

PMTCT Option B+ 2012-2018; Taking Stock: Barriers and Strategies to Improve Adherence to Option B+ in Urban and Rural Uganda

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Abstract

PMTCT Option B+ has been recommended by the World Health Organization since 2012 to reduce vertical transmission, however numerous adherence challenges remain.

We conducted a qualitative study at baseline using six focus group discussions and 14 in-depth interviews to explore knowledge, beliefs, attitudes and challenges towards the Option B+ strategy for PMTCT among HIV-infected pregnant and post-partum women and health workers engaged in Uganda's national Option B+ PMTCT programme. Data were analysed using a thematic approach to capture latent and manifest content with the social ecological model as a theoretic foundation in order to make contextual sense of key stakeholders' needs for an effective Option B+ intervention.

Overall, among all study participants, we found multi-level barriers to adhering to Option B+ cutting across all levels of the social ecological model (SEM). In line with the SEM, our study revealed barriers at personal, relational, organizational and societal levels. Some personal beliefs such as that the baby's health is more important than the mother's, organizational (negative attitudes and behavior of health workers), structural such as poverty, work conflicts, fear and lack of disclosure related to community stigma were all critical obstacles to women adhering to the Option B+ programme. We found that both health workers and participants in the programme have a relatively clear understanding of the benefits of adhering to their treatment; though a more nuanced understanding and thus emphasis in counselling on side effects, is critical to helping patients adhere.

Keywords: Uganda, Africa, PMTCT, HIV prevention

Introduction

In 2012, the World Health Organization (WHO), updated the PMTCT guidelines and recommended that women identified with HIV infection during pregnancy and breastfeeding should start antiretroviral Therapy (ART) irrespective of their CD4 cell count and WHO clinical staging, and then either stop ART after breastfeeding cessation (Option B) or continue to take ART for the rest of their lives (Option B+) (WHO, 2012). Mother-to-child HIV transmission (MTCT) in sub-Saharan Africa accounts for 90% of pediatric infections and globally more than 15% of all new HIV infections (UNAIDS, 2017). The Option B+ strategy has been widely adopted since its initiation (Chersich, Newbatt, Ng'oma, & de Zoysa, 2018; Gumede-Moyo, Filteau, Munthali, Todd, & Musonda, 2017).

Several programmatic benefits are associated with Option B+ (Shaffer, Abrams, & Becquet, 2014). These include high acceptability of the intervention and a reduced rate of mother-to-child HIV transmission with the rate of infants diagnosed with HIV in the first two months of life dropping from 15% to 45% without treatment, if a pregnant woman is living with HIV to 1-3% (Gumede-Moyo et al., 2017; Low-Beer, Yip, O'Shaughnessy, Hogg, & Montaner, 2000; Ministry of Health, 2012). Viral suppression, CD4 increase and low mortality rates have also been reported in mothers on Option B+ (Elwell, 2016; Kim et al., 2016). In an effort to eliminate MTCT, Uganda revised the national PMTCT guidelines to include Option B+ and has continued to roll out the programme nationally (Ministry of Health, 2012).

Despite these benefits however, inadequate long-term adherence to Option B+ have been reported in resource limited settings (RLS) with multiple reasons reported. These include, but are not limited to, fears of HIV disclosure to sexual partners (Chadambuka et al., 2017), HIV related stigma at the individual, family, community and facility levels (Atanga et al., 2017; Matheson et al., 2015), discrimination, poor interactions with health workers (Kim et al., 2016) and fear of/or past experience

with side effects (Phillips et al., 2016; Renju et al., 2017). Furthermore, loss-to-follow up of women initiated on Option B+ has been highlighted by some countries like Malawi, where 17% of all Option B+ patients could not be traced six months after initiation of ART (Haas et al., 2016; Tenthani et al., 2014). In one hospital in western Uganda, 36% of women enrolled into Option B+ did not return to the facility after their first visit (Schnack et al., 2016). Health facility barriers have been cited as contributing to poor adherence to Option B+, including inadequate access to early antenatal care, poor linkage between mother-baby pairs and postnatal health care services, lack of effective linkages between facility and community structures, poor systems not ensuring long term retention in care and increased workload for staff (Luzuriaga & Mofenson, 2016).

Given these challenges, it is important to design and implement innovative approaches to sustain and improve maternal adherence to Option B+. In this context, we assessed a group peer support intervention to support long-term adherence to Option B+ in Uganda through a randomized parallel controlled trial titled, “Friends for Life Circles” (FLC). This study’s aim was to improve retention in care and adherence to ART up to two years postpartum among HIV-infected women receiving PMTCT Option B+ in urban and rural government health facilities of Uganda. The study protocol included a formative research component in one urban district (Kampala) and one rural district (Mityana); started in 2016. The objective was to evaluate knowledge, attitudes and perceptions towards the Option B+ programme among HIV-infected PMTCT clients, community members and health workers. The qualitative research explored participants’ understanding of, and attitudes towards the benefits of Option B+ as well as barriers for HIV-positive asymptomatic women taking ARVs for a lifetime. We present the results of this formative research, including barriers and suggested strategies to improve adherence to the Option B+ programme and how this information has helped inform the FLC intervention.

