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"*Injectable ARVs will give me peace*" women's acceptability of injectable antiretroviral therapy in prevention of HIV vertical transmission in Uganda

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A third of women who initiate or continue antiretroviral (ARV) treatment during pregnancy are lost-to- follow-up (LTFU) within six months in sub-Saharan Africa. Clinical trials of long acting injectable Antiretroviral Therapy (LA-ART) are ongoing, including for pregnant women. The study explored women's acceptability and attitudes towards- the use of potentially discreet LA-ART in Uganda for Prevention of Vertical Transmission Program (PVT). Understanding women's perspectives of LA-ART before its introduction is critical in answering questions about acceptability and identifying interventions for future implementation and uptake. In May 2022, we purposively selected participants for eight focus group discussions (FGDs) in 5 health facilities in Kampala: 5 with retained mothers and 3 with disengaged mothers from the PVT. A woman was categorized as retained if she had at least one clinic encounter within her last visit. A total of two in-depth interviews were conducted with disengaged mothers. Luganda, the most widely spoken language in Kampala was used to conduct the FGDs and interviews. Recordings were transcribed and translated into English. Themes were mapped onto some components of the health belief model. NVivo version 14 software was used for data management. A thematic approach was used for analysis and a team-based approach was utilized. The data realized three broad themes (1) Perceived benefits from the use of the LA-ART like emotional relief from daily drugs, effective viral load suppression, reduction on stigma and discrimination, reduction of LTFU, (2) potential threats to rollout due to fear of side-effects from monthly injections, drug stock outs, the cost of LA-ART, myths about LA-ART that it cures HIV and (3) Approaches to increase access to LA-ART like prior investigations, providing bridging treatments and use peer-peer approaches. Most women in this study appeared to have positive attitudes towards the rollout of the LA-ART. LA-ART is a potential solution to LTFU which could improve retention in care for women living with HIV. To optimize the acceptability, health programs should ensure strengthened counseling and create awareness of LA-ART and use of peer- peer approaches with expert women using educational initiatives to raise awareness among other women.

Keywords Acceptability, Long-acting injectable antiretroviral, Women living with HIV, HIV treatment, Prevention of vertical transmission, Qualitative study Uganda

Abbreviations

ART	Antiretroviral treatment
FGDs	Focus group discussions
HBM	Health belief model
IDI	Infectious Diseases Institute
HC	Health centre

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HIV	Human immune virus
KCCA	Kampala City Authority
LA-ART	Long-acting injectable antiretroviral treatment
LTFU	Loss to follow up
PLHIV	People living with HIV
PVT	Prevention of vertical transmission
UCSF	University of California San Francisco
USA	United States of America

HIV care engagement during the pregnancy and postpartum periods is suboptimal in sub-Saharan Africa[1,2]. One-third of women who initiate or continue ART during pregnancy are lost to follow-up within six months[2,3]. Lifelong retention is fundamental for a mother's care, but in the elimination of mother-to-child transmission of HIV, it is vital during pregnancy and breastfeeding[4]. Despite the success of the prevention of vertical transmission (PVT) programs, low uptake of services and poor retention pose a challenge to achieving the elimination of vertical HIV transmission in low- and middle-income countries[5].

A recent study in Uganda, 2017–2018, revealed that nearly half of women engaged in PVT programs had disengaged from care[6]. Among the challenges reported by women attending PVT clinics were fear of disclosure to partners and family members through pill containers which were a potential for HIV status disclosure, lack of partner support, stigma, and discrimination, which were considered leading causes of poor adherence and loss of follow-up[2,3,6,7].Women may become demotivated to continue attending routine appointments for fear that ART tablets and pill containers were a potential for HIV status unintended disclosure and shame, leading to loss to follow-up[2,3,7,8].

To date, Participants in LA-ART trials report better satisfaction than oral therapy because it is discrete and associated with less risk of unwarranted disclosure[7]. A small quantitative study was conducted to follow-up on women living with HIV who initiated ART under the PVT program but were later lost to follow-up. Of the 83 successfully traced women, 95% (79/83) were willing to use LA-ART programs[9]. Several interventions have been put in place to prevent MTCT with robust coverage of lifelong antiretroviral therapy among pregnant and breastfeeding women living with HIV, nearing 100% in Uganda in 2022/2023 there were 6.0% infections in Uganda in exposed infants. https://www.unaids.org/sites/default/files/media_asset/transforming-vision-into-reality_en.pdf. Differentiated service delivery (DSD) models are used to provide patient-centered care[10] and they often include support mechanisms like peer groups, which provide emotional and social reinforcement alongside medical care. The use of peer support, especially through mentor mother models who are women living with HIV themselves, have completed a PVT cascade and are willing to support fellow women[11]. In the context of mother-to-mother programs, this approach fosters a unique sense of belonging and shared understanding among women, empowering them by providing support from peers who have lived similar experiences. Having someone walk with them through the treatment journey not only builds trust but also strengthens engagement in care.

