



# Experiences and Reasons of Attrition from Option B+ Among Mothers Under Prevention of Mother to Child Transmission Program in Northwest Ethiopia: Qualitative Study

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**Background:** Human immunodeficiency virus-infected children share the highest risk of death compared with all other age groups, and more than 90% of this viral infection of children was accounted for by transmission from mother to infant. This rate can be prevented and reduced with implementation of option B+ effectively. However, unacceptably high lost follow-up of mothers highly affected the effectiveness of this program. In Ethiopia, only 71% of mothers were adherent on their follow-up. So, this study was aimed to understand the reasons and experiences of lost follow-up of mothers under the prevention of mother to child transmission (option B+) program in North West Ethiopia.

**Methods:** A qualitative study using a case study design was carried out using in-depth interviews among 20 mothers who had started the option B+ treatment protocol but discontinued their follow-up for more than two months, and 6 key informants and individuals who were engaged in management and control of human immunodeficiency virus at Woreda and Zonal level. An unstructured interview guide was used and translated into the local language. Study participants were selected using purposive sampling technique. After written consent was obtained, all study participants' interviews were audio-recorded and analyzed using deductive content analysis.

**Results:** A total of 26 mothers participated in this study. Accordingly, the most frequently raised reasons were lack of formal education which affects income level, lack of disclosure, lack of partner and family support, absence of male involvement and stigma-discrimination. But, unavailability of option B+ regimens in the nearest health facility or long distance from health facility, discordance and lack of experienced professionals in terms of counseling during initiation were also essential reasons.

**Conclusion:** Educational and economic empowerment intervention (particularly for vulnerable households), promoting family support and male involvement, active counseling at initiation and during follow up and community level awareness improvement should be addressed to increase option B+ regimen adherence and retention.

**Keywords:** HIV/AIDS, loss to follow up, Ethiopia

## Introduction

Mother to Child Transmission (MTCT) of Human Immunodeficiency Virus (HIV) can occur during pregnancy, labor-delivery and breastfeeding.<sup>1</sup> In 2019, 150,000 children under 15 years were recorded as newly viral infected. More than 70% of this

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unacceptably high infection was found in Sub-Saharan Africa (SSA).<sup>2,3</sup> Nearly 90% of this infection resulted from MTCT and children face the highest risk of disease-related death compared with all other age groups.<sup>4-6</sup> MTCT can reach nearly 45% if a prevention of mother to child transmission (PMTCT) program is not implemented during pregnancy, delivery and breastfeeding.<sup>7</sup> In Ethiopia, the pooled burden of MTCT was 11.4%.<sup>8</sup> Effective and timely provision of interventions is essential to tackle these highly prevalent and burdening new HIV infections among children.<sup>9</sup>

In early 2013, the new option (B+) guideline was introduced to provide a combination of three antiretroviral drugs for all HIV-positive mothers regardless of CD4 cell count.<sup>10,11</sup> Option B+ has an advantage of further simplification of regimen and service delivery and harmonization with the programs, protection against MTCT in future pregnancies, a continuing prevention benefit against sexual transmission to sero-discordant partners, and avoiding stopping and starting of drugs.<sup>12,13</sup> Similarly, the Ethiopian government launched the country's option B+ implementation in this year. Today, the majority of HIV-infected women are on option B+ regimens to remain healthy and to prevent new HIV infections of children.<sup>14</sup>

Option B+ regimen's effectiveness depends on adherence and retention of mothers to the care.<sup>15</sup> However, a high number of mothers were lost to follow-up (LTFU) that occurs throughout the antenatal, intra-partum, and post-natal periods.<sup>16</sup> Currently, the continuum of care now become a major challenge especially in low and middle income countries which significantly undermines the success of the regimen.<sup>17,18</sup> Different scientific evidence reported that even though PMTCT using option B+ was found to be associated with high rates of maternal viral suppression and low transmission to the infant, high treatment attrition, and poor follow-up of mother-baby pairs have become important programmatic challenges globally.<sup>7,19</sup> Evidence from systematic reviews majorly consisting of studies from SSA reported that nearly half of HIV-infected mothers initiated in option B+ were LTFU.<sup>20</sup> A retrospective study held in Western Ethiopia reported an overall incidence of LTFU of 9/1000 person-months.<sup>21</sup>