Methods

We conducted a qualitative study at baseline using six focus group discussions (FGDs) to explore knowledge, beliefs, attitudes and challenges towards the Option B+ strategy for PMTCT among HIV-infected pregnant and post-partum women enrolled in Uganda's national Option B+ PMTCT programme. In addition, we completed 14 key informant interviews (KIIs) with health workers, policy makers and community leaders to document their perceptions about the Option B+ strategy. All FGDs and KIIs were conducted in the preferred language of participants (Luganda or English) using a pre-designed semi-structured, IRB approved, guide.

Written informed consent was obtained from all FGD and KII participants for their participation and permission was sought to have the discussions or interviews audio-taped and transcribed.

The tools were pre-tested in the local language (Luganda) for the FGD participants and in English for the key informants. All discussions were facilitated by an experienced social scientist with the help of a co-facilitator. Open-ended questions and probes using guides as a reference for key topics were used throughout the discussions. Topics included understanding, strategies and benefits of the PMTCT programme as well as barriers, challenges and recommendations on how to improve programme adherence.

Study population

FGD participants

Participants aged 18 years and above and willing to participate in the study were selected to participate. Six FGDs were conducted with HIV-positive pregnant, breastfeeding and non-breastfeeding women on PMTCT Option B+ from both Mulago and Mityana health units as well as male partners of

these women (Table 1). From each site, three FGDs were conducted from 10-15 March 2016 (for Mulago) and 15th-18th April 2016 (for Mityana). Interviews for FGDs were conducted in Luganda and audio recorded. The translation and transcription was done by an experienced translator.

Key informants

Fourteen key informant interviews were conducted with health workers and other stakeholders including Ministry of Health (MOH), district health officers and community leaders (Table 2). Interviews took place January through March 2016.

Data analysis

Data were analysed using a content thematic approach to capture latent and manifest content in each transcript. Three social scientists with experience in qualitative research reviewed the transcripts individually and met to discuss study themes and subthemes which were used to generate a code book. Thereafter, the transcripts were shared among the three researchers for coding. Preliminary findings were compiled and disseminated to members of the study team. Sub-group analysis involved comparing findings from women, men and key informants, and provided an opportunity for triangulation of findings. Verbatim quotes have been used in presentation of study findings.

Ethical considerations

The study was approved by the Joint Clinical Research Centre Institutional Review Board (JCRC IRB), and the Uganda National Council for Science and Technology (UNCST) in Uganda and the University of California (UCSF) IRB, San Francisco and Johns Hopkins University (JHU) IRBs in the USA. All study participants provided written informed consent before participation.

RESULTS

We have analyzed our data according to the Social Ecological Model (SEM) in order to make contextual sense of key stakeholders' needs for an effective Option B+ intervention (Figures 1 and 2). We have, thus, looked at the data through a lens of personal, relational/interpersonal, organizational (specifically health facility), community and societal barriers to adhering to the Option B+ programme. The results are arranged under two broad themes: 1) barriers to adherence to Option B+ (Table 3) and 2) suggested strategies to promote adherence to the programme. Under each of those broad themes were sub-themes that linked these formative results to ideas for building interventions on adherence to the national Option B+ programme.

I. Barriers to adherence to Option B+

1. Individual level; personal barriers

Under personal barriers, participant age and educational levels, drug side effects, and use of alcohol were stated as contributing to difficulties in adhering to Option B+ (See Table 3).

a) *Participant age and educational level as personal barriers*

Both education and age were noted as barriers; participants noted that some women with limited education may have difficulty adhering well to Option B+.

Of course, if the woman is not educated enough to understand the benefits of the medicine she is about to take, then she cannot take with proper adherence. (Interview, health policy maker 2, urban)

Others mentioned that those at higher educational levels were also not attending health services regularly as class and stigma become obstacles. With age, participants mentioned adherence being more difficult for both older and for younger women. It was primarily health workers and policy makers in both Kampala and Mityana that noted the issues of age and educational levels as barriers.

...if we are talking about the (highly) educated; . . . the elite, is still a big problem for them to accept ...They prefer death to being identified with HIV. There is a case I can give you; he knew

he was positive, they just carried him to Mityana hospital ... he just said, "Anything connected to HIV, I would rather die" the man died. (Interview, community leader 2, rural)

Age, young mothers may not fully understand why they have to take this [medication] for the rest of their lives. They still have a lot of things to go through, they haven't disclosed, even the fact that they are HIV positive is something they haven't really come to grips with, so really [this] may also deter them from being adherent. (Interview, health policy maker 1, urban).

b) Drug side effects as personal barriers

Almost all participants, pregnant women and health workers, from both districts discussed multiple ARV drug side effects from physical to mental health issues that they either experienced or heard about from others. Side effects were both short and longer-term and made it difficult to adhere over time.

I no longer weigh the same. I felt so bad and even now I feel a lot of heat in my head as if I have been burnt. I got so thirsty . . . I feel dizzy. . . (FGD, Option B+ participants, urban)

Participants also reported side effects from starting the drugs while others reported side effects when stopping the drugs. One person, the counselor from the clinic in Kampala, reported that some patients have a general fear of taking drugs. Many reported getting nightmares after initiating ART.