Therefore, for PLWH who are pregnant addition interventions to prevent vertical transmission are needed. LA-ART may help overcome challenges experienced by women who separate from PVT and reduce the rates of disengagement and vertical transmission. With LA-ART likely to be a treatment option for people living with HIV, it is critical to assess its acceptability among potential end-users[12] and feasibility in implementation of healthcare interventions[13].

LA-ART has been approved in developed countries like the United States of America and Europe[14]. Clinical trials are ongoing in African countries to determine its safety and tolerability and results from one of them were expected in 2024. These studies will potentially affect WHO guidelines because they will provide specific context information on effectiveness and feasibility. Clinical trials looking at the safety and efficacy of LA-ART in pregnant women are also ongoing (https://www.impaactnetwork.org/studies/impaact2040). Botswana is the only African country that has approved LA-ART for treatment. However, despite the approval, delivery has not yet commenced. Modelling studies also predict LAI-ART will have the greatest impact if used in patients with suboptimal adherence to ART compared to use in all populations including those with good adherence[15,16].

The study explored women's' acceptability and attitudes towards- use of potentially discreet LA-ART in Uganda. Understanding how women perceive LA-ART before introduction is critical to inform interventions for future implementation. If considered, the findings will aid in making recommendations related to facilitators, concerns and barriers of acceptability and feasibility of LA-ART. Questions remain about the acceptability of LA-ART use among women. The findings from the study will be shared with key stakeholders at the Ministry of Health and during dissemination meetings.

Materials and methods

The study utilized the Health Belief Model (HBM)[17,18]. It has been widely used in the context of sexual and reproductive health, including studies on HIV/AIDS prevention and treatment adherence[19]. We focus on the potential threats and benefits and how they will have on the roll out of LA-ART. According to the Health Belief Theory, if patients perceive that LA-ART is effective (high perceived benefits) they are more likely to be willing to use it. However, barriers such as concerns like pain, fear of injections and side effects.

Study design

We performed a qualitative implementation research study and collected data from women retained on one hand and those disengaged from PVT clinics on another hand. To determine the engagement status of a woman in a clinic, we classified her based on her clinic encounters. If a woman has had at least one clinic encounter

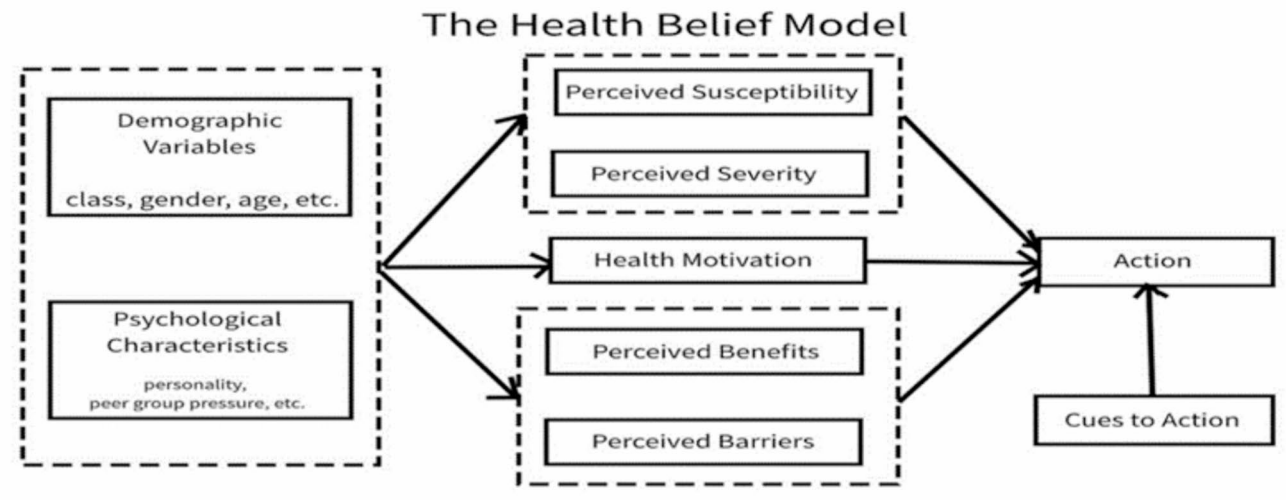


Fig. 1. The health belief model.

within her last scheduled visit, she was considered as retained. On the other hand, if a woman had no clinic encounter within the last 28 days from the scheduled visit, she was classified as disengaged.

Patients and public involvement

Patients were involved in the design and conduct of this research. Before the start of the study, patients and community representatives were engaged and the priority of the research question and methods of recruitment were informed by discussions with patients through a focus group session and two indepth interviews.

