

# Perceptions of mothers and healthcare professionals to contributors and preventions of loss-to-follow-up and child mortality at the PMTCT program after option B + guideline implementation in northwest Ethiopia

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## Research article

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# Abstract

**Background:** The third United Nations Sustainable Development Goal includes a commitment to end HIV. In lined with the Sustainable Development Goal, Option B+ programs hold great promise for preventing transmission of HIV and moving towards an “AIDS-free generation. However, an estimated 110,000 AIDS-related deaths occurred among children in 2015. The Global Plan also identified Ethiopia as one of 22 high priority countries for improved prevention of mother to child HIV transmission services. But, there is a scarcity of data on the contributors of loss to follow up and mortality after option B+ guideline implementation in the Amhara regional state, Ethiopia.

**Methods:** This study conducted in five zones of the Amhara regional state, Ethiopia. The study considers mothers that admitted to the 5-referral hospitals’ PMTCT departments, midwifery professionals who work in the respective hospital’s PMTCT departments, and HIV officers. The period for data collection was from March 21 to May 18/2019. An in-depth qualitative interview employed to gain access to the participants’ experiences and conducted an inductive qualitative content analysis.

**Results:** Mothers, health professionals, and HIV officers were asked about the contributors of lost to follow up in the Amhara region. The participants’ suggestions on the causes categorized into a health facility, stigma and discrimination, and socioeconomic status themes. On the prevention of loss to follow up, the views of study participants were categorized into health facility improvement, psychosocial support, and loss to follow up retention mechanisms. On the causes of HIV related mortality, participants’ views categorized into vertical HIV transmission, carelessness of parents, and poor socioeconomic status themes. In the recommendations to prevent loss to follow up and mortality, participants forwarded their suggestions for health facilities and professionals and civic societies. On the prevention of mortality, participants’ views categorized into health care and mothers’ awareness.

**Conclusions:** The participants were emphasizing the health facilities, health care professionals, and awareness of families to prevent loss to follow up and mortality among exposed infants after admission to the PMTCT program. Hence, concerned bodies mainly minister of health should outline on improving the service provided in the PMTCT department.

## Background

After the United Nations Millennium Declaration, great gains were made in addressing the global HIV pandemic(1). The coordinated scale-up of antiretroviral medications worldwide has contributed to the increase in life expectancy due to the decline in HIV/AIDS-related deaths (2, 3). The United Nations envisions that efforts towards the elimination of HIV and HIVAIDS related deaths will continue through the Sustainable Development Goal (SDG)(4). The biggest challenge of elimination of HIV is the high numbers of new infections in children. About 160 000 children globally are infected by HIV(5). Despite new HIV infections in children being considerably high, the HIV vertical transmission has decreased by 48% between 2009 and 2014(6). Nevertheless, vertical transmission is still attributed to about 20% of all

HIV infections in children. Therefore, more research is needed in poor performing countries (7). In 2016, the Global Plan identified Ethiopia as one of the 22 high priority countries that need improvement of the Prevention-of-Mother-to-Child HIV transmission (PMTCT) services(8).

Currently data shows that the transmission ranges between 7% and 18% in Ethiopia after the implementation of the Option B + program in the PMTCT department(9, 10). Other countries who implemented Option B + programs have seen the reduction of vertical transmission to be less than 1%, therefore Ethiopia have not yet realized the full potential of Option B + program(11). One of the biggest challenges of implementation of Option B + program in Ethiopia is the retention in care and adherence to ART in the prenatal and postpartum periods (12–14). In 2016, the global PMTCT coverage rates was 76% of the 1.5 million pregnant women living with HIV(15), but evidence suggests that low service uptake and poor retention along the clinical cascade for mothers and their infants poses a formidable challenge to achieving elimination of vertical transmission(16, 17).