[ART] causes hallucinations, causes strange dreams, weakness . . . They do not kill but if a person is dreaming about goats speaking English, it is disturbing. (Interview, medical officer , urban)

There were providers and pregnant women in both districts who reported that some women fear side effects, while others have already experienced side effects. Some reported rumors about the drug side effects; from mild to lethal.

They say that at a certain time, the regimen will be changed but when they change that regimen, your blood might fail to cope with that medicine and it ends up killing you. (FGD, Option B+ participants, rural)

The legacy of the fear of past side effects from older drug regimens also affects current practice. In addition, some participants reported that one can get the side effects only when not taking the medication correctly and others stated that there are drug interactions with contraception.

c) Stigma and Discrimination as personal barriers

As noted above in relation to women who are educated, stigma and discrimination were reported in both Kampala and Mityana by all participants and the effects were noted to hamper the programme along the PMTCT cascade from the point of HIV testing, to drug adherence. As a strategy to deal with stigma, some women were reported to be taking drugs in hiding but often participants described the challenges in taking medication secretly.

Some fear to go for testing. . . She fears being seen. That prevents her from going and she stays in the village. . . Some fear to die early. They will live in fear. (FGD, Option B+ participants, rural)

Health workers described clients who had experienced discrimination or anticipate stigma both at health facilities and in the community.

. . . They look at him (her) as not a person. . . they fear to share with that person things like food. . . one of my friends is HIV positive but is a motorcyclist...many people around him...who know him, they don't use his bodaboda (motorcycle taxi). (Interview, community leader 1, urban)

. . . I have at least 3 mothers who were sent away from home. One husband, when he saw the medicines, he sent the woman away and the woman opted to go and sleep in church... (Interview, facility health provider, urban).

For my husband, I came and tested and went back home and told him. He refused to come for testing and is currently not on medication. People fear to be seen. (Interview, community leader 2, rural)

Community members, as shown above, also explained internalized stigma described as fear of exposure that negatively affects adherence.

d) Participant denial as personal barriers

Especially for women who are healthy, denial of their own illness can be a strong barrier to drug adherence. Three key informants from Kampala mentioned denial, but none of the Mityana participants reported denial as a factor in relation to adherence. Denial was also discussed with respect to the efficacy of the drugs to prevent HIV transmission to the infant.

. . . they don't believe that they have HIV. They say, "but for me I am healthy; why do you want me to take medicine? " Or, "okay I will start" but later say "but I am healthy" and then they stop taking the medicine. (Interview, health policy maker, urban)

Mothers also mentioned that the test and start policy might encourage a loss to follow-up as it forces someone to initiate treatment immediately when some individuals may not be ready and may need additional time to understand and accept their diagnosis.

The policy says once tested positive, start ART as soon as possible. These mothers need some time to digest the information. Some know their HIV status for the first time and when someone gets that bad news, they can get so heartbroken. Going through that process of anger, grief... may take some time and some, during that time of denial, they may fall out [of care]. (Interview, facility health provider, rural).

e) *Use of alcohol as personal barrier*

Alcohol was mentioned in both districts by FGD participants as a barrier to adherence since it makes some people forgetful.

. . . She might take alcohol and forgets to take her medicine. She may just sleep when she gets home only to realize after missing [drugs] for a week. (FGD, Option B+ participants, rural)

2. Relational barriers

Barriers to adherence that have been classified as relational, include issues involving family members, the male partner as well as the employer. They include issues surrounding disclosure, or lack of support from family and partner or place of employment. Relationship challenges were brought up in both districts and included lack of male partner support, fear of partner finding out about HIV-testing, fear of finding out about a positive HIV result, and a hesitation to start taking drugs in case there might be negative consequences.

a. *Couple interactions as relational barrier*

Couple relationship challenges were described in many ways in both the interviews and focus group discussions. Participants narrated the complex intertwined hardships relating to poverty and health and how the tension of finding out you are HIV infected compounds the difficulties and stresses relationships.

Misunderstanding between a father and a mother . . . The mother will be stressed [thinking] “after all I am pregnant” . . . Poverty, failure to accept- then blaming each other. He [husband] just says, “you are the one who brought this” also the mother is saying “you are the one”; the time they would [have]

spent to take care of the baby in the womb, they spend it quarrelling. Then bring in stress which affects the baby inside. (Interview, community leader 2, urban)

A couple involved in an undisclosed polygamous marriage can also be a reason not to spend time at the health facility.

The inhibitor could be that a man is having more than one wife . . . They will know that I am having another wife outside. So, this one has led to men saying that they don't have time. (Interview, community leader 2, rural)

It was also explained that, since men often do not access health facilities, they rely on their wives to such an extent that health workers reported that some share their partner's ARVs. In addition, the high prevalence of intimate partner violence was raised, specifically in Mityana, by both health workers and pregnant women. Violence can be triggered by a male partner finding out his wife is HIV infected.

He said that, "When you go, test and find that you are HIV positive" he would kill me...saying I am the one who brought the sickness. I fear and that is why I don't want to spend a lot of time here. (FGD, Option B+ participants, rural)

b. Non-Disclosure to spouse, other family members or one's employer as relational barrier

In relation to sexual partners, disclosure examples ranged from a woman being afraid to take her medication when she hasn't disclosed to a partner, to not wanting his wife to take her drugs in fear of others finding out about HIV infection in the family.

