

Investigate and Understand Barriers for Successful Uptake and Implementation of Prevention of Mother to Child (PMTCT) Services in Mulanje Mission Hospital, Malawi

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Abstract

Objectives: The aim of this study was to investigate and understand the barriers that contribute to successful uptake and implementation of Prevention of Mother to Child Transmission (PMTCT) services for pregnant and breastfeeding mothers at Mulanje Mission Hospital in Malawi.

Methods: A Qualitative study was conducted with data collected through in-depth interviews and focus group discussions. A total of 64 participants were interviewed.

Results: The main barriers to uptake and implementation of PMTCT services were stigma and discrimination against those infected with HIV, traditional and religious beliefs, long waiting time at PMTCT clinic, lack of male involvement, opposition from male partner leading to divorce and gender-based violence and lack of privacy due to non-conducive infrastructure.

Conclusion: In order to promote successful uptake and implementation of PMTCT service, male involvement in reproductive issues has to be enhanced by raising community awareness. In addition, HIV testing and counseling should also be an agenda of community awareness so that women should not wait to be pregnant and then go for testing. Issues of stigma and discrimination should be dealt with during campaign and community meeting with chiefs. Staffing in health facilities should be improved to minimize the waiting time and also improve the quality of care given.

Introduction

In 2016 an estimated 36.7 million people worldwide were infected with HIV, 20.9 million people living with HIV were getting antiretroviral therapy, of these 17.8 million are women from 15 years and above while 2.1 million are children below the age of 15 (UNAIDS, 2016). Eastern and Southern Africa is the worst affected region in the world with 19.4 million adults and children living with HIV (UNAIDS 2016).

Malawi is in the Eastern and Southern part of Africa is among the countries affected by HIV epidemic with 10.3% prevalence rate. The number of people living with HIV and AIDS is estimated at about 1 million which includes 850,000 people aged 15 and above and 170,000 children below 15 years of age (MDHS, 2015).

Malawi in strategic plan for 2015-2020 aims to increase the number of pregnant women attending at least one antenatal visit by 50,000. The plan envisages increasing the HIV ascertainment rate amongst pregnant women from 67% in 2013 to 85% in 2020 and increase the uptake by HIV positive pregnant women from 81% in 2013 to 85% in 2020 (NSP, 2015).

The Malawi government through the Ministry of Health and with collaboration with its stakeholders have developed and implemented several preventive strategies into reversing the course of the HIV epidemic through the Primary Health Care Approach. Prevention of Mother to Child Transmission of HIV started in 2002 with the use of single dose Nevirapine during labour and then was changed to Option A which was a combination of Zidovudine and Lamivudine and a single dose of Nevirapine during labour. In July 2011 Malawi introduced Option B+; it was incorporated into WHO guidelines in 2012 and implemented by several other African countries, including Uganda and Tanzania, in 2013 (Speight, 2013). In Option B+ all HIV positive pregnant and breastfeeding mothers are offered triple therapy of Tenofovir, Lamivudine and Efavirenz for lifelong regardless of Clinical status or CD4 count.

Even though lifelong therapy has shown to be effective, health facilities in Malawi reported poor retention by 71% of pregnant and breastfeeding mother initiated on antiretroviral therapy within 24 months. 30% of HIV positive pregnant mothers attending antenatal care are not receiving treatment and 50% of exposed newborns are not tested for HIV (NSP 2015-2020). For Option B+ to succeed, it is necessary to identify optimal models of care that support maternal adherence and maternal and infant retention through the care continuum. There is a need to investigate efficacious, cost-effective, and sustainable interventions to improve maternal and infant retention and adherence to lifelong ART in the setting of Option B+.

Methodology

Study design and site

This was a qualitative study conducted in rural area of Mulanje District at Mulanje Mission Hospital. Mulanje District is in the Southern part of Malawi in the region with the highest HIV prevalence of 12.8% in Malawi (MDHS 2015). Mulanje Mission Hospital is the study facility providing PMTCT services including Option + which is integrated into the antenatal clinic.

Recruitment of study participants

Purposeful sampling was used for selection of participants. This procedure was used to achieve the selection of participants with varying characteristics. A total of 64 participants were selected; 20 breast feeding mothers who are HIV positive, 4 pregnant women HIV positive, 30 pregnant women from antenatal clinic and 10 health care providers (ART providers, HIV Counselors and PMTCT providers).