Increased risk of advanced AIDS progression, viral load, and risk of first-line regimens resistance were increased with attrition from option B+ which in turn increased MTCT.<sup>22,23</sup> In addition to this, LTFU from option B+ care is associated with treatment failure and leads to unnecessary use of second-line regimens (expensive).<sup>24</sup>

So, LTFU is still a serious challenge which is slowing down the success of the program. In Ethiopia, despite studies quantifying the magnitude of LTFU, qualitative studies exploring reasons and experience for LTFU towards the option B+ PMTCT intervention from each patient's perspective directly is limited and there is no evidence-based published qualitative study. Therefore, conducting this study is indispensable in order to explore experiences and for deeper understanding of the reasons for attrition from care among mothers who start the option B+ treatment protocol. The result gained from this study will be used as a baseline and initiator for policymakers, implementers and health professionals to inform future evidence-based practice that aims at enhancing retention, preventing and reducing new HIV-infections in children and lost follow up.

## Method

### Study Area and Design

This study was nested at East Gojjam Zone, Northwest Ethiopia. It has 60 PMTCT centers and 18 ART with PMTCT sites. From these centers, study participants were recruited from three PMTCT centers (Bichena, Lumame, and Dejen centers) which had high case loads. These three PMTCT serve the surrounding rural and urban population. A qualitative study using a case study design in-depth interview was carried out from January 1 to January 30, 2018. Qualitative technique was employed to elicit data that would enable researchers to explain experiences and reasons of attrition from option B+ from mothers, individuals plus key informants who enrolled and engaged option B+ treatment protocol.

### Study Population

An in-depth interview was conducted among women who were enrolled with option B+ treatment protocol but discontinued their follow up for more than two months without recorded transfer out. Individuals and key informants who were engaged for management and control of MTCT of HIV/AIDS at Woreda and Zonal level such as PMTCT focal person, health-care giver and mother to mother support groups were also included.

### Sample Size Calculation and Sampling Procedure

Twenty-six study participants including HIV-positive women, responsible individuals and key informants who were employed at PMTCT sites were included in this study. But,

saturation of ideas in relation to the interview guides were considered which affect the sample size. Study participants were selected using a purposive sampling technique from selected PMTCT sites which had high LTFU rate of option B+ treatment protocol using evidence from secondary data (Lumame, Bichena and Dejen districts). Those selected participants were recruited and identified by using either their registered own or supporter phone number or by searching for their details in Woreda and Kebele in collaboration with community health extension workers and mother to mother support groups. They are from both rural and urban centers and the majority of mothers were LTFU during pregnancy (75%) and the rest after delivery.

## Study Tools

An unstructured interview guide was formulated using National PMTCT guidelines of Ethiopia. The following points were addressed: effectiveness, importance of initiation and duration or treatment time of option B+, reasons or barriers for loss to follow up and facilitation to be re-enrolled, their experiences about option B+ treatment protocol and their reasons that made them discontinue this protocol, and further recommended suggestions for future improvement. Data collection tools were first prepared in English, then translated to local Amharic language to simplify the collection.

## Data Collection Methods and Procedures

Interview was carried out in local Amharic language based on their local context. After written informed consent was obtained, all mothers, responsible individuals and key informants were interviewed. A supportive note-taking were also undertaken. Experienced personnel with similar issues were considered for data collection. Interview guidelines were developed by principal investigators. The objective of the study was briefly stated to participants before the interview was undertaken. The experiences and reasons for attrition from the care of mothers were assessed by the moderator independently and participants were encouraged to explain it in unpretentious ways. Overall 26 participants, including mothers who had experience of loss to follow up from option B+ treatment protocol, health professionals and mother to mother support group who work at PMTCT clinics, and key informants who are employed at Woreda and Zonal level to manage and control MTCT of HIV/AIDS were interviewed. Ten participants were from Bichena district, 9 participants from Lumame and the other 7 participants were from Dejen district. Each in-depth interview was

took between 25 and 56 minutes. For the purpose of community perception and protection of their privacy, the setting was arranged based on respondent's preference. Data collection and probing of ideas were continued to the point of saturation.