... probably she lost a husband somewhere and she remarries, knowing she is HIV positive and she gets a new catch [A new partner]. She doesn't want to tell this new catch she is positive. (FGD, Option B+ participants, rural).

Mothers in both districts described the difficulty in disclosing to their children. Some women found it easier to tell their children that they have a less stigmatizing illness rather than to talk about HIV.

One of these days my son asked me "Mum you frequent Mulago so much these days, what work do you do there?" . . . They had diagnosed cancer in my intestines (FGD Option B+ participants, Kampala).

Then at home, she may not have disclosed and she may take the drug . . . in an improper way. Hiding away, . . . she fears children to see her, fears the husband to see her, even other women!" (Interview, facility health provider, rural).

Another category of difficult disclosure is with an employer.

. . . some employers do not understand and these mothers don't want to disclose. . . They can lose their jobs, if they are teachers they are not trusted by both the employers and parents [who] don't trust them with their children. . . (Interview, medical officer, urban)

One woman in the Mityana focus group discussion narrated how preserving the relationships around her was so important that she did not want to risk disclosing.

Another participant explained that some jobs may limit a woman's ability to easily take her drugs. She may believe that if she takes the medication she may not be able to perform her job adequately; the employer may not allow any free time to take medication or visit the health facility.

. . . a mother [who] is having a lot of responsibilities at home, at work and you find that some employers, they don't give time for people to . . . take medication. She needs some rest of at least ten minutes; but some employers may not give that time . . . she has a lot of responsibilities at home, taking care of other people. So that responsibility may [prevent] her from taking medication because she may think that "If I take the [tablets] I may become weak, I may not get time to rest, I have to work" and then she dodges the medication. (Interview community leader, urban)

3. Organizational Barriers

The key organizational barriers discussed included: distance to the health facility both in Kampala and Mityana, lengthy time spent at the facility, crowding at facilities, breaks in the supply chain of drugs and poor attitudes of health workers. These were all factors reported as hindering adherence to appointments or taking medication.

a. Access and human resources at health facilities as organizational barrier

Cost and distance to facilities can prove to be an insurmountable challenge to consistent adherence to the programme. This was reported in both districts by both staff and pregnant women.

... one may have to walk a long distance and it involves having money for transport and ...that money may not be there. So, we have to wait until we get money to go. (Interview, community leader 2, rural)

Both districts had participants reporting similar issues including factors associated with human resources in health facilities. These included a lack of sufficient numbers of health workers, transfer of staff to

different facilities, lack of training and poor attitudes of health workers. In addition, the consequences of inadequate numbers of staff and large numbers of patients could sometimes result in lack of confidentiality and long waiting times at the facility.

Because they still think that each time you go to the hospital you have to spend much time. They query “why, why do you take long!” ... we do not begin in time, we do not observe time, we come late and we begin providing the services late. . . (Interview, medical officer, urban)

The health facilities are not friendly for men to attend. (Interview, medical officer, urban)

We went to [health facility] on Tuesday, I think that a patient had missed an appointment but the health worker was so tough on her; she threw the book to her and told her “Go, let the others attend to you.” Such a lady will go back home and say “why should I bother, they were so rude to me.”.., they should handle us like human beings. One time they got so rude I even shed tears... (Interview, Community Leader, Mityana).

b. Counseling & lack of confidentiality as organizational barriers

Poor counseling can result in mothers not understanding that they have to take medication during ante-natal and post-natal, or not understanding the dosage can result in poor adherence.

. . . Like one time we got a mother here, “you told me this drug was for my baby. So, the baby is out (delivered), it [the baby] is okay so I will not continue.”(Interview, health provider, rural)

I have had cases where somebody is given treatment for three months and on each packet..., there is one times one [1x1] and that is for one month but this individual goes home and goes on picking one tablet from each packet which should have been for another month that is overdose. (Interview community leader 2 –rural)

Participants reported a lack of confidentiality in health facilities in Mityana.

. . one goes into a health facility and before even the individual reaches home somebody has heard on the phone that “Are you aware? This one has been tested positive.” So that kind of . . . irresponsibility.” (Interview, community leader 2 –rural)

In Mityana, one participant noted that when there is a specified day for HIV services, this may hinder patients accessing the services.

...if it is Tuesday, people are going for HIV. . . ” What if somebody was free to go and receive their treatment at any other time without the days attached to HIV ... (Interview, Community Leader 2, Mityana)

c. *Health care coordination and documentation including supply chain as organizational barriers*

Patient tracking between departments and supply stock-outs were issues mentioned in both districts and related to programme adherence.

Implementing partners... come with different requests. One comes "...me I am on adherence, I want everything like this like this." Another one comes, " I am interested in TB. . ."[Laughing].(Interview, facility health provider, rural)

In addition, one health worker noted that the barrier is in tracking patients and not losing them in the system.

....these mothers actually are not lost to follow-up, they have their preferred sites. . but you never know . . . (Interview, facility health provider, urban)

In Mityana, health workers noted that when patients are discharged from one department and referred to another they may drop out of care.