Setting

The study took place in Uganda at five public health facilities located in the Kampala and Wakiso districts. It was conducted at the Infectious Diseases Institute (IDI) adult HIV clinic and its partner clinics under the Kampala City Council Authority (KCCA). The IDI was established within Makerere University College of Health Sciences and opened in 2002. The IDI adult HIV clinic currently provides care and treatment services to approximately 8000 people living with HIV in urban and rural settings in Uganda [41]. At the time of the study, IDI also supported the KCCA clinic network of 10 facilities to build capacity for prevention, care and treatment of infectious diseases within Kampala City. For this study, we specifically selected four KCCA clinics: Kisenyi, Kiswa, Kawala, and Kitebi. Some of the study activities leveraged the routine services offered at the PMTCT clinics for newly diagnosed pregnant women, which included pre-ART adherence counseling, and same-day ART initiation *of tenofovir + lamivudine + efavirenz* (TDF + 3TC + EFV)[6].

Sampling

We purposively selected five clinics; IDI and four KCCA clinics Kisenyi, Kitebi, Kawala and Kiswa based on the high-volume of patients in the PVT clinics. Women engaged in care were purposively selected from the PVT clinics to take part in the focus group discussions (FGDs). Systematic sampling was used to identify disengaged women from the PVT list and every 3rd participant was selected. Peer mothers contacted the women who disengaged from care by phone to attend the FGD. For women who were still engaged in care, a research assistant purposively selected eligible women from the PVT clinic and requested to speak with them.

All the public healthcare facilities and communities selected were based on potential future plan to roll out LA-ART.

Research team and reflexivity

The team employed two research assistants who were social scientists, independently participated in the consenting process and were not influenced by the study. The participants were encouraged to freely express themselves and were reminded that their identity would be kept confidential. The research assistants were mindful of their emotions as they engaged with the pregnant and breastfeeding mothers.

Trustworthiness

To reduce threats to validity, the study employed qualified research assistants who underwent training on the protocol and the tools. The guides were initially developed by the lead author and refined with input from the other authors. The questions were arranged in a logical sequence, beginning with simpler, more general topics to help participants feel comfortable before progressing to more sensitive or complex issues. The questions were aligned with the study's objectives to ensure that the guides collected relevant data. Open-ended questions were formulated to encourage participants to provide detailed responses. Additionally, the guides were piloted with a small group of individuals to assess their clarity and comprehension. To ensure credibility and dependability of the data, transcripts were reviewed by an independent person to ensure they were a true reflection of the

FGD No.	Health facility	Age range	No. of participants	Group type	Employment type	Employed	Unemployed	Self-employed
1	Kisenyi HC	24–30	5	Engaged	Teacher	1	1	3
2	Kisenyi HC	18–30	7	Disengaged	—	0	4	3
3	Kitebi HC	19–30	6	Engaged	Nurse, Assistant Manager	2	2	2
4	Kitebi HC	18–30	6	Disengaged	—	0	3	3
5	Kawala HC	22–30	7	Engaged	—	0	2	5
6	Kawala HC	20–30	6	Disengaged	Cleaner	1	3	2

Table 1. Focus group discussion overview.

IDI NO	Health facility	Age range	Category	Employment category
1	IDI Mulago	35 years	Disengaged	Teacher
2	IDI Mulago	28 years	Disengaged	Teacher

Table 2. Overview of indepth interviews.

recordings. Discussion on the identified themes was held with the principal investigator. Analysis of data was team based rather than conducted on an individual basis[20].

Data collection

Data were collected through FGDs and indepth interviews using health belief model that looked at the perceived benefits, threats, perceived susceptibility, and modifying factors [47]. A total of eight FGDs were conducted from five health facilities with 5–8 participants in each group. FGDs 1 and 8 had the lowest number of participants while FGD 5 had the highest number. FGDs were used to broadly explore attitudes and willingness to use LA-ART. FGDs were conducted in a dedicated meeting room as appropriate at the IDI clinic and KCCA clinics. Each session lasted approximately 45 min to one hour and a discussion guide was used to direct the FGDs. FGDs were split into subgroups by age to ensure engaged participation of all members. They were further split into categories: retained in care in the PVT clinics and disengaged from care. A total of seven FGDs were conducted with participants 15–30 years and one with participants ≥ 30 years. A total of three FGDs were conducted with disengaged women.

A total of two in-depth interviews were conducted with women who disengaged from care at the IDI Mulago clinic.

The lead author developed topic guides, which included open-ended questions that were used to facilitate the discussions. The social scientist facilitated the discussions and a rapporteur took notes, and recorded the non-verbal communication recorded. All discussions were conducted in Luganda captured using a digital voice recorder. Recordings were translated directly and transcribed into English.

The transcripts were checked for accuracy against the original recordings and field notes by members of the field team. The transcripts and discussion notes were reviewed for themes and re-organized according to discussion topics.