## Trustworthiness of the Study

Prolonged engagement within the study participants was maintained to understand their culture, the overall setting and their phenomenon of interest. Data triangulation from different patient participants, key informants and health professionals using different methodologies, and member checks was done to maintain the credibility of data. Transferability related questionnaire was asked for the study participants after data collection, analysis and interpretation. Then transferability was mediated based on their explanation.

External auditors were used to maintain the validity or accuracy of the data collected. For each data collected, external auditors will follow it to check the adequacy of data collected and its preliminary results. Then afterwards the need of additional data gathering will depend on the external auditors of this study. This method was conducted at the same time as dependability is conducted. Audit trial and triangulation was used accordingly for maintaining the quality of the records.

## Data Analysis

After data collection, all interviews were translated back to English for analysis using thematic areas by two authors (TG and AN). First, these two authors read all the recorded data. Then, coding and interpretation were followed; any disagreement was solved using discussion and census, if not the third author was involved. The process of coding was done using main components of study guidelines. Analysis was conducted using already grouped themes, but also allowing for exploration of themes that emerged during the analysis. The main grouped themes used were: understanding option B+ treatment protocol; feasibility of treatment based on their understanding, their experiences and reasons for attrition from the care and transferability of their barriers for attrition from the care. Data were organized using manual methods and ATlasti software.

## Ethics

Ethical clearance was obtained from Institutional Review Board of College of Medicine and Health Science, Debre Markos University. Responsible officials and managers at Zone, District and Hospitals were communicated with and

permission letters were obtained. Informed written consent was obtained from each of the study participants. The results of the study was used only for study purposes. Data recording tools were discarded based on Debre Markos University Legislation after accomplishment of the study.

## Results

### Sociodemographic Characteristics

Twenty-six study participants (20 HIV infected mothers (3 of them were from mother to mother support group and the remaining were out of care for at least 2 months after initiation) and 3 health professional and 3 key informants) were interviewed in this study. All study participants were from Amhara regional state. The mean age was  $28.3 \pm 2.34$  years old. Majority of the study participants were uneducated (57.7%) and rural residents (65.3%) (Table 1).

### Importance of Option B+ Protocol

Regarding the importance of option B+, participants stated that the present treatment regimen is very crucial to reduce the new occurrence of HIV-infected children, and should be taken daily which need lifelong commitment. All the women understood this and stated that the drug should be taken on daily based in line with nutritional status.

... this program was established eight years before ... which includes both PMTCT and ART services. By using those programs MTCT was reduced. I am a customer for PMTCT services for this health center for the last 8 years ... I gave 3 children in this year using the present PMTCT services and I assured all of the children were free of the infection. (LosM-3)

... before this program there were other protocols which depend on Cd<sub>4</sub> count (treatment started when Cd<sub>4</sub> count

decreased) but I know the treatment initiates immediately after the virus found in the blood irrespective of Cd<sub>4</sub> count. This is one of the importance of option B+ over the previous protocol because it will prevent MTCT by reducing the viral load and keep the mother healthy by tackling opportunistic infection. Related to this, I am one example for the effectiveness of the protocol because I have a five years old female child free from HIV. By using this evidence knowledge I am working in a mother group in the nearby health center to support those mothers who had HIV in their blood and start the treatment, by sharing my experience in turn to help them not to be lost from their treatment as much as possible. (MTMS-1)

Almost all interviewed HIV-positive women (15/17) had HIV-free children. In the previous history of their follow up, they have taken their medication and follow up strictly. But, in the recent follow up due to sociodemographic reasons, there was interruption of their follow up.