Evidence suggests that poor retention of clients in the PMTCT program in sub-Saharan Africa is a major contributor to increased vertical HIV infection(18). The loss-to-follow-up(LTFU) in most of sub-Saharan states range from as low as 9.6% to a high of 61% depending on level of PMTCT cascade and settings (18).The LTFU in Ethiopia is estimated to between 12% and 23% depending on the level of PMTCT cascade. Evidence suggests that younger women, stigma and discrimination and lack of spousal involvement as the main contributors to LTFU and eventual child mortality(18, 19). These factors vary by country and sometimes the national factors are not similar with the district level factors. Therefore, to successful develop interventions that reduce LTFU, researchers need to focus on smaller scales such as district level factors. Although the PMTCT program is critical in preventing both HIV infection and mortality of children and their mothers after enrollment to the program, there is a scarcity of data on the contributors to LTFU and eventually mortality of children after option B + program implementation in the Amhara regional state, Ethiopia. Therefore, the objective of this study is to explore the perception of mothers and healthcare providers on contributors to LTFU among mothers and infants and mortality among HIV exposed infants after implementing option B + program and how LTFU and mortality can be reduced in the Amhara regional state, Ethiopia.

## **Methods**

### **Design, study setting and period**

This study used a explorative descriptive qualitative design(20, 21). The study was conducted in five zones of the Amhara regional state, Ethiopia. Amhara region is located to the southwest of Ethiopia and has 15 administrative zones. The region has 5 referral hospitals that provide PMTCT services in accordance with the option B + national guideline(22). The referral hospitals were found in north Shewa zone (Debrebirhan referral hospital, Debrebirhan, Ethiopia), south Wollo zone, (Dessie referral hospital, Dessie, Ethiopia), North Gonder zone, (Gonder referral hospital, Gonder, Ethiopia), west Gojjam zone,

(Felege-Hiwote referral hospital, Bahirdar, Ethiopia), and east Gojjam zone (Debremarkos referral hospital, Debremarkos, Ethiopia). The period for data collection was from March 21 to May 18, 2019.

### **Population and eligibility**

The target population was mothers admitted to the five referral hospitals PMTCT departments and healthcare professionals working in the PMTCT departments or in the respective zonal health departments as HIV officers. The eligibility criteria for mothers were 1) the mother should be expecting a child, 2) HIV positive and enrolled in the option B + program at one of the 5-referral hospitals of the Amhara region between January 01/2018 and September 2019. 3) Able to read or understand consent in Amharic or English. Eligibility for health professionals was 1) working for at-least two years as an HIV officer or 2) having 2 years of more working in any of the five-referral hospitals PMTCT departments. Mothers were not considered if 1) they had several co-morbidities, 2) having antiretroviral failure, while healthcare providers were not considered if working on half-day basis.

### **Sampling and sample size**

Purposive sampling was used for selection of subjects. Purposive sampling was used to ensure that the sample was heterogeneous and richness in data to ensure rigor. A sample size of 46 subjects was selected. A total of 24 mothers enrolled in the PMTCT department, 12 health professionals working in the PMCT departments, and 10 zonal HIV officers. The sample size was based on data saturation.

### **Ethics**

An ethical clearance obtained from Woldia University institutional review board committee. An official permission letter got from zonal health departments and town administrators. Written consent was obtained from all participants and when necessary the interviews were terminated at the behest of participants. All data was de-identified.

### **Data Collection Tools And Procedures**

Data was collected through individual interviews with a member of the research team. The interview was audio-taped and lasted from one and a half to two and a half hours. Five open-ended questions were used. The interview guides developed in English guided by(23), and translated to Amharic by an independent person and translated back to English by an independent person to ensure consistency. The interview guide was pretested on seven participants in Debretabore town and contributed to some adjustments to the interview guide. Interviews were conducted during the mothers stay at the hospital on a single occasion and during working hours in the facility for health workers. Data was collected by trained data collectors with at-least one previous experience of qualitative data collection.

### **Data Processing, Quality Assurance And Data Management**

Transcribers were trained from the data collectors. The interviews were transcribed by experienced and certified qualitative data transcribers and translators. Two independent transcribers listened to audio record and transcribed the interviews verbatim. The difference between the audio record and transcribed text was verified through member check. The transcripts where then translated to English and verified

through member check if it has captured the essence of their experience. The transcripts were then read by the researchers to obtain a preliminary understanding of the participants' experiences and the context(24). Where it was not clear the researchers listened to the tapes and clarified with the transcribers. Data was organized and managed through the NVivo 10 software (28).