Data analysis

Thematic analysis was grounded on the health belief model which looked at the perceived benefits, threats and perceived susceptibility [47]. This involved multiple readings which helped the researchers to familiarize, mark, and memo the data and design an initial code book. The process was open to identifying new themes from the data, which was integrated into the pre-existing themes. Data management was done using qualitative data analysis software NVivo (version 14). Thematic analysis generated a coding frame and categorized key themes and concepts from the responses. A team-based approach of coding and analysis was utilized where two team members participated in coding independently and any discrepancy was resolved by an independent checker[21]. Illustrative quotations for each emergent theme were selected for results narration. We applied the consolidated criteria for reporting qualitative research (COREQ) checklist for qualitative studies to the presentation of findings[22].

Results

Participant characteristics

Participant demographic information like age and occupation were ascertained from the participants and captured during the discussions and indepth interviews.

Several participants were either self-employed or unemployed, with only a few engaged in formal employment, such as teachers, nurses, cleaners, and assistant managers (refer to Table 1).

Two women participated in the indepth interviews at IDI Mulago and their demographics are presented (refer to Table 2).

Both the FGD and in-depth interview participants seemed to be aware of LA-ART and attributed this knowledge to sources of media search as radios, television and through rumours from fellow clients at the health facilities.

Themes	Sub theme
1.Perceived benefit	• *Convenient, time saving and easy to take* • *Improve ART adherence* • *Minimize disengagement and reduce the anxiety associated with missing clinic appointments* • *Reduce stigma and discrimination*
2.Potential threats	• *Fear of drug stock out and limited access* • *Financial worry* • *Socio-cultural context* • *Myths about injectable*
3. Approaches to increase access to LA-ART	• Individual factors (autonomy) • Health facility factors: (peer to peer approaches, bridging treatments, sensitization, availability of the injection, increase numbers of health care workers)

Table 3. Main themes identified.

Themes	Illustrative quotes
1.Perceived benefit	***Convenient, time saving and easy to take*** *"It is very convenient for me. That, I know will benefit us. Who will disturb you? Who will make you panic? You know, when we get the ARVs, we have to move by taxi—now for me, when I get it, I wrap the mask inside so as to contain the sound—but when you sit in the taxi, they tend to make a certain sound and everyone looks at you. Those who are familiar with the sound can tell that you are coming from the clinic."* -- FGD, engaged mothers, Kisenyi). *"I am sure that LA-ART will be very convenient for me, with my kind of job, I am always so afraid that my fellow teachers may accidentally find me taking my medicine and that is why I even disappeared from the clinic" (*Disengaged, IDI, Mulago). ***Improve ART adherence*** *"They will accept the drug because of the fact that it is required–because I have ever heard on the radio about the school children, especially those in the boarding schools who find it challenging to swallow the medicine when their peers are watching them"* -- FGD, engaged mothers, Kiswa HC. ***Minimize disengagement and reduce the anxiety associated with missing clinic appointments***: *"Doctor, it will be better. For instance, if they inject me and tell me to return after 1–3 months—don't you think it would be enough time for me to save 5000 shillings for transport regardless the distance from my place of residence since I will have the zeal to do so? You can't compare the reality of having to move with these ARVs every day to having the injectable administered in your body without having to worry about being exposed and moving on with your life freely"* -- FGD, disengaged mothers Kawala HC. ***Reduce stigma and discrimination***: *It solves hiding the tablet issue. They will not even know about it. No one will discriminate you; who will discriminate you when you have not told them about it or when they have not seen your treatment documents? Those issues of people checking your bag"* -- FGD, engaged mothers Kawaala HC.
2.Potential threats	***Adverse events***: *"When this injectable ART is introduced, will it have any side effects? Are there any risks if not administered on time? When you swallow the tablets for a month, you have side-effects like headaches, fever. But if I am given that injection and I suffer from those side effects, what would I do during that time".* ***Fear of drug stock out and limited access***: *"if it is the LA-ART and the health worker says they do not have it in stock, what will you do? How will you survive until you come back? The injection dose is finished, you don't have anything to take yet you are anticipating returning to Kitebi the following week for medicine, but previously you would run to the nearest health Centre. So, what will you do in this case?"* ***Financial worry***: *"I have also ever heard about it but they claim that it is for the rich; those that can afford to pay 100,000, 200,000 shillings* (Approx.*25–50 USD) rumor has it. My Aunt in Entebbe upgraded from the pills to that injection… There is a certain pharmacy, grade B where she goes to receive her injection from. She told me they inject her every month. She said that it is sold at a price ranging from 100,000 to 200,000 shillings depending on the bargain*" - FGD, disengaged mothers Kawala HC. ***Socio-cultural context***: *Me I can't join anything like that without permission from my husband. What if something happens to the baby and he blames me for it? (FGD, engaged mothers, Kisenyi HC)* ***Myths about injectable***: *"But doctor, they say that this injection cures. I heard people say that it cures very well. By the way, Initially, I heard them talking about tablets saying, "If you take a long time on those tablets…what I know is, when you take the medication, the virus becomes dormant and when your stop taking the medication, it reactivates"* -- FGD, disengaged mothers Kisenyi HC.
3. Approaches to increase access to LA-ART	***Individual*** ***Autonomy***; *They should increase the number of doctors—okay, I stopped accessing my medication from here and resorted to a pharmacy. The problem is I am not even motivated anymore. My businesses would be affected because I would spend the whole day here. I was fed up and that is why I find it so difficult to come this side—I left many years back. I resorted to another place.* ***Peer to peer approaches***: *What can entice the women to embrace it; just like you have invited us here; you can initiate some patients to the injectable once it is rolled out. Those will tell their fellow patients about how it is, how it works, how it reacts and the like. Therefore, in that way, they will understand it"* **Health facility interventions** ***Bridging treatments***: *"But if we start receiving these injectable ARVs, we have our health Centres that are deep in the villages where we usually visit. Now I might go today on Tuesday, the injection dose ends the following Tuesday but I don't expect to go there so I go to the nearest health Centre in the village, and they tell me they have no injectable ARVs; what do I do in that case?"* ***Preliminary tests***: *There are some blood types that might not be compatible with the injectable ART. So, they have to first test me and find out whether my blood is compatible with the injectable or remain on the tablets"*

