in the district, were interviewed for the study. Similarly, a total of 20 IDIs were conducted, ten with PMTCT clients who were still active in the clinic, and ten with PMTCT clients who had been LTFU. These clients were chosen because they were presumed to be more “knowledge rich” on the study topic in their own situations than anybody else.¹⁵ The IDIs were randomly selected by their dates of enrollment using the PMTCT or ART registers. The two groups were chosen in order to allow comparative analysis of the factors affecting retention or LTFU under PMTCT. A guide covering individual and family background, prior PMTCT exposure, knowledge of PMTCT and its importance, knowledge of infant feeding for HIV-positive infants, conditions associated with adherence to the PMTCT schedule, and social networks and how these affected individual health-seeking behavior was used for the interviews. Interviews stopped when it was judged that the point of saturation had been reached and no more new information could be retrieved.

Ten FGDs were conducted with community members who lived with or looked after the PMTCT clients to generate debate and explore views on reasons for LTFU under PMTCT. The FGD informants were volunteered and proposed by the PMTCT clients themselves. We did not carry out FGDs with the PMTCT clients themselves, because many of them had not disclosed their status to outsiders and therefore did not want to discuss their personal treatment in groups. We held five FGDs with men and five with women separately to give women a chance to express themselves more freely. Each group comprised six to twelve participants, reaching a total of 112 members for the ten focus groups.

All the data-collection process was supervised by the first author, who is an indigenous public health physician, and the second author, who is a social scientist with experience in qualitative research. Two research assistants who come from the study area, chosen on the basis of their training and experience in carrying out social research, moderated and took notes for the study. The authors trained the research assistants for 2 days on the study aim, design, and tools. Role plays were used to prepare the research assistants for the different situations that could arise in their interactions with the informants. Experiences from the role plays were discussed at an extra session, and further methodological guidance was given.

Data analysis was done by all the authors. It was iterative, including reviews and discussions at different stages of data collection, and appropriate modifications were made in the tools to address emerging issues. All the interviews were tape-recorded, transcribed, and translated verbatim. The units of analysis were the transcripts from the KIIs, FGDs, and IDIs. Content analysis was used to analyze the scripts, and this entailed reading and reviewing texts of the entire interview back and forth to identify meaningful units.¹⁶ Meaningful units explaining motivators or barriers to retention in PMTCT were identified and condensed into codes, categories, and themes. The researchers shared and debated the way each of them understood or coded the data, until consensus was reached on the appropriate coding.

This study was approved by the Busoga University research and ethical review board, the Uganda National Council for Science and Technology, and the district authorities in Iganga. Respondents were informed about the aims of the study, their freedom to participate or withdraw at any time, confidentiality issues, and possible harm and benefits of the study to the community. All the study participants signed consent forms before the interviews commenced. To ensure confidentiality and minimize defections due to stigma, the PMTCT clients were first approached by the clinic staff who had attended to them during voluntary counseling and testing or initiation of ART.

Results

Reasons for LTFU to PMTCT in the perspective of the PMTCT clients, their caretakers, or the health workers cited in this study include sex inequality, unaffordable transport costs, inadequate counseling, lack of disclosure of HIV status, and the isolated/open location of the ART clinic. See Tables 1 and 2 for the general characteristics of the study interviewees.

Sex inequality

From the accounts of some PMTCT clients LTFU, sex inequality influenced whether someone continued coming for the services or not. Some clients LTFU could not access ART services, either because they were denied permission from their husbands or did not get the required financial support from their spouses to access the services regularly, as in the accounts below.

“For me, I knew I was supposed to go back, but my husband could not give me permission. Instead, he kept blaming me for bringing the disease. Even when I wanted to escape in his absence, I did not have any money on me.” (Female, 35 years old, LTFU)

Table 1 General characteristics of the in-depth interviewees (mothers under care for prevention of mother-to-child transmission) (n = 20)