... this program helps me to stay as healthy and it prevents my child from HIV infection. At third month of my gestation age, my care giver told me the status was reactive, the therapy was mandatory and start option B+ immediately, and then I am taking my medication strictly for the rest of my life, due to this me and my child stay well. (Lost M-1)

### Reasons for LTFU

Socioeconomic and personal barriers were the most frequent raised reasons for LTFU. Lack of education, and poverty characterized with lack of transportation and consuming of time with day to day finding of food, and lack of family and partner support were important barriers faced. Among 17 mothers who had interrupted their care, 15 of them were uneducated. The majority of these women related their LTFU with education status, characterized with inability to read their appointment details, and lack of permanent source of income even for transportation and food source.

....I didn't want to be lost from my follow up, but sometimes I didn't remember my appointment. All my families (my mother, me and my kid) cannot read and write. No other relatives were around me (I was divorced from my husband because of discordance). As I was not educated, I had no permanent source of income even for day to day consumption. We are living with income that I have got by selling a traditional rural cereal storage called "gota". Even sometimes I didn't get money for transportation which obligates to loss. Lost M-8

**Table 1** Sociodemographic Characteristics of Study Participants

Characteristics		N	%
Residence	Rural	17	65.3
	Urban	9	34.7
Marital status	Married	16	61.5
	Single	2	7.7
	Divorced	8	30.7
Education	Formal education	10	38.4
	No formal education	16	61.6
Disclosure	Yes	7	41.2
	No	10	58.8

... lack of formal education regarding both family and the client, lack of transport related to distance of the facility and lack of money, are the most pertinent reasons mostly I encounter when I am working as mother to mother support group. Even there are mothers who have difficulty in reading their appointment time, due to lack of education and even to ask help from family or neighbors they fear disclosure and stigma. (MTMS-2)

... the main reason why I was lost from my treatment is due to forgetting my appointment day because both my mother (family) and I were uneducated. So I can't read. Even though it was not the main reason, lack of money for transport was another cofactor (distance and economic) for my lost ... even sometimes extension worker (community health worker) gives money for transport. Otherwise I would be used my leg or option of lost. As I have said before I hadn't constant work to source food even to hand to mouth for my family (economic) ... which added another burden to lost from my treatment. (Lost M-2)

In addition, lack of male involvement, discordance and disclosure of status were also put as a significant burden on LTFU. During implementation of PMTCT particularly during option B+, male involvement or engagement and support should be strictly considered. More than half of women who did not disclose their result in turn were living in good relations with their community while known infected mothers faced stigmatization.

... there are also mothers who are lost due to discordant and lack of acceptance ...today there are so many couples who are discordant and after the result they said "I didn't believe it because nothing do out of my husband and nothing use with my neighbors" so they think it as incorrect result and didn't accept the counseling ... they also assume that their husband may kill them due to the reason that where you get ....so they preferred not to accept their status. (KI-3)

Even though many women were in relationships and had a strong desire to be tested together (asking many times even with invitation letter), two-thirds of their husband refused to do so. Although a few of them were tested, nothing was disclosed about their result. Others also stated that their result caused discordance, their husband did not support them financially and emotionally, leaving them alone and exacerbating their feeling of isolation. This could be due to the majority of rural women being economically dependent on their male partners.

... For example, regarding to disclosure status; I have one experience. I got one woman who put the medication as it

was in pack for one month and when I asked her she said "simply I put it in my house" because I feared my husband. She said if he know I was a HIV positive, he may divorce me and I will be left alone. So it is better to leave the medication rather than to divorce .... some mothers also are lost due to lack of education ... even they didn't remember and read when it was the appointment time. (MTMS-3)

Community level stigma-discrimination and long distance from health facility or unavailability regimens in the nearby health post were other frequently raised barriers for option B+ treatment protocol particularly in rural areas. Three HIV-positive women were faced with social isolation (stigma) after disclosure while the other five women were stigmatized with suspicion. Those women who had not disclosed their status decided to be lost from the follow up so that their community would not find out and to avoid social isolation. This is also happening at family member and partner level. Another key issues affecting option B+ adherence for mothers was long distance of health facilities particularly in rural areas. Three out of 14 interviewed women described that they did not get enough counseling during testing and initiation, even one woman said that she had not taken enough deeper counseling at all.