Table 4. Illustrative quotes.

Thematic analysis of the FGDs revealed three main themes, which are summarized in Table 3. These themes include: (1) perceived benefits and motivation of taking LA-ART, (2) potential threats, and (3) approaches to increase access to LA-RT.

To support the thematic findings, illustrative quotes from participants are presented in (Table 4). These quotes were selected to reflect the diversity and depth of participant experiences and perspectives across different themes and sub-themes.

Perceived benefits and motivation of taking la-art

Convenient, time saving and easy to take

LA-ART was considered to be convenient, time saving and easy to take. The constant daily reminder of being HIV positive by having to swallow tablets daily coupled with the sight of the pill containers wasn't pleasant to the mothers during pregnancy or breast feeding. LA-ART was considered as a solution to this challenging situation

as it would offer emotional relief from taking daily tablets and travelling with the drugs. LA-ART will address one significant inconvenience—eliminating the noisy pill bottles that could raise suspicions and compromise privacy.

Both engaged and disengaged respondents indicated how LA-ART would be very convenient for them.

"It is very convenient for me. That, I know will benefit us. Who will disturb you? Who will make you panic? You know, when we get the ARVs, we have to move by taxi—now for me, when I get it, I wrap the mask inside so as to contain the sound—but when you sit in the taxi, they tend to make a certain sound and everyone looks at you. Those who are familiar with the sound can tell that you are coming from the clinic." -- FGD, engaged mothers, Kisenyi).

I am sure that LA-ART will be very convenient for me, with my kind of job, I am always so afraid that my fellow teachers may accidentally find me taking my medicine and that is why I even disappeared from the clinic (Disengaged, IDI, Mulago).

Both disengaged and engaged women from different facilities stated that the LA-ART would give them peace of mind. This is because they would not worry of the time to take tablets, costs associated with taking tablets like buying water and food. Tablets were described as burdensome to take on a daily basis and it was hectic to swallow due to big size during pregnancy.

"Concerning LA-ART, I think that it will give me more peace than I would get from swallowing the tablets. Whenever it is time to swallow them, I tend to get worried but if one is injected, they have to deal with it only once in a while at their own will. I would prefer the injectable ART".

-- FGD, engaged mothers Kitebi HC.

Injectable ARVS would be taken without tension, and no worry of missing the set time.

You have the time because when it comes to the tablets, you are always on tension waiting for the time to swallow. For the injection, you are steady; regardless of whether you are somewhere many miles away, you are still steady.

-- FGD, disengaged mothers Kiswa HC.

Improve ART adherence

A summary of the findings showed that the roll out of LA-ART could improve adherence for pregnant or breast-feeding women who had trouble taking ARVS or difficulty swallowing tablets by reducing pill burden. Pregnant and especially breast feeding mothers are usually very busy involved taking care of the little babies. Their busy schedules sometimes may place them at risk of poor adherence. Additionally, LA-ART could improve adherence generally for workers with busy work schedules and school children who did not want to be seen swallowing medication at school due to non-disclosure:

"They will accept the drug because of the fact that it is required–because I have ever heard on the radio about the school children, especially those in the boarding schools who find it challenging to swallow the medicine when their peers are watching them" -- FGD, engaged mothers, Kiswa HC.

Many women reported taking their medication in secret and often missed clinic appointments, delayed taking antiretroviral therapy (ART), or missed doses altogether when their partners were present, which resulted in elevated viral loads. Numerous participants expressed concerns about disclosing their HIV status to their spouses, as many were financially dependent on them. This uncertainty about their partners' potential reactions if they were to find out unintentionally caused significant anxiety and fear.