Usually after 18 months, we could discharge them and send them to the other side. They ...lose interest and they don't adhere to treatment. .. they just stop taking drugs. (Interview, facility health provider, rural)

4. Community and Societal Barriers

Limitations in nutritional knowledge and food security, religious beliefs, and delivery outside of health facilities were additional factors reported to have an effect on adherence.

a) *Nutrition, food security, community and societal barriers*

The factors that are related to nutrition and adherence included mother's, infants' and whole family's nutritional and food security challenges. The lack of land, the diversity of diet, or nutritional knowledge exacerbated by being pregnant were all factors mentioned in both districts.

Some mothers are, you know, less privileged, like getting food is not easy, even for themselves, even land to cultivate.. . and the mother may not know what to eat. (Interview, Facility Health provider, Mityana)

b) *Religious beliefs as community and societal barrier*

Both in Mityana and Kampala participants mentioned that Born Again pastors claimed prayer would heal their practitioners; who should, thus, not take ARVs. Attending overnight prayer meetings was mentioned as a potential hindrance to consistent adherence. In Mityana, the chairperson of PLHA also mentioned that the belief that one is bewitched has prevented adherence to ART.

The Born Again; a pastor might say “Jesus will heal you” so you might stop taking ARVs because my husband stopped taking. He got saved when he was taking ARVs but when he joined them they told him that Jesus would heal him and he also stopped. He got sick again and appeared like someone who had never taken any medicine; he got herpes zoster and lost his hair until he died and we buried him.
(Interview, facility health provider, urban)

II. STRATEGIES TO PROMOTE ADHERENCE TO OPTION B+

The strategies to promote adherence to Option B+ were grouped under: 1) ensuring correct health education and counselling, 2) promote male partner involvement and support from other family members and friends, 3) address health system gaps, 4) facility and community linkages, 5) Support for income generation (Figure 1).

1. Ensure correct health education and counseling

Most study participants stressed the significant role of health education and quality counseling regarding the Option B+ programme as a key strategy to understand and appreciate their HIV status, the benefits of taking ARVs and related side effects.

I think one of the greatest strategies is being counseled very well to understand what their problem is. Secondly, is acceptance on the patient’s side; a patient accepting that “yes, I am positive, and I need to take action and this is good for my baby” (Interview, policy maker 1, urban).

Others emphasized that for mothers to adhere well, counseling should be continuous to address emerging issues and challenges along the path of treatment including treatment fatigue and side effects:

When they experience ...side effects they will still continue because you have informed them that those side effects are expected.... ...she will still persist with the treatment and ...seek... advice.
(Interview, facility health provider-urban).

Some participants highlighted the importance of health education about Option B+ including its availability, target groups, benefits and side effects. This is important to increase utilization of such services but also to respond to any emerging community concerns.

They (messages) could be on radio, in churches, mosques, or wherever they are or where they go. Some of them who go for funeral rites something should be mentioned that "A mother who is pregnant, there is something..." (Interview, community leader 2 -rural)

Another strategy in counselling is to continuously identify barriers and support women to make and review adherence plans.

Since this is a long term treatment, you sit down with them and make plans on how they are going to adhere,you agree on remindersIf it is a phone....an alarm clock or anything; it should come from the mother (Interview medical officer, PMTCT unit, urban).

2. Promote male partner involvement and support from family and community

a) Ensuring male partner involvement and support

Study participants highlighted the need to promote couple testing where health workers can have an opportunity to counsel women and their male partners together and encourage men to support their women in the programme.

Because if we all tested for HIV..... maybe we are both HIV positive, if you are taking the drugs, then you also encourage me to take the drug.... (Interview, policy maker, rural).

Most study participants mentioned that given the key role of men as major providers and decision makers at family level, involving them in Option B+ can help women access the emotional and practical help they need to adhere to ARVs. It was noted that when involved, men can encourage and remind their women to take ARVs, to go for drug refills or help with collecting drugs, reminders and other practical issues.

The partners are the financial controllers of the home; they give transport to the health facilities, they ... help mothers to have food at home . . . (Interview, facility health care provider, urban).

Most study participants mentioned that women whose partners are involved were more likely to adhere to Option B+ than those whose partners are not involved. The need for women to disclose their HIV status to their partners emerged as a necessity to elicit partner support. One strategy that can help to address

the fear by women to disclose their HIV status to their partners was for health workers to invite men to accompany their wives to health facilities so that health workers can assist with disclosure.

It should have been that when a woman comes for testing and is found HIV positive, you should ask her to come with her husband to pick medicine. (FGD, male partner of Option B+ participant, rural)

Other study participants recommended use of by-laws to force men to support their wives to test for HIV, enroll and remain in care as one participant noted:

if you do not come with your wife, you need to get a letter from the LC¹ explaining your problem , that you did not come with your wife.... (Interview, policy maker, rural).

b) Receiving support from family members, friends and peers

Eliciting support from other family members and friends was another key strategy that can promote women's adherence to Option B+. It was noted that mothers should be asked to identify trusted family members or friends who can be counseled, and health educated to play a role of treatment supporters. These can ensure that the mother adheres to treatment regulations and clinic appointments.