## Prevention of LTFU and Reasons for Re-Start the Treatment

Male involvement is very important especially at the time of initiation. Moreover, sharing experiences with mother to mother support group and availability of regimens in the nearest health facility are the common issues to be addressed in order for those women who had been lost from option B+ treatment to be re-enrolled.

... This a challenge for us since they didn't come again once they default from the program. The best alternative to reduce lost to follow up among newly initiated mothers was to invite their sexual partner and they should come together at the same time. This makes easier for PMTCT focal person to counsel about the benefit of the program for both their health and newly coming infant. KI-4

... lost to follow up becomes one of the main reason for prevalence of MTCT. So, to tackle this problem and to prevent burden of HIV disease in children, at least one mother to mother support group experience sharing is essential for those women engaged in option B+ treatment protocol, the government must avail drugs to the nearest health facility as much as possible, community and



individual level education and awareness creation using different methods including social media and short- and long-term socioeconomic support for vulnerable households. After all, disclosing of status to their family particularly for sexual partner is important. All these things have their own impact on LTFU. For example ‘my husband and I take our medication at the same time. Because when I see my husband was taking his medication, I rehearse my medication time’. Even in discordant status sexual partner tell to take the medication when it is lost. Lost M-10

Giving counseling depending on the socio-demographic background of the patient was an important issue raised by experienced health professionals. It is very important to support and stand at their side among vulnerable population group like sex worker and students particularly in small town surrounded by rural areas.

... this needs professional commitment to counsel about the side effects and benefits of the drug. First of all, it is better to identify their educational background, since their counseling mechanism for non-educated and educated individuals are automatically different. So, with a lack of professional experience to counsel those individuals, family related issues such as “fear of divorce from the family”, geographic variation (for example “the radius of this health center” in which it becomes far away from the health center increases attrition from the care) and individuals from hot or “qola” area are more at-risk groups. In my experience, I have observed different categories of individuals under this program. There were HIV-positive students (due to fear of their family they prefer to default and even feeling suicide) and some of them were commercial sex workers-these individuals fear that loss of their sexual customer if their enrollment under this program is exposed. KI-6

## Discussion

Generally, we have identified socio-demographic and economic barriers such as educational status, low income level, distance from health facility or unavailability of regimens in the nearest health facility, societal barriers such as stigma discrimination, lack of experiences during counseling, discordant in sero-status with sexual partner and absence of disclosure with family members as the most common barriers for attrition from the care. In addition, male involvement, availability of regimens in the nearest health facility and sharing experiences of mothers with similar experiences (mother to mother support group)

were important factors in the re-enrollment of women who had been lost to follow up of option B+.

Socioeconomic barriers such as educational status and financial reasons characterized by lack of transportation and losing time in each day by finding a source of food were the most common stated reasons for attrition from the treatment protocol and consistent with findings done elsewhere.<sup>25–27</sup> This finding is supported with meta analysis conducted in Sub Saharan Africa which declared that poverty and lack of education influence families to adhere to the treatment protocol.<sup>28</sup> In most developing counties like Ethiopia, education is considered as the major source of income. And more than two-thirds of the population were resident in rural areas, in turn associated with educational level as manifested with poor socioeconomic status and limited source of income. So, short- and long-term societal safety nets targeting such households is needed.