"The man I live with does not know that I am positive. So sometimes he has not left early… since I take my medicine at 8pm. So, if he comes back at 8pm, I start to panic, sometimes I skip the dose. Sometimes he stays at home till night time, in that case I spend up to a week without getting time to swallow the medicine because you are panicking" (FGD_DISENGAGED MOTHERS_KITEBI HC).

Minimize disengagement and reduce the anxiety associated with missing clinic appointments

The LA-ART would reduce the anxiety associated with fear of missing clinic appointments. Maintaining clinic appointments remains a challenge due to non-disclosure among the majority of the women and the dependence on their male partners. Many of them end up getting lost from the clinics. One of the participants noted that if given a return appointment of 1–3 months, she would be in position to afford the transport and return to the clinic.

"Doctor, it will be better. For instance, if they inject me and tell me to return after 1–3 months—don't you think it would be enough time for me to save 5000 shillings for transport regardless the distance from my place of residence since I will have the zeal to do so? You can't compare the reality of having to move with these ARVs every day to having the injectable administered in your body without having to worry about being exposed and moving on with your life freely".

-- FGD, disengaged mothers Kawala HC.

Reduce stigma and discrimination

Some women viewed LA-ART as a way to reduce stigma and discrimination associated with HIV treatment. Unlike daily oral medications that may require regular clinic visits or visible pill-taking, LA-ART allows them to visit the clinic, receive their injection discreetly, and leave quickly minimizing the likelihood of being seen by others who may know them.

"It solves hiding the tablet issue. They will not even know about it. No one will discriminate you; who will discriminate you when you have not told them about it or when they have not seen your treatment documents? Those issues of people checking your bag" -- FGD, engaged mothers Kawaala HC.

Potential threats of la-art

Adverse events

Reflections from the data showed that women expressed concern about the use of LA-ART among pregnant or breastfeeding women due to fear of side-effects and the unknown to the mother and baby (Table 3). Women had concerns about whether LA-ART would affect a pregnant woman as well as on the unborn child.

"When this injectable ART is introduced, will it have any side effects? Are there any risks if not administered on time? When you swallow the tablets for a month, you have side-effects like headaches, fever. But if I am given that injection and I suffer from those side effects, what would I do during that time".

Some women feared injections and they wondered which position the healthcare workers would inject. They also worried about deformity after receiving constant injections over time. They said they would rather swallow tablets:

"I would like to know which position that injectable will be administered because some of us fear them. There is a possibility of constantly injecting one's body. Will that not get me deformed?"

-- FGD, engaged mothers Kiswa HC.

Fear of drug stock out and limited access

Some women expressed concern that LA-ART could face similar stock-outs and delays as oral tablets, particularly in lower-level or hard-to-reach health facilities. These concerns were shaped not only by past experiences but also by cultural expectations that injectables are more effective and dependable. This perception heightened fears about what would happen if the treatment became unavailable, as stock-outs could erode trust in both the medication and the health system. These concerns reflected a gap between participants' hopes for LA- ART as a more effective and preferred option, and their fears about the health system's ability to provide it reliably, especially in lower-level or remote facilities.

"if it is the LA-ART and the health worker says they do not have it in stock, what will you do? How will you survive until you come back? The injection dose is finished, you don't have anything to take yet you are anticipating returning to Kitebi the following week for medicine, but previously you would run to the nearest health Centre. So, what will you do in this case?" -- FGD, disengaged mothers Kitebi HC.

Financial worry

The findings revealed that women expressed significant concern about the potential cost of LA-ART. There was considerable uncertainty about whether it would be provided free of charge, as is the case with oral ART. Some participants reported hearing that LA-ART might be expensive, raising fears that they would not be able to afford the treatment if payment were required.

"I have also ever heard about it but they claim that it is for the rich; those that can afford to pay 100,000, 200,000 shillings (Approx.25–50 USD) rumor has it. My Aunt in Entebbe upgraded from the pills to that injection… There is a certain pharmacy, grade B where she goes to receive her injection from. She told me they inject her every month. She said that it is sold at a price ranging from 100,000 to 200,000 shillings depending on the bargain" - FGD, disengaged mothers Kawala HC.

Socio-cultural context

Findings from the FGDs revealed that, within the prevailing socio-cultural context where men are typically seen as primary decision-makers, many women felt they could not make health-related decisions such as switching to LA-ART without first seeking their husbands' approval. This reliance was not only rooted in cultural norms but also in the fact that several women were entirely dependent on their spouses for financial and logistical support, including transport to health facilities and meeting other basic needs. As such, the decision to change to injectable ART was often viewed as a joint or male-determined choice, rather than an individual one.