## Data Analysis

Thematic analysis was used for data analysis(25). Two authors independently read and coded the transcripts. In the initial exploration of the interview, the whole interview was read to capture the essence of the entire transcription. The authors then read the first four interviews (2 from mothers and 2 from healthcare professionals) and generated the initial codes which were compared, disagreements on the interpretation of meaning units, code labels and categories were discussed until agreement was reached and the final codes were confirmed with an additional third author. Consequently, NVivo 10 software(26) was used to extract the data from the interviews including expanding the codes when necessary using sentences and text passages(27). Following the initial coding, a manual inductive analytic approach was used to expand the extracted codes using open codes and notes (25, 28). In the initial coding cycle(29), the meaning units emerged freely from the text and had been given a descriptive code label (Table 1).

Table 1  
Examples of meaning units, condensed meaning units and codes

<b>In-text statements</b>	<b>Condensed meaning unit</b>	<b>Code</b>
Lack of commitment	Health facility related factors	
Fear of family response	Stigma and discrimination	
Poverty	Socioeconomic status	
Admitted to civic societies	Psychosocial support, empowerment	
In the second coding cycle(27), codes were sorted into mutually exclusive categories and sub-categories (Table 2).		

Table 2  
An example of category, sub-category and descriptive codes

Codes	Sub-category	Category
Lack of professionals in number Lack of professionals with better education Lack of counseling training for professionals	Shortage of adequately trained staff	Health facility related factors
Poor professional ethics in the PMTCT	Poor customer service	Health care providers attitudes
Mother should appreciate the signs that caused them to visit health facilities Mothers should be counseled to visit health facility together with their children for screening	Health seeking behaviors	Parental awareness
The categories and sub-categories were revised several times to ensure that the contributors to mortality and LTFU reflected the participants' perceptions(27). Data saturation was reached when the redundancy in the responses was recorded at least 10 times and when no new concepts emerged regarding the perception of LTFU and mortality.		

## Trustworthiness

Cognitive interviews were used to ensure that the interview guide was reliable and valid in Debretabore town, which is 50 km from Bahirdar, the capital city of the Amhara region. Checking was used at the transcription stage to ensure that the transcribers captured the participants view correctly and was there a difference. Member check was used to ensure that the transcripts were capturing the essence of their experiences. The credibility, dependability, conformability, transferability, and authenticity were used to ensure trustworthiness(30). To ensure credibility(20), we selected a maximum variation sample to capture the range and variations of the first-hand perception of mothers and stakeholders(31–33). The interviews had open-ended questions, allowing the participants to speak freely, using their own logic(31). Dependability(20) was guaranteed by recruiting participants who had experience or understanding the phenomenon at first hand and having a team of coders rather than individuals and use of field notes(21). Conformability(20) was guaranteed by two authors independently coding the transcripts. Transferability(20) was sought by providing detailed descriptions of all aspects of the study, helping readers to judge whether the findings would be applicable in other contexts. To ensure authenticity(34), the findings reflect multiple realities and differences in functional ability at each phase of the trajectory.

## Results

### Demographic characteristics

Forty-six participants completed interviews between March 10 and April 27/ 2019 against the 57 expected interviews due to data saturation. The sample consisted of mainly females (73.9%) with age ranging from 20–59 years and 30–39 age groups being the modal age group (31.1%). Mothers and HIV officers constituted 52% and 22% respectively. More demographic characteristics are presented in Table 3.

Table 3  
The demographic characteristics of participants

<b>Variables</b>	<b>Categories</b>	<b>Frequency</b>	<b>Percent</b>	<b>Mean</b>
Gender	Male	12	26.1	
	Female	34	73.9	
	Total	46	100	
Stream of participants	Mothers	24	52.2	
	Professionals at the included hospital	12	26.1	
	HIV officer at zonal health department	10	21.7	
Age	Mothers			36.21
	Hospital Health professionals			32.17
	HIV Officer at Zonal health department			43
Age group	20–29	12	26.1	
	30–39	18	31.1	
	40–49	10	21.7	
	50–59	6	13.0	
Mothers Parity	1st Pregnancy	4	16.67	
	2nd Pregnancy	12	50	
	More than 3 pregnancies	8	33.33	
Mothers HIV + Status	New (during antenatal care	5	20.83	
	Known on ART	19	79.17	
	Known not on ART	0	0.00	
Mothers education	Primary	9	37.5	
	Secondary	5	20.83	
	College/university	10	41.67	
Profession	Housewife	12	26.1	
	Government employee	30	65.2	
	Merchant	4	8.7	