No	Age	Sex	Education	Religion	Marriage status	Occupation
1	39	F	Primary	Catholic	Married	Subsistence farmer
2	35	F	Primary	Muslim	Married	Subsistence farmer
3	24	F	Secondary	Catholic	Married	Subsistence farmer
4	41	F	None	Catholic	Widowed	Subsistence farmer
5	25	F	None	Muslim	Married	Subsistence farmer
6	41	F	Primary	Anglican	Widowed	Subsistence farmer
7	31	F	Primary	Muslim	Widowed	Subsistence farmer
8	48	F	None	Catholic	Married	Subsistence farmer
9	35	F	Primary	Muslim	Married	Trader
10	42	F	Secondary	Anglican	Married	Teacher
11	33	F	Primary	Catholic	Married	Subsistence farmer
12	35	F	Primary	Muslim	Married	Subsistence farmer
13	48	F	Secondary	Catholic	Married	Subsistence farmer
14	33	F	None	Catholic	Widowed	Subsistence farmer
15	28	F	None	Muslim	Married	Trader
16	45	F	Primary	Anglican	Widowed	Subsistence farmer
17	32	F	Primary	Muslim	Married	Subsistence farmer
18	36	F	None	Catholic	Married	Subsistence farmer
19	48	F	Primary	Muslim	Married	Trader
20	29	F	Secondary	Anglican	Married	Teacher

The phenomenon of sex inequality was also echoed by the key informants and FGDs, members, as in the accounts below.

“Some clients are LTFU, and when we occasionally meet them in the community while on other activities and you ask them why they say they did not have permission to access the service from their husbands, actually some say they just escape to come for the service.” (Female health worker)

“Even us, the men, we have a problem. For me, when I knew my wife was sick, I started bringing her here for treatment, but I know of some husbands who cannot allow their wives to come for the service or even refuse to give them the support. Others, when they realize their wives are sick, they just send them away. We also need to be sensitized.” (Male FGD participant)

Table 2 General characteristics of focus-group discussion interviewees (caretakers of antiretroviral therapy clients, n = 112)

	Characteristic number (n = 112)	Percentage
Age (years)		
30–39	48	42.8
40–49	32	28.5
50–59	20	17.9
60–69	12	10.8
Sex		
Male	66	58.9
Female	46	41.1
Education		
None	53	47.3
Primary	47	42.0
Secondary	10	8.9
Tertiary	2	1.8
Occupation		
Subsistence farmer	59	52.7
Trader	34	30.3
Salary/wage earner	19	17.0
Religion		
Anglican	49	43.8
Catholic	58	51.7
Muslim	5	4.5
Relationship with people living with HIV		
Relative	108	96.4
Friend	4	3.6

High transport costs

High transport costs were often mentioned by clients LTFU as a barrier to retention under PMTCT care. Some clients LTFU reported that much as they knew they were HIV-positive and needed to come and also bring their children to the centers for treatment, they did not have money for transport and had to seek alternative assistance to access the services. Others reported that they had to sell off some of their hard-earned assets to access the service.

“The problem is transport. Some of us, like me, I come from far, about 80 kms, and I failed to go back because of lack of money for transport. I have only two goats in my life, and I can't sell them because I have to save them for my children's school fees. Actually, we wish there was a way the government could help us with the transport.” (Female, 41 years old, LTFU)

The transport barrier was echoed by some members of the FGDs, who also thought that many PMTCT clients would adhere to the PMTCT care if the government could provide transport.

“Transport is a big problem. Like me, my relative had been ill for long, but could not go for treatment because of lack of transport. It was not until I came, and yet this was late. I think if government could give the clients transport, many of them would come always in time.” (Male FGD participant)

Some clients who had been retained in PMTCT care pointed to the high transport costs as a barrier to regular attendance of PMTCT services.

“Some women don’t come back because they don’t have money for transport. For me, I am lucky, I was able and my children are also able to help me, but sincerely some of our friends come from very far, and yet they are very poor to afford transport.” (Female, 31 years old, regular PMTCT attendant)

Inadequate counseling

A few informants indicated that the posttest counseling given to the pregnant mothers during ANC at the time of testing HIV-positive was inadequate. The staff also acknowledged that because of the many clients and activities they offer in a day, they are often overloaded and do not offer enough time to counsel the HIV-positive mothers during ANC. Some mothers even thought they were only supposed to go back to the clinic when either they or their children were sick or to go for immunization.

“Honestly, the mothers are always many, and we have to do so many things in a single day. Sometimes, we are overwhelmed, and I confess we don’t give them enough time talking to make them understand, but what to do?” (Female health worker)

“I only know I should go to the hospital if I have a problem or my child is sick. Are we supposed to go back? Me, I was told to make sure I take my child for immunization only.” (Female, 48 years old, LTFU)

In contrast, the PMTCT clients who adhered to the services acknowledged the importance of adequate counseling.