Me I can't join anything like that without permission from my husband. What if something happens to the baby and he blames me for it? (FGD, engaged mothers, Kisenyi HC)

Myths about injectable

Some women were uncertain about using LA-ART due to a lack of knowledge on the subject. Awareness of LA-ART among women was low and often accompanied by misconceptions, such as the belief that LA-ART could cure HIV. Additionally, some women expressed concerns that frequent injections might harm or deform unborn babies. There was also a belief among some that all healthcare workers attending to them were HIV-positive, with some suggesting that the injection should be tested on these providers before being administered to patients.

But doctor, they say that this injection cures. I heard people say that it cures very well. By the way, Initially, I heard them talking about tablets saying, "If you take a long time on those tablets…what I know is, when you take the medication, the virus becomes dormant and when your stop taking the medication, it reactivates.

-- FGD, disengaged mothers Kisenyi HC.

Approaches to increase access to la-art

Individual factors

Autonomy

Insights from the data showed that women are given the opportunity to make informed decisions about their treatment such as choosing between LA-ART and oral medication, they are more likely to develop a sense of ownership and commitment to their chosen regimen. This autonomy enhances adherence, as women feel respected, empowered, and engagedly involved in their own care. They indicated that ensuring that the informed consent process clearly communicates available options and supports women in making decisions that align with their preferences is very helpful.

Some women expressed a desire to have the option to choose between LA-ART and oral medications (Table 4).

"What I am trying to say is that the injectable will not be compulsory and enforced on everyone. What I am suggesting is that whoever prefers the ARVs, should stick to them and whoever prefers the injectable, should receive it. How is that?"

(FGD, engagedengaged mothers Kiswa HC).

Peer to peer approaches:. Women recommended the use of peer-to-peer approaches as a supportive strategy in the rollout of injectable ART. Expert women could create awareness about injectable ARVS to fellow women using educational approaches. This could create a sense of trust and safety, as individuals are more likely to relate to and believe in the experiences of people from similar backgrounds.

"What can entice the women to embrace it; just like you have invited us here; you can initiate some patients to the injectable once it is rolled out. Those will tell their fellow patients about how it is, how it works, how it reacts and the like. Therefore, in that way, they will understand it".

(FGD, disengaged mothers Kawaala HC)

Health facility factors

Bridging treatments

Participants recommended that emergency oral tablets be made available alongside LA-ART to provide a safety net in cases where patients are unable to return to the clinic on their scheduled injection date. This precaution is important because injectable ARVs may not always be accessible at nearby health facilities for unscheduled refills or dose adjustments. Providing emergency tablets would help prevent treatment interruptions, reduce the risk of viral rebound, and maintain adherence during unforeseen delays, thereby ensuring continuous and effective HIV management.

"But if we start receiving these injectable ARVs, we have our health Centres that are deep in the villages where we usually visit. Now I might go today on Tuesday, the injection dose ends the following Tuesday but I don't expect to go there so I go to the nearest health Centre in the village, and they tell me they have no injectable ARVs; what do I do in that case?"

(FGD, disengaged mothers Kawala HC)

Sensitization and education

Healthcare workers should engage in thorough sensitization and education of women prior to the rollout of LA-ART, ensuring they understand both the benefits and potential drawbacks of this treatment option. This preparation is essential to build trust, address concerns, and support informed decision-making. Additionally, the rollout should be gradual and well-planned rather than abrupt, allowing sufficient time for communities and health systems to adapt and for any challenges to be identified and addressed early.

"Health facilities should introduce the injectable but we need to be aware of its benefits and its disadvantages…. Before they roll it out, they should first sensitize us. In addition, what I want to know is; do they administer that injectable basing on the quality of one's blood? Do they first weigh your kilograms? That is what I want to know".

(FGD, engaged mothers Kiswa HC)

The availability of LA-ART should be ensured at all times to avoid treatment interruptions. To safeguard against potential stock-outs of LA-ART, its administration should be coordinated alongside oral tablet ART, allowing patients to continue their treatment seamlessly if injectables are temporarily unavailable. They perceived the dual availability to be critical to maintaining adherence and preventing the risk of viral rebound or resistance.

In case it is out of stock—for instance if they give me a 3month's dose, but they give me excess tablets in case I fail to come during those 3months, they could give me some tablets to sustain me for about a week as I wait for injection.

-- FGD, engaged mothers Kisenyi HC.

Preliminary investigations

Preliminary investigations, including blood compatibility tests, should be conducted before the introduction of injectable treatment. This approach will help ensure compatibility and enhance the safety and effectiveness of the treatment.

"There are some blood types that might not be compatible with the injectable ART. So, they have to first test me and find out whether my blood is compatible with the injectable or remain on the tablets".

(FGD, engaged mothers Kisenyi HC).

Highlights from the data showed that increasing the number of doctors and healthcare staff to effectively manage the anticipated rise in patient volume was recommended. They linked it to the fact that administering LA-ART requires private consultations and takes longer than providing oral medications, adequate staffing is necessary to ensure timely, confidential care without overburdening the system.