Variables	Categories	Frequency	Percent	Mean
Length in profession	2–4 years	13	54.17	
	5–8 years	7	29.17	
	More than 8 years	4	16.67	
Health professional education Level	Certificate	0	0.00	
	Diploma	6	25	
	Degree	18	75	
Place of participants	Debreworkose	8	13.4	
	Gondar	10	21.7	
	Bahirdar	12	26.1	
	Dessie	8	13.4	
	Debreberhan	8	13.4	

## Themes

The results were categorized into two major groups; first addressing contributors to loss to follow-up and child mortality, and secondly possible solutions to prevent loss to follow-up and child mortality due to HIV in Amhara region. Five (5) themes were identified for contributors to loss to follow-up and child mortality while four (4) themes were deduced for prevention of loss to follow-up and child mortality.

### Contributors to loss to follow-up and child mortality

Contributors to loss to follow-up and child mortality are categorized into five themes; 1) Carelessness- addressing parents' attitudes towards their child's health and willingness to commit to option B + program, 2) Stigma and discrimination- capturing the parents' fear of isolation from family and the community, self-blame and lack of disclosure of the status. 3) Access - elucidating on physical barriers to access such as distance to ART centers and resource shortages in ART centers. 4) Health care providers behavior and attitudes- highlight the lack of commitment and negative attitudes exhibited to PMTCT users by healthcare providers in the region, and 5) social determinants of health- discussing how poverty in the region lead to loss to follow-up and child mortality.

### Carelessness

*"...Sometimes I missed the time of my follow up without any apparent reason, but when health care professionals contacted me through the phone, I came back again..."M2.*

Both parents and health care providers indicated that mothers' carelessness affects their decisions to continue with option B + program despite being aware of the benefits it carries for the child. Carelessness

was also identified as a major factor in child poor nutrition and consequently leading to illnesses and death. Mothers did not care for their children because of the probability that their child was free from HIV. Mothers also opted for mixed feeding rather than exclusive breastfeeding or complementary feeding because they believed the chances of their child contacting HIV was low.

*"...mostly mothers did not care for their children. Seriously, even when their status is disclosed, they deny ART for their children, and refuse them getting HIV test...they also practice mixed feeding..."HP7*

Carelessness also was apparent among health care professionals lack of drive for the program and patient centeredness. Health care professionals often collected incomplete history, inconsistency in prescribing medicine and conducting required investigations. There was lack of strict guidelines on medication administration, follow-up care on children and when to test them despite the WHO guidelines being available. Also, there was no clear hospital/center record on when the mothers should come for follow-up, therefore when a mother misses her appointment; it takes time to know about it. In addition when it is apparent that the mother is lost to follow-up, healthcare professionals did not usually call the mothers despite having access to their contact details, phones to call and/or even transport to check on the patients in their villages when necessary.

*"...she is not prescribed medications like Cotrimoxazole, if the child looks healthy most of the time I was not sending sample to the laboratory, if the mothers did not complain that their children had GI, GU, and other sign of illness..." HP12*

### **Stigma and discrimination**

*"...the emotion of my family is variable, and they discriminate and condemned me as a guilty. Thus, I am not interested and focused for the follow-up; rather I worried about the view and opinion of my family..." M10*

Stigma and discrimination were identified as a major hurdle for parents to continue with the PMTCT and also to adhere to exclusive breastfeeding or formula feeding leading to the HIV infection of the children. It was also indicated as a direct cause of mortality due to lack of testing of children by parents despite knowing the risk the child faces. In Amhara region, stigma and discrimination emanate from the lack of acceptance by the family and lack of understanding by the health professionals.