Data collection

Questionnaire guides for focus group discussions and in-depth interviews were developed. Three trained and experienced data collectors were employed. The questionnaires were translated to local language (Chichewa). Focus group discussions were held for pregnant women in antenatal and health care providers. Each group composed of 10 participants. Face to face in-depth interviews were conducted for pregnant and breastfeeding mothers from PMTCT clinic. Data was audio-recorded, transcribed and translated into English. Data quality was ensured through training of data collectors, piloting and refining of data collection tools and ongoing review of transcripts by a senior researcher during data collection.

Data analysis

Nvivo was used for qualitative data analysis, which followed a thematic framework. First, tapes from focus groups and interviews were transcribed and translated from Chichewa to English before they were double checked for consistency and accuracy by the author and other independent native speakers of Chichewa. Where possible, transcripts were sent back to each interviewee for validation and to ensure accuracy in the data generated before analysis. Following this, the author independently reviewed the transcripts several times to become familiar with the content before the process of sorting, coding, and theme identification.

Following data validation, themes were developed based on an inductive and deductive process of issues that emerged from the interviews. The themes were then applied to the data.

Descriptive data matrices were also developed to summarize key respondents' information and facilitate the process of comparison across the various respondent categories. Descriptive statistics were used to summarize respondents' sociodemographic data.

Ethical approval

The study was approved by University of Malawi- College of Medicine Research and Ethics Committee (COMREC). Informed consent form was given to all eligible participants. They were assured that their participation was entirely voluntary. Further consent was obtained from the Medical Director of Mulanje Mission Hospital.

Results

A total of 64 participants were interviewed; 4 pregnant women on Antiretroviral therapy, 20 breastfeeding mothers on Antiretroviral therapy, 30 pregnant women in antenatal clinic and 10 health care providers from HIV testing and counseling, ART and PMTCT providers.

In-depth interview with 24 mothers who are taking antiretroviral therapy

The participants interviewed during in-depth, 14 had never been tested for HIV before until they were tested during ANC and discovered that they were HIV positive during first and subsequent antenatal visit. 5 of the participants went for voluntary counseling and testing after hearing about husband infidelity and shockingly discovered to be HIV positive, while the other 5 went for voluntary counseling and testing because they were sick for some time or a child, they had was sick for a long time. The common cited barrier after going testing and counseling was disclosure to their partner as most of the participants had tested alone. Most participants were happier to disclose to mothers, sisters and not their partners.

The 24 participants interviewed, 6 had tested together with the husbands while 18 participants tested alone. From the 18 participants, only 6 disclosed immediately the results to their husbands and most of these were those who had been sick or child had been sick. 12 of the participants disclosed results immediately to their sister, mother, grandmother or brother because they needed to bring a guardian to hospital. The guardian would undergo education on ARVs so as to support the client in adherence to treatment. 8 of the participants stated to disclosing to husband after several months on ARVs but 4 of the participants have not disclosed to husbands because they are unsure of the husband's reaction to the results of HIV positive.

25 years old with 2 children on ARVs for 2 years, "*I got tested when I came for ANC but I did not tell the results to my husband at first. I was afraid so I told my mother who supported me. After 1 year I told my husband that am HIV positive, fearing that if he discovered maybe he would abuse or even divorce me. Surprisingly we got tested together but he is negative and I am still positive, and he still supports me.*"

20 years old with 2 children on ARVs for 4 months, "*I was never tested with my first pregnancy because I was in remote area and I delivered at Traditional Birth Attendant, so when I came here and started ANC with my second pregnancy I was tested and was very shocked with the HIV positive results. I have not told my husband yet as I have seen one of my friends get divorced from her husband after knowing the HIV results*"

Furthermore, participants found it difficult to immediately start taking antiretroviral therapy after testing positive for HIV. The decision to be on lifelong therapy was overwhelming and information was too much to be absorbed in such a short time. Most participants stated that to know that they were HIV positive and then start lifelong therapy on the same day was too much to take in.

35 years old with 5 children on ARVs for 5 years, "*When I was discovered HIV positive with my 3rd pregnancy, I was shocked despite the support from the hospital. I was given ARVs on the same day but I did not swallow them. I used to come to collect but I never swallowed and after delivery the baby died at 3 months in addition to this, I was sick. I got tested again with my fourth pregnancy and was still HIV positive so when I was giving the ARVs I started swallowing that same day until today.*"

The participants reported religious and traditional beliefs was another barrier in taking ARVs. Traditional medicine is considered strong and better than modern medicine as this has been there for a long time.