“I was encouraged to go back because of the counseling I received and the treatment that I always get from the clinic.” (Female, 38 years old, PMTCT attendant)

Lack of disclosure of HIV status

Some PMTCT clients LTFU confessed that they had not disclosed their HIV status to either their spouses or immediate friends. This made it difficult, therefore, for them to explain their visits to the health centers, especially after delivery.

“Anyway, for me, my problem is that I did not disclose my HIV status to my husband. I therefore find it difficult to explain why I should be going to the center since I delivered. It is hard to find a reason.” (Female, 25 years old, LTFU)

The issue of disclosure was also given by some FGD participants as a barrier to regular PMTCT attendance.

“The other problem is that some of our wives also don’t tell us when they test positive, so they cannot explain coming to the center often after delivery. For me, my wife first hid it, but one day she confessed to our pastor and then I came with her at the centre. Nowadays, we even go together.” (Male 38 years old, FGD participant)

Isolated/exposed clinic location

PMTCT clients who had been LTFU often reported that the isolated location of the ART clinic exposed them to lack of privacy and in a way breached confidentiality. By their own account, the public knew that whoever went to that clinic had to be on ART, and yet many of them did not want to declare their HIV or treatment status to the public. This was a major demotivating factor, deterring PMTCT clients referred to the ART clinic from seeking care.

“The problem is the location of the clinic. It is put in an open place, so whoever goes there, people will know that they are infected with HIV, yet some of us have not disclosed our status because of fear of losing respect. For me, this really stopped me from coming.” (Female, 41 years old, LTFU)

The exposed clinic location account was echoed by the key informants and the FGD participants as a barrier to regular attendance of ART, especially for the mothers referred from the PMTCT clinic to the ART clinic.

“Some clients complain that our clinic is so exposed, and whoever comes here, people will know they are on ART, and yet many of them don’t want the public to know their status, so it makes them delay or refuse to come.” (Female health worker)

“Really, I think something has to be done to change that ART clinic so that it’s mixed with the other clinics or hidden. For example, my client, it took us a lot of time to convince him to come here because he did not want to be seen by the public going to that clinic. Even if it were me, it would be the same. Why do they expose patients to the public? They should be mixed with the others, like those who come with malaria.” (Female FGD participant)

Discussion

Our findings indicate that LTFU of PMTCT clients in Uganda and other similar contexts is not only a function of the individual will of the PLHIV but a complexity of other factors that includes sex inequality that negatively impacts on women's ability to access the services, unaffordable high transport costs for PLHIV to access the service, inadequate counseling, which predisposes them to lack of awareness, lack of disclosure of the HIV status, and the isolated/exposed location of the ART clinic, which robs the PLHIV of their privacy and in a way breaches confidentiality.

Sex inequality negatively impacted on adherence to PMTCT care especially for the females. Exclusive male financial dominance and social decision-making is characteristic of sub-Saharan Africa, where women lack information, finances, and the independence to make their own decisions about their health, including access to timely ART. Similar findings in Tanzania show that women could not access HIV services like VCT because of a lack of decision-making powers on when and where to seek the care (WHO, 2003).¹⁷ The phenomenon of sex inequality and health-seeking behavior with regard to HIV prevention, care, and treatment is highlighted by several similar studies.^{18–24}

Another obstacle often mentioned by LTFU PMTCT clients as a barrier to regular PMTCT care-seeking was the unaffordable high transport costs to access the service. Clients who lived far from the facilities had to incur costs for transport to access the service. Sometimes, this may involve selling off assets to get the money for transport. Transport costs as a barrier to care-seeking and treatment adherence for PLHIV have been established by similar studies in Uganda, Botswana, Tanzania, South Africa, and Zambia.^{25–27} The finding, however, highlights the fact that despite a rapid increase in the number of accredited sites offering ART from 48 to 205 sites between 2003 and 2009,^{28,29} access to ART is still low, especially for the poorest of the poor, and more efforts need to be put into taking ART services as close to the PLHIV as possible. Inadequate posttest counseling was one of the reasons PMTCT clients got LTFU. The introduction of PMTCT care in the ordinary health facilities was not accompanied with recruitment of appropriate staff. The available staff were overwhelmed with work at the time of VCT and other ANC services. This culminated in heavy workloads and inadequate posttest counseling. The newly screened HIV-positive pregnant mothers were therefore not given adequate information about the importance of PMTCT care or the danger of dropping out of PMTCT and subsequent ART. A similar finding was established in a study in South Africa.³⁰

