Original Article

An Exploration of Barriers and Enablers of Retention in a Program to Reduce Vertical Transmission of HIV at Health Centers in Zimbabwe

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Abstract

Background: Poor retention in the prevention of women in prevention of vertical transmission programs remains a formidable common setback in elimination of HIV/AIDS. It creates new problems such as poor health outcomes and increased incidence of vertical transmission of HIV. There is a dearth of qualitative information to explain poor retention of women in prevention of mother-to-child transmission (PMTCT) programs in Zimbabwe. The purpose of the study was to explore the enablers and barriers of retention of women in PMTCT programs. **Methods:** This was a basic qualitative study conducted at four health centers in Zimbabwe. Four audiotaped focus group discussions were conducted with 34 pregnant or breastfeeding women coming for PMTCT services at the health centers. Descriptive statistics was used for sample demographics. Transcripts were analyzed through latent content analysis based on the Graneheim and Lundman method. **Results:** Maternal determination, a four-tier support system, and an inspiring health package were enablers to retention in the PMTCT program while uninspired individual engagement, paternalism, and undesirable PMTCT-related events were barriers to retention of women in the PMTCT program. **Conclusions:** Reinforcing hope for the women and their children, active management of side effects of antiretroviral medicine, consistent peer support, enhancing confidentiality among community cadres, and commitment from community or religious leaders may improve retention of women in PMTCT programs; for women with HIV during pregnancy, delivery and post-natal care.

Keywords: *HIV infection, prevention and control, retention, vertical infection transmission*

Introduction

Poor retention through loss to follow-up (LTFU) and death remains a common setback in both HIV and prevention of mother-to-child transmission (PMTCT) programs. Retention refers to regular engagement of women in prescribed and unscheduled PMTCT visits.[1]

Poor retention of women in PMTCT programs can be due to LTFU or death. An individual is lost to follow-up after missing a scheduled PMTCT visit by 180 days.[2] In a cohort study in Haiti, it was found that retention in PMTCT programs dropped to 80% during time of child birth and down to 57% by 2 years after child birth.[3] According to results of a survey in 2012 in Zimbabwe, retention of women in PMTCT program dropped to 43% by the time of the second pickup of antiretroviral (ARV) drugs.[4]

Owing to diminished ease of patient monitoring, poor retention of women in PMTCT programs has been reported to be associated with increase in viral load, clinical and immunological deterioration, increased chances of vertical transmission of HIV to offspring, and increased resistance to ARV drugs.[1] Zimbabwe is experiencing an increase in prevalence of drug-resistant HIV. For instance, 35% of people on ARV therapy (ART) are on second-line drug regimens due to failure on first-line ARV medicine.[5]

While some innovative strategies have been tried to improve retention, they have not greatly paid off in public health practice due to technical and sustainability issues. A systematic review in 2016 reported a pooled increase in effect size of some interventions on retention in PMTCT (pooled relative risk = 1.18, 95% confidence interval = 0.93; 1.09, I^2 = 69%). The interventions to improve retention included male involvement in PMTCT, short message service reminders, conditional cash transfer, midwife training, task shifting, integration of PMTCT services, peer support, and improved referral.[6-8]

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Zimbabwe began the PMTCT program with a pilot at 3 sites in 1999. The national PMTCT program evolved from Option A, Option B, Option B + and ultimately the test and treat option in tandem with the dynamic Word Health Organization PMTCT guidelines.[9-11]

Most studies on challenges and enablers of retention were quantitative in nature and tended to focus on single steps in the PMTCT cascade. There is dearth of qualitative studies on enablers and barriers of retention of women in PMTCT programs. On the other hand, getting accepted by the spouse facilitated collective proactive planning and continual of participants in the PMTCT program. The benefits of this will include improved health outcomes for women on ARVs and reduced HIV transmission rates from mothers to their children and sexual partners. The purpose of this study was to explore the enablers and barriers to retention of women in PMTCT.