*"...When I was going to hospital for follow-up, the reactions of health professionals are not welcoming. Sometimes, health professionals closed the PMTCT clinic, and sometimes they show uncomfortable facial expression while I ask them to provide the necessary care..."M6*

Therefore, mothers do everything in their powers not to disclose their status or allow their children to be tested for HIV. To ensure that their status is not disclosed, mothers also practiced mixed feeding or breastfeeding beyond the recommended time. The stigma and discrimination is also exacerbated by the lack of privacy when breastfeeding and fathers uncooperativeness and negligence about their own HIV status. Also, the lack of understanding of mothers and children needs and challenges by the health

professionals leads to stigma and discrimination tendencies despite ethical conducts guidelines being in place

*"...when I oppose breastfeed for the child, all the families pointed towards me as are you HIV positive or. Thus, I forced to continuing breastfeeding till 2 years old of my child unless I was risky for discrimination..."* M14

Health providers also identified stigma and discrimination as a major risk for LFTU and HIV child mortality in the region. Health workers stated that due to fear of stigma and discrimination many mother do not opt for the PMTCT program and those that do, some do not complete the program due to fear and as such exposing children through mixed feeding and eventual not showing up for testing while the virus is affecting the baby if he/she is positive.

*"...if mothers disclosed their status, the communities including families discriminate them in different events like delivery of first aid measures if mothers faced accident that cause bleeding, and annual cultural celebrations..."*HP3

### **Access**

Access to services was identified as one major factor in LTFU and child mortality due to HIV. Access to service theme include; the physical structure of the health facilities, resource availability, and distance to ART services for patients. The physical structure of health facilities were identified as a major hurdle to privacy of patients and as such lead to patients not willing to participate in the PMTCT program. For instance, the lack of counseling room in majority of PMTCT facilities was cited as a major reason for LTFU and parents' unwillingness to bring their babies for testing.

*"...when I visit the clinic for ANC service, they transferred me to another room that is labeled as PMTCT room...thus, it might be good, if all the services provided for women handled in secret room without label if we want to keep women's status a secret..."*M18

*"...The structure of the clinic might not respect the privacy and confidentiality of mother who visit the clinic. Mostly the room is arranged in nearby to ANC rooms. Thus, if mothers are positive, they are referred to PMTCT room which might be considered as discrimination for mothers..."*HP16

Also, resource availability was identified as a major barrier towards access to the PMTCT program and often leads to parents losing trust in the program and abandoning it. Both parents and health care professionals cited the chronic shortage of PMTCT service providers. The shortage of healthcare providers often lead to lengthy waiting periods, long queues for services which often exacerbate suspicion from families and friends hence leading to stigma and discrimination. This also affects the women's contribution to their homestead and further putting them into poverty.

*"...when we visit the clinic, the professionals are not available in the clinic, and we forced to turn back home without receiving the care and booking the next appointment..."*M21

*"...currently the attention towards PMTCT service is not good as previous. Some managers think the unit as extra duty not as routine duty. They did not assign sufficient staff in the PMTCT room, even when the hospital has many professionals. Furthermore, the staffs assigned in the PMTCT room did not receive any training..."HP22*

Shortage and interrupted supplies of medicines was also identified as a major reason for LTFU and child mortality due to HIV. Shortage of medicines used in Option B + program was identified as a major issue as some centers can go for some months without essential drugs such as Nevirapine leading to patients being referred to other centers. When patients are referred to other centers, sometimes they get confused on where to continue with the services and some do not go but rather go home leading to LTFU and eventually child infection and possible deaths. As one ART officer stated, the absence of medications like Nevirapine cause referring patients to other ART centers, but some patients were not going to other ART centers and consequently go back home

*"...Most of the time the health care professionals tell us that medicine is not available, and instructs us to visit other centers..."M9*

*"...medicines particularly syrup preparations are frequently out of stock in ART centers and patients get tired on checking or being referred to other centers and they usually don't come for follow up..."HP19*

Lastly, participants particularly mothers indicate that distance to ART centers are a huge problem for many of them. In addition, ART centers were reported to be isolated from other services so patients cannot get comprehensive health services and had to go to other services for those services.

*"...Some of the women are coming out of the town, which are far more than 10 km. This is a challenge in particular when medications are not there and appointments moved to other days..."M11*

*"...According to the minister of health current PMTCT structure, the service is provided for the community in cluster that expose some mothers for long journey..."HP15*

### **Healthcare providers' attitudes**

*"...professionals assigned in the PMTCT department are not involved in other services, and therefore not benefiting from some of the incentives others have. Also, the professionals are part of the community in which cultural practices are ingrained and HIV and sexuality topics are a taboo, therefore, they might display negative attitude to these women based on myths or cultural perspectives. Consequently, the quality of health service provided for these women is usually compromised..."HP9*

Participants also indicated that the healthcare providers often display negative attitudes toward PMTCT service consumers and also lack commitment to the program. The negative attitudes and lack of commitment to the program has led some users to develop distrust in the program hence dropping or stopping to use the services altogether. Health care providers' lack of interest in the program and welfare of the participants also lead some users who have lost-to follow-up does not seek services when the child gets ill or getting the child tested leading to complications and sometimes death.