Our finding also revealed that lack of disclosure to sexual partner and other family members and lack of sexual partner support were described as major reasons. In many Sub Saharan African countries including Ethiopia, the husband is the primary decision maker regarding family issues and most women are economically dependent on men partners. Lack of sexual partner support in PMTCT was also a pertinent determinant and frequently raised reason. Different evidences supported that engagement of male partner in PMTCT program improves disclosure, support and better communication, and better follow-up outcomes.<sup>29,30</sup>

In adding to this, stigma-discrimination was also still a common barrier for LTFU in Ethiopia. This indicated that there is a need for community level measures to prevent associated stigma at domestic and societal level. These findings are supported and consistent with other findings.<sup>25,31–34</sup> A systematic review held in Sub Saharan Africa evidenced that stigma, fear of disclosure and lack of partner support were not changed over time in Africa and continued to be a plague of PMTCT programs.<sup>35</sup> A qualitative study done in Malawi confirmed that lack of support from husband or family member, long distance from health facilities, poverty and community level stigma were reasons contributing to LTFU.<sup>36</sup> Another mixed study conducted in Uganda also confirmed that HIV/AIDS related stigma discrimination, distance from health facilities and lack of transportation to health facilities contributed to LTFU of mothers.<sup>37</sup>

Long distance from health facility and unavailability of the regimens in the nearby health facilities also another

important barriers identified for LTFU from option B+ and consistent with previous studies.<sup>38–40</sup> All these findings were supported by the finding of a clinical audit conducted in Guinea which stated that long distance from health facilities and lower educational attainment have negative impact of retention on the program.<sup>41</sup> This could be due to the majority of the study population being resident in rural areas in which transport is costly as a result of poor socio-economic status and leads mothers to walk long distances to get the service.

Furthermore, forgetting appointments, and absence of constant work were also raised as barriers for LTFU. Moreover, sharing experience to newly coming HIV positive women with experienced mothers (such as mother to mother support group), and appropriate counseling with experienced health-care provider were very important to address their fear, social isolation and challenges faced.

Our study has a main strength and some limitations. Firstly, this study was done in triangulation form which includes HIV-positive women experiencing loss to follow up, key informants and mother to mother support groups having similar experiences, and assesses reasons at different aspects. In addition, this study was conducted at both community and institutional level which addressed all issues. These qualitative results provided arguably the most useful insights, for example describing barriers and facilitating factors from the perspective of the patient or provider and how they affected ART uptake. But, our study was conducted on small sample of study participants even though important issues were addressed and idea saturation was considered. In addition, this study used purposive sampling to select study participants (non-probability), which might be difficult to generalize.

## Conclusion

The present study confirmed that educational status, financial issues, partner or family member support, distance from health facility, disclosure status, stigma and discrimination were important barriers leading to LTFU. In addition, this study also highlights the need for having experienced counseling, advocating education and empowering women, availability of treatment regimens in the nearest health facility and creating awareness at community level to avoid stigma. This implied that PMTCT is not a simple program, which requires a multidisciplinary and multifaceted, community-based approach and country-level efforts like economic reforms to ensure option B+ protocol is correctly applied, MTCT is minimized and to increase retention in care.

## Abbreviations

AIDS, acquired immunodeficiency syndrome; ART, antiretroviral therapy; HIV, human immunodeficiency virus; LTFU, lost to follow up; MTCT, mother to child transmission; PMTCT, prevention of mother to child transmission; SSA-Sub-Saharan Africa; WHO, World Health Organization.

## Data Sharing Statement

The datasets analyzed during the current study are available from the corresponding author upon reasonable request.

## Ethics Approval and Consent to Participate

Ethical clearance was obtained from the Institutional Review Board of Debre Markos University's College of Medicine and Health Sciences. Then, officials at different levels were communicated with. Then, informed written consent from all participants were obtained. Confidentiality of the information was secured throughout the study process and consent was obtained on publication of anonymized responses. In addition, all methods were carried out in accordance with declaration of Helsinki (ethical principles for medical researches involving human subjects) and relevant guidelines and regulations.

## Consent for Publication

Not applicable.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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## Disclosure

The authors declare that they have no competing interests.

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