The importance of counseling as a prerequisite for retention in HIV care programs has been highlighted in studies in Africa and Asia.^{5,31–33}

Lack of disclosure of HIV status was reported as a barrier to regular PMTCT attendance. Low rates of HIV serostatus disclosure reported among women in antenatal settings have several implications for PMTCT, as the optimal uptake and adherence to such programs is difficult for women whose partners are either unaware or not supportive of their participation.³⁴ Disclosure offers a number of important benefits to the infected individual and to the general public. Disclosure of HIV test results to sexual partners is associated with less anxiety and increased social support among many women.³⁵ In addition, HIV status disclosure may lead to improved access to HIV prevention and treatment programs, increased opportunities for risk reduction, and increased opportunities to plan for the future. This finding is supported by other studies, where disclosure has been found to expand the awareness of HIV risk to untested partners, which can lead to greater uptake of voluntary HIV testing and counseling changes in HIV risk behaviors and family support.^{35,36}

The isolated/exposed location of the ART clinic negatively impacted PMTCT continuity of services, especially for clients that had been referred from the PMTCT clinic. Many clients on ART do not disclose their HIV status to the public or even their closest relatives or employers. Making them seek a service in an environment where they will be easily identified or labeled as clients on ART is therefore likely to repel even the most ardent of willing clients.

The finding of client privacy and confidentiality as a cornerstone for health-seeking behavior is supported by similar studies from Uganda, Ethiopia, and Pakistan, where provider confidentiality was a significant factor in determining health-seeking behavior and drug adherence.^{37–41} The stigma associated with the exposed location of the clinic could be a function of individual PLHIV failing to live positively with HIV/AIDS, inadequate posttest counseling, or a negative social support network/community that labels or instills self-blame for PLHIV. Facility-based stigma as a barrier to HIV care and treatment-seeking has also been found in studies in other resource-poor settings.^{42–47} The policy implication of the finding, however, is that authorities should consider integrating ART services with the other regular outpatient services to avoid labeling stigma. Improving the quality and quantity of posttest counseling for PLHIV could also help the PLHIV live positively with HIV and prevent stigma.

We triangulated our data collection methods (KIIs, FGDs, IDIs). This helped us to check for consistency and

contradictions inside and across the groups and interviewees. The multidisciplinary and native research team was useful in understanding the contextual aspects relating to LTFU of PMTCT clients from the perspective of the participants. We feel that the content analysis employed for this study has achieved appropriate in-depth analysis for the purpose of the study.

Study limitations

We did not observe how posttest counseling is conducted at the ANC. This could have helped us assess the quality and quantity of counseling and its contextual relationship with PMTCT. Conducting FGDs with friends, relatives, or caretakers of PMTCT clients instead of the clients themselves was also a limitation, since it generated collateral information for validation. The fact that the FGD interviewees lived with the PMTCT clients, however, strengthens the concept that the data derived from the FGDs was objective to the topic of the study.

Conclusion

There is a need for sex-sensitive tailored approaches to improving PMTCT. Efforts should be taken towards empowering women with social capital, knowledge, and skills to influence their health-seeking practices. High transport costs were found to be a deterrent to retention in PMTCT care. There is a need, therefore, to train low-ranking staff and take PMTCT services closer to the clients by accrediting more ART sites at the lower-level units. This would help reduce the burden of transport costs for the clients and make the services more affordable for poor and rural clients. As well, there is a need to improve on the quality and quantity of posttest counseling, so that the PMTCT clients appreciate the importance of adhering to the PMTCT services. The number of staff in the ANC clinic should be increased to match the client numbers, and they should be trained in basic counseling skills for improved posttest counseling during ANC. The counseling should emphasize the importance of HIV status disclosure to the partners, and where possible the mothers should be encouraged to come along with their husbands during subsequent ANC visits for additional counseling and enhancement of the desired partner support.

The exposed and isolated location of the ART clinic was a barrier to timely initiation of ART, as PLHIV feared that by attending the clinic they would be labeled as clients on ART. Integrating ART services with the other regular outpatient services could be a sustainable solution to the labeling stigma.

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Disclosure

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