*“...The facial expression and gestures of health professionals while you visit OPD or other health care service and PMTCT service are different. The PMTCT staffs deny our interests; they don't want to listen about the side effects of the drugs, and cannot accept other laboratory investigations requests...” M2*

*“...The PMTCT service provision culture needs to be modified. The mothers' expectations when they visit PMTCT service are ideal. In opposite, the hospitals did not fulfill the requirement for the services as they advertise them to the mothers. Thus, the burden is for the PMTCT professionals, and would have negative attitude as a reaction for the mothers' expectations and hospitals preparation...” HP1*

### **Social determinants**

*“...the social determinants like poverty, lack of husband support, and other familial responsibilities placed a burden on women, which are repeatedly reported from mothers as a cause to LTFU in the program and latter cause to child mortality.” HP19*

Social determinants theme emanated from reports of poverty and socio-cultural challenges facing women in the PMTCT program such as poverty and lack of involvement of spouses. Poverty was identified as a major factor in both women loss-to follow-up and child mortality related to HIV. Poor women often did not have access to services due to distance, competing priorities of feeding their families and attending PMTCT programs. Poverty was also highlighted as a major contributor to poor nutrition and lack of care that exposes the child to many illnesses including death.

*“...Mothers from a poor household might face multiple problems. The woman might become malnourished and fasten the progress of the [HIV] infection, which might also increase the risk of the transmission to the child, or the woman might busy on finding jobs to feed their family, and the child might become undernourished and develop other infections. All such scenarios might cause mothers to loss hope on life and might discontinue the PMTCT service...” HP4*

Also, socio-cultural issues relating to lack of spousal involvement in maternal and child health issues were evident as contributors to LTFU and child mortality and mothers decried the lack of spousal involvement as one reason. Most women and health professionals stated the long-held cultural practices in the country aid husbands to neglect children and mothers. Usually, husbands spent the working days from Monday to Friday away from home at work, and appointments of mothers for PMTCT are also during these working hours. Therefore, if there are responsibilities that require the presence of a family member in the home during the working days, the woman is forced to discontinue the follow up, unless there is a provision where the husband can miss work to supports them.

*“...The cause for the infection is my husband, but he always claims it's me. He has not agreed on the follow-up and is not willing to visit the clinic together with me. He forced me to discontinue the care; I refused and took precautions for my child...” M3*

*“...I am not sure about the source of infection, but my husband always blamed me and he thought as I am the source of infection. Thus, he is thinking that neglecting me means just punishing me for my faults. He*

*frequently insults me and also uses physical force on the days of my follow up to prevent from visiting the clinic...*"M20

### **Prevention of loss-to follow-up and child mortality**

Prevention of loss-to follow-up and child mortality is divided into four themes; 1) Access - addressing improvement of physical barriers, resource availability and mechanisms for follow-up, 2) Psychosocial support- capturing avenues to avail psychosocial support and building community networks for resilience, 3) Education and awareness- addressing parental and healthcare providers awareness on issues of loss-to follow-up, child mortality and making PMTCT facilities clients focused, 4) Empowerment- elucidating on areas that could be tapped into to reduce disparities and address social determinants of health.

### **Access**

Access theme under improvement of PMTCT aimed at eliminating both physical barriers, resource shortages, improving quality of services and devising mechanisms for follow-up. While participants acknowledged the limitation of the physical barriers, they understood that building more structures comes at a cost therefore they advocated re-designation of spaces to improve patient flow.

*"...the ART pharmacy, and follow up OPD is a separate building, which is a challenge for woman who have not disclosed their HIV status. Thus, if the pharmacy and follow up of HIV positive mothers is hidden, it respects their privacy and confidentiality, particularly who are not disclosed their status..."M7*

Participants also indicated that ethical issues need to be addressed in counseling and health care providers be trained in sensitivity of HIV issues and how they can best support the mothers during these difficult times. HIV officers also stated the unethical conduct of professionals was one of the reasons for mothers' loss to follow up and other consequence of LTFU.