Methods

The study followed a basic qualitative design. Four audio-taped exploratory focus group discussions (FGDs) were conducted, each with between 6 and 12 participants. The emphasis was on theoretical transferability according to Kitzinger.[12] The focus groups were done at four PMTCT sites in Mashonaland East Province, Zimbabwe, namely Chivhu Polyclinic, Epworth Polyclinic, Kunaka Hospital, and Murewa Hospital. PMTCT sites are health centers which offer PMTCT services. Murewa Hospital and Chivhu Polyclinic are situated in growth points along the country's major highways. Mobility is among the key drivers of the HIV epidemic in Southern Africa.[13] Murewa is along the highway leading to Mozambique while Chivhu is along the highway leading to South Africa. Both Murewa and Chivhu are small towns. Epworth Polyclinic is located in a periurban area 15 km South east of the capital city, Harare. Kunaka Hospital is located in a rural area. Thus, it was possible to have participants from diverse backgrounds. Twelve women per site, who were either pregnant or breastfeeding, coming for routine PMTCT visits at the health centers were approached and asked to participate in the FGDs. The women were selected to produce a maximal variation purposive sample based on age, discordant, or concordance of partner's HIV results and period on ART.

The study was approved by both the Joint Research Ethics Committee for University of Zimbabwe College of Health Sciences and the Parirenyatwa Group of Hospitals and MRCZ (Medical Research Council of Zimbabwe). Participants gave documented, voluntary, written informed consent before participating in the FGDs. Transport reimbursement of US$5 and lunch were provided for all participants.

All the FGDs were conducted in vernacular Shona language, in closed rooms at the respective health centers. The duration of each FGD ranged between 58 and 70 min. The tapes were transcribed verbatim and translated into English by a qualified linguist. Each FGD was analyzed separately. Data were analyzed through latent content analysis based on Graneheim and Lundman method. The method initially involves repeated reading of the transcript until the coder fully comprehends the whole transcript. Then, paragraphs with a similar idea called meaning units are defined. Each meaning unit is then summarized into condensed units and given codes. Similar codes are grouped into summarized short phrases called categories and ultimately themes which have a high degree of abstraction. That is, they are more general than concrete.[14,15] Each FGD was analyzed before the subsequent FGDs were conducted. Analysis was iteratively continued until there was consensus among three coders. After the fourth FGD, there was no more new theme. Conducting further FGDs seemed to not yield any further scientific value. Member checking was done with two participants.

Results

A total of 34 women agreed to participate in the study. The age of the women, which ranged between 18 and 41 years, was normally distributed (mean 29 years, standard deviation = 2.4 years). Participant's period on ART ranged between 1 and 112 months (Median = 16 months, interquartile range = 43 months).

Findings from the study showed that determination, a four-tier support system, and an inspiring health package enabled retention in the PMTCT program. Determination involved ignoring setbacks and focusing on PMTCT for personal, child, and spousal health. A four-tier support system meant support from spouse, family, community, including peers and clinicians. The final enabler of retention, an inspiring health package, meant being managed with ARV medicine with tolerable or no side effects, getting quality health care from accommodating clinicians, getting food aid to mitigate side effects of ART and getting tangible benefits from the PMTCT program such as giving birth to a child free of HIV infection and experiencing improvement of personal health.

On the other hand, uninspired individual engagement, paternalism, and undesirable PMTCT-related outcomes were barriers to retention of women in the PMTCT program. Uninspired individual engagement meant engaging in PMTCT with hopelessness while not prepared to disclose the HIV status to close acquaintances and not bothering to know about PMTCT or ARV medicine. Paternalism was from a spouse, relative, or clinicians who made unilateral decisions for the women in PMTCT without considering their insight. Undesirable PMTCT-related events included having transmitted HIV to offspring or uncomfortable side effects from ARV medicine.

Facilitators of retention

Determination

Participants' ultimate determination either based on the desire to protect the offspring from HIV or based on

knowledge about PMTCT appeared to facilitate retention in PMTCT.

I began to take medicine. After 2 months, I quit but continued to give the child. When the child was tested at 6 months of age and found to be negative, I was glad that I had attained my goal, so I stopped PMTCT and medicine altogether [Participant 3, FGD#3].