Others choose their husbands, others choose their children, others choose a close friend; somebody who is close to them such that they can be reminded "take your medicine, it is supposed to be up at this time . . . (Interview, Policy Maker 2, Urban).

Peer support can be at individual or group levels. Most study participants emphasized the need to identify and train HIV positive women who can mentor and support others especially the newly diagnosed HIV positive women. Peer support groups were understood to help mothers living with HIV to identify with others with the same HIV status thus overcoming feelings of loneliness but also as a source of encouragement and learning from other women's shared experiences.

3. Addressing health system gaps including supply chain

Most study participants stressed the need to ensure constant availability of HIV testing kits and antiretroviral drugs for mothers and their babies for women to adhere to Option B+.

¹ LC refers to "local council" which is a form of locally elected government within the Districts in Uganda

ARVs should be as close as possible. If I come today and you tell me I am stocked out come again after a few days... getting transport is difficult (Interview, Policy Maker 1, Kampala).

As a coping strategy to stock outs, some health workers gave women under Option B+ fewer drugs and shorter drug refill intervals. While these adjustments were rational on the part of health workers, they constituted a strain on the part of women especially those struggling to find transport to health facilities.

The need to improve customer care was emphasized as a key strategy to promote women's adherence to Option B+ as some participants explained:

Using good language, not barking at clients A patient will be encouraging more people to come and adhere because she enjoys coming to the facility (Interview, Policy Maker, Mityana).

Emerging from the above is the need to re-orient health workers in pro-people skills, nurturing and practicing positive attitudes towards their patients.

4. Facility and Community Linkages and Income Generation Support

The Option B+ programme should have a strong link between health facilities and communities to better meet the needs of HIV positive women and their families. Such linkages should provide for effective follow-up and support of mothers.

When mothers don't come back to the facility . . usually the community has solutions. (Interview, Facility Health worker, Kampala).

Study participants suggested supporting women on Option B+ to start income generation activities to enable them to afford transport costs to and from health facilities, buy food, drinks and other necessities.

Discussion

Retention in care for women initiated into the Option B+ programme has been challenging in many African countries since the programme began (Miller, Muyindike, Matthews, Kanyesigye, & Siedner, 2017). Barriers to optimal retention have been documented elsewhere (Okoko et al., 2017; Tenthani et al., 2014; Tweya et al., 2014) and include obstacles at personal levels such as stigma and denial of HIV status (Atanga et al., 2017); relational level (Besada et al., 2016; Chadambuka et al., 2017), and facility

level barriers including lack of quality counselling, and high staff turnover (McLean et al., 2017). Less well known however are the strategies and interventions that will effectively overcome these complex multi-level barriers (Cataldo et al., 2018; Chadambuka et al., 2017; Kieffer et al., 2014; Phiri et al., 2017). Others have found that the position of community health worker and peer support models in tracking women who were possibly lost to follow-up were two approaches that were found helpful in sub-Saharan PMTCT Option B+ programmes (Phiri et al., 2017). In addition, increased emphasis on leadership and coordination has been recommended as useful strategies to improving programme effectiveness (Kalua et al., 2017). The importance of male involvement in encouraging and supporting adherence to the programme has been emphasized in many sub-Saharan African studies as well (Besada et al., 2016; Chadambuka et al., 2017; Peltzer, Jones, Weiss, & Shikwane, 2011).

In order to usefully inform our intervention development, we conducted a qualitative study asking beneficiaries and implementers of the programme their views about what is hindering ideal adherence and how to improve the programme implementation. We drew on the social ecological model (SEM) (Gombachika et al., 2012) to interpret and describe our results (Figures 1 and 2). Overall, among all study participants, we found multi-level barriers to adhering to Option B+ cutting across all levels of the social ecological model. In line with the SEM, our study revealed perceived barriers at personal, relational, organizational and societal levels. These barriers were interconnected and played out in different ways for different individuals in both contexts. Others who interviewed HIV positive women during the pregnancy and post-partum periods found similar barriers when studying adherence to Option B+ programmes in South Africa and elsewhere (Atanga et al., 2017; Clouse et al., 2014; Okoko et al., 2017). Similar to our study, Clouse et al. (2014) found that some personal beliefs such as that the baby's health was more important than the mother's, organizational (negative attitudes and behavior of health workers), structural such as poverty, work conflicts, fear and lack of disclosure related to

community stigma were all critical obstacles to women adhering the Option B+ programme guidance (Tabatabai et al., 2014).

Our study revealed that promoting correct health education and counselling, promoting male partner involvement and support, enhancing community-facility linkages, support for income generation support and addressing health system gaps such as shortage of supplies and negative attitude of health workers were key strategies needed to optimize retention of women in the Option B+ programme.

In examining the PMTCT cascade data from 11 African countries, Kieffer et al. (2014) found strategies to improving retention in the Option B+ programme. They noted that having specific PMTCT counselling and ensuring that counselling was ongoing rather than once at enrolment, endeavoring to engage male partners, and including community support to assist mothers with programme requirements were all important strategies. The challenges to optimum uptake and adherence to PMTCT Option B+ that the literature and our current study revealed at the individual, relational and structural levels provided valuable lessons to the growing body of knowledge within the current emphasis on universal test and treat strategies.