*"...One health professional insulted me using a strong term that related to HIV. Most health professionals are also thought that all the woman who acquire HIV because of their sexual misconducts and consider them as whores..."M23*

For shortage of drugs and interruption of supplies, participants suggested that health care providers form a network so that they know where clients can get the services or even have the drugs shipped to areas where they are rather than referring the patients to other centers.

*"...When mothers come to take medicine and we fail to give them, we feel sorrowful, because we understand the challenges they face, particularly if they have not disclosed their status. Thus, I recommend the center should borrow medicine from nearby centers or call the centers to notify them on the mothers expected visit and facilitate an appointment for them or make appointment for other days if the medicine are not available around the communities..."HP21*

Participants also advocated for the centers to be proactive and develop a mechanism to trace patients to improve children's outcomes rather than just labeling them lost to follow-up. Some of the suggested

mechanisms include phone-based communication, group-based communication or reaching out to the patient contact person.

*"...Most of the health professionals who are working in the PMTCT department are not checked whom lost the follow up regularly. If the PMTCT staffs call before couple of days of appointment to show respect and degree of care, the mothers might visit timely. In addition, the professionals or health facilities should consider different tracking mechanism starting phone communication to group communication and then contact person, who may be closed person..."* HP7

### **Psychosocial support**

Psychosocial support was identified as a solution to fight against stigma and discrimination and carelessness of the mothers. Avenues identified include building social networks for support and resilience as well as involving other family members in sexual and reproductive health of the mothers. Social networks identified include support groups such as mother –to- mother association and volunteers visiting mothers in homes to provide both emotional support and assistance to mothers.

*"...The mother-to-mother association is significantly important in breaking the community negative perceptions about HIV positive people in different methods. For example, when mothers visit HIV positive mothers frequently, care for the children born to HIV positive mothers, and teach the people who hold negative thought about HIV positive mothers..."* M24

*"...The social networks and civic associations like mother-to-mother association, and other charity associations have significant role in returning HIV positive mothers to the community, improving their economy, family and social life..."* HP16

Improving the quality of counseling to broader aspects of the woman's life was also identified as possible interventions for loss to follow-up and prevention of child mortality. Also training health workers to be sensitive to the needs of the women was identified as a form of support that could encourage more women to join the program and keep the ones that have joined the program until the end.

*"...the quality of counseling including the eye contact, facial expression, and other body gestures are very important to retain mothers to the end of the program. Such quality among PMCT professionals would be occurred through frequent training..."* HP17

*"...Most PMTCT professionals who work in health facilities are not trained; the training was given for former staffs. Thus, we are working with our basic education, thus, training should be given periodically..."* HP20

### **Education and awareness**

The health and awareness theme focuses on improving the healthcare-seeking behavior of parents to improve adherence to treatment and also continued screening of children in post-natal period to reduce deaths and LTFU. Education and awareness will also open avenues for other family members particularly spouses to be involved in the maternal and child health.

*“...if mothers disclosed their status to their husbands or other family members, it would be good to add ensure that education is also provided for the family and husbands, because they will remind the mothers about follow-up care when they do not go...” HP2*

## **Empowerment**

Empowerment theme came as a response to social determinants such as poverty as major contributor to LFTU and death. Participants suggested that women should be empowered through civic societies to mitigate the effects of poverty. Most health professionals who work in the hospitals and HIV officers stated that Mothers association and other civic societies are important to prevent from losing the appointment and to retain the lost mothers.

*“...mothers association is very important in which mothers can visit HIV positive mothers in their homes, arrange financial support and motivate them to complete their follow up and may also provide care for their children during their visit, which encourage mothers to accomplish the follow up and prevent death...”HP3*

## **Discussion**

This study add to the existing evidence of factors that contributes to LTFU, but bring a new perspective by looking at both providers and mothers as well as addressing possible reasons for child mortality in addition to LTFU among this group. The study also give an unique view of factors that contributes to LTFU and child mortality due to HIV at a district level, using multi-sites and suggests community informed multifaceted interventions that can adopted to improve the retention of mothers and children in option B+ and ultimately reduce mortality of children due to HIV.