Other participants preferred to keep the child HIV negative while hoping that a cure for HIV would be found and they too would become negative:

Because if we concentrate on the immediate future, how about the future of my children?… as for me I am just positive. There is a time when the cure for HIV will be found… [Participant 6; FGD#1].

For most participants, protecting the growing innocent child motivated continuation in PMTCT.

I may skip medicine; however, I will be harming your child [Participant 1; FGD#2].

If you stop, you lose your life…imagine leaving behind young children. The child will grow without motherly love. Nobody else besides the real mother can give such love to a child [Participant 1; FGD#1].

For other participants, coming for PMTCT visits was a way of showing their innocence to society by not deliberately infecting anybody with HIV and demonstrating care to their children and spouses.

If you reject [PMTCT] *your child will blame you, that you did him bad, infecting him with HIV* [Participant 4; FGD4].

After all, isn't it me who would be blamed for the death of my husband and child. They (in-laws) *accepted it and implored me to follow PMTCT requirements* [Participant 8; FGD#4].

When the child grows up, they may get their own HIV infection, because they would have acquired the infection on their own [Participant 1; FGD#2].

Empowered women would not be easily swayed by contradictory advice:

Faith healers told me, "the way you have lost weight, if you go to clinic they may tell you that you have HIV infection when in fact it's evil spirits." It's true, evil spirits are there but they should not be associated with pills.

Finally, acceptance of HIV status was a facilitator for retention in PMTCT as women would not waste time getting retesting to confirm their HIV-positive status.

Four-tier support system

Participants preferred to involve acquaintances who could keep the HIV information confidentially.

In the village, I may notice women in a similar situation with me. If she is approachable, I give her my advice and assistance based on my experience [Participant 3; FGD#2].

Some participants' consanguineal family motivated them to attend PMTCT visits. On the other hand, getting accepted by the spouse facilitated collective proactive planning and continual of participants in the PMTCT program.

When we got to know that the ball had been scored (pregnancy), *we took to serious planning* [Participant 4; FGD#4].

To have sustainable support, participants felt the need for social support groups for their spouses. However, findings show that sometimes peer support groups fell apart due to member absenteeism.

Inspiring prevention of mother-to-child transmission package

The package included favorable health care and outcomes; for example, a private consultation environment, health worker competence tolerability of ART, or knowing someone who gave birth to a child free from HIV. Complementary food handouts and conditional cash transfers offset unplanned costs incurred during PMTCT visits. In some cases, participants had been obliged to comply with PMTCT in order to get antenatal, labor and delivery and postnatal care.

Finally, convenience at health institutions encouraged women to keep coming for visits; for instance, being served quickly, traveling short distances to PMTCT sites, or getting diagnostic test results and all medicine on the same day. Flexible drug dispensing or processing of transfer in women were found to also facilitate retention in PMTCT. More so, participants felt motivated by confidentiality demonstrated by clinical counselors, nurses, or doctors unlike community health workers who could not keep secrets but "*spread the news*."

Barriers to retention

Uninspired engagement

Retention in PMTCT seemed to be weighed down by competing interests such as lying to save a marriage or dignity. Fear of inevitable impending death and overwhelming requirements including an expensive diet, denial, or discordant results also hampered earnest engagement in PMTCT. Impoverished participants were afraid of failing to meet dietary requirements of ART.

When I got tested, I failed to accept HIV-positive results. How could I afford it during the economic recession? Haaa haaa [laughing] [Participant1; FGD#1].

Paternalism

Participants raised concerns about religious, health worker, and spousal paternalism which sometimes violated their perceived rights. The community

stereotyped women as bearers of family failure or shame. HIV infection in the family was blamed on women. Some participants' spouses forbade women to comply with PMTCT.

He tells you "the hospital cannot tell me what to do! You do as I say, if you insist on condoms then go back to your parents." Sometimes you may end up in a fist fight [Participant 3; FGD#3].

The faith healer said, "you were given wrong treatment, stop it. Throw the pills in a river, you illness will flow away with the water." [Participant 2; FGD#1].

Some health workers were paternalistic when imposing visits by the women even at inconvenient times. Participant would rather skip visits than face such clinicians.