There were limitations to this study. We have, thus far, only analyzed the data cross-sectionally, so cannot infer how these barriers and proposed strategies will play out over time. However, we intended this to be a baseline for both informing the development of the intervention and to be compared longitudinally to follow-up qualitative interviews. We can only generalize these results to the geographic areas where our participants come from. However, our findings further suggest that the

barriers to Option B+ adherence have remained consistent since its implementation. Our findings resonate well with what has been documented elsewhere that to address these persistent barriers, engaging male partners, continuously implementing quality counselling, addressing structural obstacles in a differentiated manner may impact the program.

Following the formative research results, we developed and are in process of implementing an intervention that addresses some of the barriers that we identified in this study and takes into consideration the strategies and recommendations that participants suggested. Our intervention brings women together into groups, these groups meet regularly and have the aims of strengthening friendship support while promoting adherence, increasing health literacy around Option B+ (including lengthy and multiple discussions on disclosure), assisting the access to drugs by bringing them to community distribution points, and initiating income generating activities to help ensure further adherence. If the groups are successful, they will help alleviate some of the critical obstacles that women face in adhering to the programme requirements. Some of the income generating projects include vegetable growing, jewelry and sandal making, book binding, goat rearing and snack selling that could potentially help with nutrition, food security as well as providing critically needed income.

Conclusions

Our study contributes to the Option B+ programme body of work in many ways. Since Option B+ is a relatively new prevention programme, insights into what works and what doesn't are invaluable to inform interventions that can enable better adherence to ART in pregnant and postpartum women. We found that both health workers and participants in the programme have a relatively clear understanding of the benefits of adhering to their treatment; though a more nuanced understanding and thus emphasis in counselling on side effects is critical to helping patients adhere. Clarifying more in-depth the

relationships between individual and relational barriers and between organizational and structural barriers can help in identifying more effective ways to mediate these obstacles leading to the potential success of programme interventions. The obstacles and their possible solutions will continue to play out in similar patterns with universal test and treat programmes, so paying close attention, continuing to critically question our programs and our data will inform better, more effective prevention programming today and in the future.

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Table 1: Characteristics of FGD Participants, n = 51

| Category of FGDs | Role | Number of participants |
|---|----------------------------------|------------------------|
| Mulago site (Urban) | | |
| Pregnant HIV infected women on PMTCT option B+ | Users of Option B+ | 8 |
| Postpartum mothers breastfeeding and non-breastfeeding on PMTCT option B+ | Users of Option B+ | 9 |
| Male partners of women on PMTCT option B+ | Male partner involvement in care | 9 |
| Mityana site (Rural) | | |
| Pregnant HIV infected women on PMTCT option B+ | Users of Option B+ | 9 |
| Postpartum mothers breastfeeding and non-breastfeeding on PMTCT option B+ | Users of Option B+ | 8 |
| Male partners of women on PMTCT option B+ | Male partner involvement in care | 8 |

Table 2: Characteristics of key informants, n = 14

| Category of Key Informant | Role |
|-----------------------------|---|
| Mulago site (Urban) | |
| Health worker | Nursing Officer, ANC Mulago Hospital |
| Health worker | Medical Officer, PMTCT Unit |
| Health worker | Counselor, PMTCT Unit |
| Community leader | Councilor/member Public Health Committee, Kawempe Division |
| Community leader | Nursing Officer/ Community Educator/ Counselor Trainer |
| Policy maker 1 | Program Officer PMTCT |
| Policy maker 2 | Program Officer |
| Mityana site (Rural) | |
| Policy maker | District Health Team Member 1 |
| Policy maker | District Health Team Member 2 |
| Community leader 1 | District Council Member |
| Community leader 2 | Network of People Living with HIV |
| Health worker | Medical Officer, Health Center IV, Mityana |
| Health worker | Health Worker MCH Unit, Mityana Hospital |
| Health worker | Health Worker Early Infant Diagnosis Unit, Mityana Hospital |

Table 3: Themes on perceptions of barriers to Option B+ among policy makers, community leaders, health care providers and Option B+ participants; interviews and focus group discussions