The results of this study demonstrates that multi-factors play a role in mothers choice of continuation with PMTCT services and are similar to studies in Gomba district, Uganda(35), in Cote-d'Ivoire(36), in Malawi (37)and in Malawi and Uganda(38). The themes of stigma and discrimination, social determinants and partial access reported in this study are shared across these studies as major barriers to retention in PMTCT program (35, 37-40).

Stigma and discrimination is reported as a major barrier across studies and countries and it was reported as a major issue by the participants including internalized stigma (35, 37, 38, 40, 41). Despite, information on HIV be widely available through all media, this study confirmed that stigma and discrimination are still a major issue in HIV in Ethiopia and in other African states stigma (35, 37, 38, 40, 41)). Unlike findings from Schechter et al (40) stigma in Amhara region is not largely internalized but rather from the community and sometimes health care professionals.

The social determinants of poverty, cultural taboos, and lack of spousal support as important barriers for women to access services or continue with services was also a critical result in this study. This also compounded the struggle with stigma and discrimination as some women would choose to protect their relationships through leverage of husbands' absence at Antenatal care and cultural practices that would

raise flag in mothers do not breastfeed the child. Similar results were reported elsewhere (38) as their main finding in Malawi and Uganda populations and in Malawi(41). Poverty as a barrier reported here has also been reported by other studies as lack of funds to travel for Antenatal care (37, 40).

Access is reported as a major barrier in this study focusing on structure, disruption of supply of medications, and distance of ART centers. Other studies reported on this theme focusing mainly on the distance of ART centers and the cost of care (19, 37, 40). This study brings in a new perspective to the access theme by highlighting how physical structure and labeling of the buildings perpetuate the self-stigma and discrimination which lead to LTFU except in a study by Bwirire et al(37)where they alluded to the long quest at ANC as a reason for LTFU. Also, this study brings in a system issue on the supply of ART drugs in the region which other studies do not report.

The study findings also reported on the theme of carelessness and healthcare professionals' attitudes. The findings of carelessness are opposite those reported by Kiwanuka et al (35)and Schechter et al (40)where participants were reported to see participation in PMTCT program as a positive attribute for hope, being alive and be able to raise a HIV free or healthy child. In this study mothers were reported not to care for their children's outcomes and often did not bring children to health canter when sick despite knowing that they may be HIV exposed. Such behavior was also reported by Kebede and Taye (42) in Amhara region, where they reported that mothers who attended ANC reduced chances of their child infection compared to those who did not. The healthcare professionals' attitudes are largely not alluded to in literature within the region but were reported to be critical to ensure the success of PMTCT program in Brazil(43).

The findings of this study relating to access, stigma and discrimination, social determinants and healthcare professionals attitudes could explain why mostly younger women, patient initiated on ART on the same day and those attending antennal care at hospitals are more likely to be lost to follow-up as reported by Mitiku et al(39).

The interventions suggested by the participants are also alluded as successful measures in other sub-Saharan Africa countries. For instance, Geldesetzer et al(44)in their review emphasis that most of LFTU interventions are successful in sub- Saharan Africa including phone calls and text messages to reminder clients to come back for services. The peer, community lay person support system has been implemented in Uganda and also showed an increase in retention among HIV positive mothers on follow-up care(45). But results from(36) in Zimbabwe shows that peer support group did not show any difference in retention of mothers.

The limitation of this study is that it was conducted in one region and might not be generalized to other regions with different contexts. The study used a convenience sampling. Also, social desirability bias cannot be ruled out from the interview's answers. Data was also collected in Amharic and while translation was verified some of the context may not be represented well in English or lost in translation.

# Conclusion

Contributors to LTFU and child mortality are critical barriers to successfully raising HIV free generation in Amahra Region, Ethiopia. Both mothers and healthcare providers identified carelessness, lack of access, stigma and discrimination, healthcare professionals' attitudes and social determinants as major contributors to LTFU and child mortality. While psychosocial support through peer support group, women empowerment, improvement of access to services including constant supply of medications, physical planning of buildings, engagement of civic societies and education and awareness are considered possible interventions to reduce LTFU and child mortality.

# Declarations

## Availability of data and material

The raw materials that support the conclusion of this research will be available to researchers needing the data to use for non-commercial purposes through requesting the authors through their e-mail.

## Competing interests

The authors declare that they have no conflicting of interests

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