34 years old with 2 children on ARVs for 6 years, "*Most people die because of religious beliefs where they are told to stop taking ARVs and pray for healing. Others are told that traditional medicine is stronger than modern medicine so they are told to stop taking the antiretroviral therapy and eventually they die faster.*"

It was also reported that stigma and discrimination was a barrier to accessing PMTCT services. Mothers who are HIV positive are stigmatized by relatives and even the community where they come from.

39 years old with 4 children on ARVs for 6 years, "*My aunt was HIV positive and she was isolated by her husband including all her relatives because of HIV. She was given her own plate of food and*

slept in her own house. But she has since died and the child who was born to her because she did not take ARVs. I also feared that I would be stigmatized by my own people.”

In addition to stigma from community participants reported that they felt that the PMTCT clinic setting was another way of promoting stigma as they were isolated in a corner in the same building as women who came for antenatal as well as under five clinics.

29 years old with 3 children on ARVs for 2 years, “*The corner where we sit as we come for treatment and everyone is looking at us and asking why are those sitting there. People are pointing and talking about us and we feel that this promotes stigma, we should sit with everyone else.*”

Participants reported the long waiting time was another barrier to PMTCT services. They come early but usually have to wait for a long time before accessing the services.

39 years old with 4 children on ARVs for 6 years, “*I used to come together with my husband but the waiting period is too long so he decided to be getting his medicine from another hospital where they are faster. As for me, I sit there with my baby waiting for the treatment even though it takes long time.*”

Focus group discussion with pregnant mothers in antenatal clinic

Similarly, in the focus group discussions barriers to PMTCT were stigma and discrimination, religious and traditional beliefs. It was expressed that setting of the clinic was not conducive as women who come for services know where HIV positive women sit as they come for treatment.

29 years with fourth pregnancy, “*Most of the mothers who come to the hospital know the place where HIV positive women sit to get therapy. It is very visible and those that do not know are informed of why that group is sitting separately. I think it promotes stigma.*”

33 years with third pregnancy, “*I know several mothers who died after stopping ARVs because they were told to join the church and pray. Some other mothers went to traditional healers and they stopped taking the ARVs but took the herbs. They became very sick and died very fast.*”

Focus group discussion with health care providers from HIV testing and counseling, ART and PMTCT clinic

The health care providers perceived that the barrier to PMTCT was shortage of staff to fully support the services. Though they are able to counsel the clients but they are limited with the amount of time that they can spend with each client. The more time they spend with one client it means others are waiting for their turn as well.

ART provider, “*There is shortage of staff in providing services because the same staffs working in the hospital are the same ones expected to provide outreach services and this leads to work overload resulting in ineffective service provision.*”

Discussion

This study was designed to know whether there are barriers to uptake and implementation of PMTCT services from perception of pregnant and breastfeeding women who are ARVs, pregnant women who come for antenatal services and health care providers.

Mulanje Mission Hospital has an integration of PMTCT into MCH and this is associated with higher levels of ART initiation. This improves uptake and timely initiation of ART among pregnant and breastfeeding women.

Several factors influencing Barriers for successful uptake and implementation of prevention of mother to child transmission of HIV services were brought to light by the Pregnant and Breast-feeding women on ARVs, Pregnant women being attended in Antenatal clinic and Health Service Providers in HTC, PMTCT and ART clinic in Mulanje mission hospital.

Pregnant women are tested at initial ANC visit and after 3 months from date of initial testing to determine their HIV status. Once the woman is HIV positive, she is immediately initiated on ARVs and asked to return the next day with a relative or someone whom she really trusts to be a guardian. This guardian will undergo counseling and education on ARVs, benefits, side effects and adherence including prophylaxis for the baby once it's born.

Disclosure of results

When diagnosed HIV positive women might experience emotional turmoil which could affect their ability to disclose their HIV status to significant others especially spouse (Mbokane et al, 2016).

Most of the participants were unable to immediately disclose their HIV results to their partners.

According to WHO voluntary disclosure of HIV status should be encouraged as this will result in partner testing. Disclosure of HIV status to sexual partner is very important as it's associated with less anxiety, increased social support and lead to awareness of HIV risk to untested partner, which can lead to greater uptake of HTC including changes in risky behavior.

However along with these benefits disclosure of HIV status has led to divorce, gender-based violence and discrimination. These risks may lead women to choose not to share the HIV status with partner and family. This leads to lost opportunity for prevention of new infections, and for the ability of these women to access appropriate treatment, care and support (WHO 2011).