| THEME | QUOTES | ATTRIBUTE |
|--|---|---|
| INDIVIDUAL LEVEL; PERSONAL BARRIERS | | |
| a) Participant educational level & age | <i>Of course, if the woman is not educated enough to understand the benefits of the medicine she is about to take, then she cannot take with proper adherence</i> | Interview, Health Policy Maker 2, Kampala |
| | <i>if we are talking about the educated; . . . the elite, is still a big problem for them to accept ...They prefer death than being identified with HIV. There is a case I can give you; he knew he was positive, they just carried him to Mityana hospital ... he just said, "Anything connected to HIV, I would rather die" the man died</i> | Interview, Community Leader, Mityana |
| | <i>Age, young mothers may not fully understand why they have to take this [medication] for the rest of their lives. They still have a lot of things to go through, they haven't disclosed well, even the fact that they are HIV positive is something they haven't really come to grips with, so really [this] may also deter them from being adherent.</i> | Interview, Health Policy Maker, Kampala |
| b) Drug side effects | <i>I felt so bad and even now I feel a lot of heat in my head as if I have been burnt. I got so thirsty . . . I feel dizzy.</i> | FGD, with women Option B+ participants, Kampala |
| | <i>causes hallucinations, causes strange dreams, weakness . . . They do not kill but if a person is dreaming about goats speaking English, it is disturbing</i> | Interview, Facility Health Care Provider, Kampala |
| c) Stigma and Discrimination | <i>I have at least 3 mothers who were sent away from home. One husband, when he saw the medicines, he sent the woman away and the woman opted to go and sleep in church</i> | Interview, Facility Health Care Provider, Kampala |
| | <i>For my husband, I came and tested and went back home and told him. He refused to come for testing and is currently not on medication. People fear to be seen.</i> | Interview, Community Leader 2, Mityana |
| d) Participant denial | <i>they don't believe that they have HIV. They say, "but for me I am healthy; why do you want me to take medicine?" Or, "okay I will start" but later say "but I am healthy" and then they stop taking the medicine</i> | Interview, Health Policy Maker, Kampala |
| e) Use of alcohol | <i>She might take alcohol and forgets to take her medicine. She may just sleep when she gets home only to realize after missing [drugs] for a week</i> | FGD, Option B+ participants, Mityana |
| RELATIONAL /INTERPERSONAL BARRIERS | | |
| a) Couple relations | <i>The inhibitor could be that a man is having more than one wife . . . They will know that I am having another wife outside. So, this one has led to men saying that they don't have time</i> | Interview, Community Leader, Mityana |
| b) Non-Disclosure | <i>Then at home, she may not have disclosed and she may take the drug . . . in an improper way. Hiding away, . . . she fears children to see her, fears the husband to see her, even other women</i> | Interview, Facility Health care provider, Mityana |
| ORGANIZATIONAL BARRIERS (HEALTH FACILITY) | | |

| | | |
|--|---|--|
| a) Access and Human resources at health facilities | <i>Because they still think that each time you go to the hospital you have to spend much time. They query “why, why do you take long!” ... we do not begin in time, we do not observe time, we come late and we begin providing the services late</i> | Interview, Medical officer, Kampala |
| b) Counseling & Lack of confidentiality | <i>. . one goes into a health facility and before even the individual reaches home somebody has heard on the phone that “Are you aware? This one has been tested positive.” So that kind of . . . irresponsibility.”</i> | Interview, Community Leader, Mityana |
| c) Health care coordination / documentation including supply chain | <i>these mothers actually are not lost to follow-up, they have their preferred sites . . . but you never know</i> | Interview, Facility Health provider, Kampala |
| COMMUNITY AND SOCIETAL BARRIERS | | |
| a) Nutrition | <i>Some mothers are, you know, less privileged, like getting food is not easy, even for themselves, even land to cultivate.. . and the mother may not know what to eat</i> | Interview, Facility Health provider, Mityana |
| b) Religious beliefs | <i>The Born again, a pastor might say “Jesus will heal you” so you might stop taking ARVs because my husband stopped taking. He got saved when he was taking ARVs but when he joined them they told him that Jesus would heal him and he also stopped. He got sick again and appeared like someone who had never taken any medicine; he got herpes zoster and lost his hair until he died and we buried him</i> | Interview, Facility Health provider, Kampala |

FIGURE 1: FRAMEWORK USING THE SOCIAL ECOLOGICAL MODEL

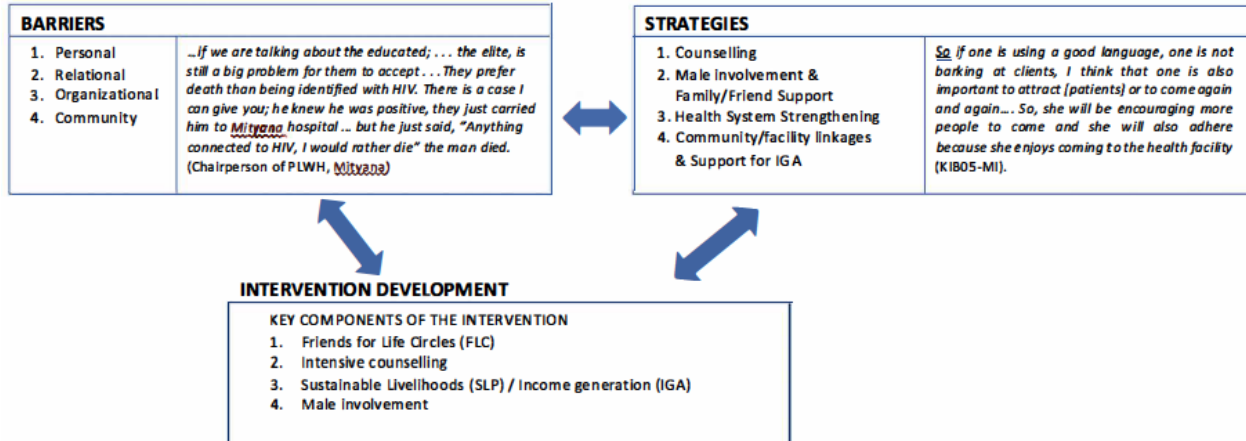


Figure 2: Social Ecological Model