Undesirable prevention of mother-to-child transmission-related events

Uncomfortable situations which arose due to PMTCT also perturbed retention efforts. For instance, drug side effects, inconvenient appointments, drug failure, or ultimate vertical transmission of HIV. Participants felt that side effects were not adequately alleviated at PMTCT centers. Hence, some participants resorted to informal complementary and alternative medicine use. Health worker negligence which put the child at risk of vertical transmission of HIV also discouraged women.

I had a very bitter experience. I delivered my baby onto the floor, my child got soaked in blood… yet I am (HIV) *positive. Putting my child in danger. What's the use then of PMTCT?* [Participant 8; FGD1].

Uncomfortable ARV side effects made some participants hesitate to take the drugs:

The pills are really big, some give them a nickname "maragada," the head spins. The pills cause dizziness [Participant 5; FGD#4].

Some relatives thwarted participants through insensitivity, abandonment, or chastisement for being in the PMTCT program. In the community, stigma and discrimination were the huge barriers to retention:

Even when you move around, they will be saying, " you see, she is losing weight, that's why she is like this these days…that's why she has facial spots, don't let her cook our food!" [Participant 2; FGD#2].

You end up stopping PMTCT, because people talk [Participant 7; FGD#4].

One participant was told:

The whole family, the entire family having AIDS, you're all dead and rotten. You are walking corpses [Participant 5; FGD#4].

Some community and religious leaders also showed indifference in promoting retention in the PMTCT program.

Discussion

Findings from this study showed that determination, a multilevel support system, and an inspiring PMTCT package may enable retention in PMTCT. On the contrary, barriers to retention in PMTCT include uninspired engagement, paternalism, and undesirable PMTCT-related events.

Facilitators

The need by women to have HIV-negative children and be alive as the children grew up is a known enabler of retention in PMTCT.[16,17] Women are generally stereotyped as carers for the sick. Sometimes, women overlook their health problems as they care for sick children, spouses, or relatives.[18] Thus, cognitive interventions to improve maternal determination may facilitate retention in PMTCT programs.

Partner and peer support were found to enhance retention in PMTCT programs.[19,20] However, findings from this study showed that it is difficult to sustain peer support as groups tend to fall apart.

Findings in this study showed that empathetic clinicians, privacy, tolerable ARV side effects, and tangible efficacy of ARVs as indicated by HIV-free children facilitated retention. These factors were reported in literature to improve satisfaction with services.[21]

Barriers

At individual levels, the barriers included poverty. This may explain why in some studies, conditional cash transfers enhance retention through poverty alleviation.[22,23] Lack of support in the community is a known barrier to retention in PMTCT programs. Some male spouses were found to resist health advice, to the extent of even denying their partner's persistence in the PMTCT program.

Stigma has been reported in a systematic review to impede adherence or uptake of PMTCT.[16,24] In a qualitative study in Bulawayo, Zimbabwe, stigma was found to have declined.[25] In this study, participants were really overwhelmed by stigma. On the other hand, religion has been found to discourage ART in some settings.[26] Religious doctrine needs to be incorporated in PMTCT retention efforts.

Uncomfortable side effects and lack of collaboration between health workers and women on PMTCT have been reported elsewhere as barriers to retention of women.[16,20] While other studies have alluded to inconvenience,[24] in the current study, inconvenience was a perceived barrier to retention in the PMTCT program.

Women in the study were quite open to share their PMTCT experiences in focus groups. Due to group discussions, some sensitive issues might not have been explored. The themes which emerged in the study may be examined in a cohort study to determine their impact on retention in PMTCT.

Conclusions

Interventions to improve retention need to focus on increasing hope, empathy, management of ART side effects, poverty alleviation, confidentiality, consistent social support, and commitment from community or religious leaders to improve retention of women in PMTCT. On the other hand, paternalism, uninspired engagement, and undesirable PMTCT-related outcomes need to be addressed to reduce barriers to retention in PMTCT. Efforts to improve retention of women in PMTCT should address women empowerment.

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Conflicts of interest

There are no conflicts of interest.

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