Despite the ability to disclose, Mbokane et al, 2016 stated in a study that unless women disclose their HIV status, their partners would be ignorant about this issue and these women are unlikely to use condoms consistently, adhere to ARVs and implement appropriate breastfeeding options.

In a study done by Tenthani et al, 2014 stated that under Option B+ on average 17% of all women were lost in follow up in Malawi 6 months after initiation of ART, citing reasons that they dropped out due to fear of stigma, divorce and physical violence from partner if discovered to be HIV positive.

Morfaw, 2013 found that no one method of facilitated HIV disclosure will be appropriate for every pregnant woman and the content in which the woman lives must be taken into consideration when HIV disclosure is being recommended.

Testing for HIV together as a couple was by far the most preferred method, primarily because it provides an opportunity to remove the burden of disclosure on any one individual thus no one can be blamed for infecting the other.

Mbokane et al, 2016 also encourages couple testing together in order to prevent negative outcomes of results of HIV disclosure to partner.

Stigma and discrimination

Most of the participants stated that stigma and discrimination is the one issue that acts as a barrier to clients accessing HIV/AIDS services. In some communities' individuals are even stigmatized by their own relatives including the community as a whole. Stigma has led to refusal of HIV testing, non-disclosure to partner, non-adherence to HIV treatment. Internalized stigma has led to loss of follow up or defaulter from treatment of HIV infected clients (UNAIDS, 2014).

Participants stated that most people who stopped taking ARVs had internalized stigma and once they became very sick and despite being re-started on ARVs they died prematurely.

Dahlui et al, 2015 concluded in a study that education play a role in society with respect to stigma and discrimination. Educating the population with factual information on HIV/AIDS is needed to reduce HIV stigma and discrimination.

Santos et al, 2014 identified four areas in a study in South Africa to address HIV stigma and discrimination; such as fostering awareness and knowledge among the public, educating people living with HIV/AIDS, advocating for the rights of HIV infected persons and providing emotional as well as physical support.

Shortage of health care providers

In a study by Bwirire et al, 2008 stated that women gave the following reasons for loss to follow up such not being prepared for HIV testing, fear of stigma, discrimination, household conflict and even divorce on disclosure of HIV status, lack of support from husband, long waiting at hospital and inability to afford transport cost related to the long distances to the hospital.

Shortage of health care providers leads to a lot of challenges in accessing health services such as long waiting time, limited time in counseling clients and exhaustion by staff. Health care providers need to assess each mother as an individual with different circumstance requiring attention and time. Time is required to explain HIV transmission, treatment, breastfeeding, adherence and child treatment including testing. Without appropriate staff time for counseling, PMTCT service cannot be effectively implemented and utilized (WHO &UNICEF, 2003).

Ahimbisibwe et al, 2014 reported that women had difficulty around learning their HIV status and initiating ARVs on the same day. They were overwhelmed with information, needed time to think about their HIV status, ART initiation and wanted to first discuss with their partners before committing to lifelong treatment.

Study limitations

The study conducted in a rural health setting and the population demographics may not be similar to urban health setting. The study has small sample therefore results cannot be generalized to the broader population of Mulanje. The study did not include women who were loss to follow up resulting in omission of perspective from these women. Despite the important roles carried out by husbands and partners in this context, males were not interviewed. Furthermore, the purposeful sampling method of recruiting participants means that data were collected from unrepresentative study informants, and the results cannot be generalized to a wider population. However, the qualitative data collected was relevant to the study topic.

Conclusion

Participants in the study were quite knowledgeable about mother to child transmission of HIV. Prenatal HIV testing was considered as a good initiative for PMTCT. The perceived benefits were: enrolment into the PMTCT program if the mother was HIV positive and getting early antiretroviral therapy. Knowing one's HIV status was seen as the most important reason for HCT as such knowledge would help reduce HIV risk behaviour. Barriers to PMTCT were cited as stigma and discrimination, failure to disclose HIV positive results, religious belief, traditional beliefs and abandonment and psychological distress leading to divorce. Intervention of PMTCT programmes can only be successful implemented if men were more involved and equipped with knowledge in PMTCT, more staff were deployed in PMTCT, women were given time to express fears and concerns, staff giving correct information, more community sensitization was done in relation to HIV/AIDS and thus combating more issues related to stigma and discrimination.

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