They should increase the number of doctors—okay, I stopped accessing my medication from here and resorted to a pharmacy. The problem is I am not even motivated anymore. My businesses would be affected because I would spend the whole day here. I was fed up and that is why I find it so difficult to come this side—I left many years back. I resorted to another place.

-- FGD, disengaged mothers Kisenyi HC.

Discussion

In this urban population of women living with HIV attending PVT clinics, we found a high likelihood of adopting long-acting antiretroviral therapy (LA-ART) if it were rolled out. Through the health belief model, we placed emphasis on the perceived benefits, threats and approaches to improve the roll out of LA-ART. Women perceived LA-ART as convenient, time saving and easy to take discreet dosing as which were promising for improved

viral suppression[6,9,23]. These findings are supported by studies that show most women enthusiastically endorsed monthly LA-ART and preferred it over pills because of convenience, the emotional benefit of eliminating the daily reminder of living with HIV[23,24].

LA-ART has the potential to improve ART adherence which remains a challenge among most women attending PVT clinics in most countries in sub-Saharan Africa who hadn't disclosed their status[3]. Challenges with adherence to daily oral ART among people living with HIV (PLHIV) have stimulated development of injectable long-acting (LA) regimens [3]. The regimen Cabotegravir is approved for use in combination with rilpivirine and is available as a long-acting injectable formulation dosed every month in the United States [23]. Simplified regimens are widely promoted to improve adherence, and there is scientific rationale for this practice[25].

When comparing women who remained engaged in care with those who disengaged, both groups acknowledged the emotional relief that LA-ART could provide, as well as its potential to improve adherence, eliminate the need to carry pill containers, and reduce stigma. However, women who had disengaged from care raised more concerns, including the high cost, drug stockouts, limited access, and uncertainty about what to do in the event of missed appointments. The findings reveal that LA-ART has the potential to reduce stigma and discrimination which could be brought about from other clinic attendees who may very well also be seeking HIV care. This is similar to other studies, which showed that implementation of LA-ART may reduce stigma and discrimination among women. The continued salience of stigma in the lives of women has a potentially negative role in treatment adherence[26–28]. While Ekusai 2025 acknowledges that LA-ART has the potential to reduce stigma by offering a more discreet treatment option, she also points out that the need for regular clinic visits for injections could itself become a source of stigma, potentially leading to breaches of participant privacy[29]. A study conducted in Uganda, showed that nearly half of women engaged in PVT programs had disengaged from care due to stigma[22].

Several perceived threats to optimal acceptability of LA-ART included concerns about fear of the unknown, side effects from LA-ART such as fear of injections and pain. However, similar research has shown that using LA-ART is still more convenient to taking the medication orally despite the side effects[7,30]. While several women raised concerns around the increased frequency to the clinics which would come along with the rollout of LA-ART, there appeared to be age related variation in views among older and younger women. While long-term stable patients expressed concerns about having to return to the clinic on a monthly or bi-monthly basis especially since many currently only visit the health facility every six months for drug refills at the community level—a few younger participants mentioned that even if they were required to return every 1–3 months, they still preferred this option over carrying around the noisy pill containers. They indicated that they would be motivated to find transport and return to the clinic, thereby reducing the likelihood of LTFU. The findings are not in agreement with a study done by Laker et al.[9] who showed that age was not associated with willingness to use LA-ART. Additionally, concerns about financial worry, affordability and access remains a challenge for the women who are vulnerable and often housewives and thus depend on the spouses for financial support[31]. Some women from hard-to-reach areas expressed concerns about limited access to LA-ART and the need for bridging treatments in cases of missed appointments. They also raised questions about what to do if they were unable to access LA-ART from nearby health facilities or in situations of drug stock outs. These findings highlighting the importance of availing bridging treatment for women in hard-to-reach areas in cases of missed appointments align with similar recommendations as a means of preventing poor adherence[29,32].

This study highlights the important role of peer-to-peer and bridging strategies in supporting the use of LA-ART within PVT programs. Differentiated service delivery (DSD) models are used to provide patient-centered care[10] and have been recommended and includes support mechanisms like peer groups, which provide emotional and social reinforcement alongside medical care.This is a peer-led initiative aimed at supporting HIV-positive mothers through mentorship and counseling to improve retention in prevention of PVT of HIV services[11]. Our findings align with a study conducted in Mozambique, which found that mother-to-mother programs serve as an effective peer-support approach that enhances mothers engagement in HIV care, reduces stigma, and improves retention in PMTCT programs. Research conducted in Zambia indicates that while DSD for PLHIV has been widely adopted in sub-Saharan Africa, it is lacking for women and infants enrolled in PVT clinics.

In the African socio-cultural context, where traditional norms often limit women's decision-making capacity, many women tend to seek approval from men, because husbands are typically seen as the primary decision-makers. As a result, women may need to obtain their consent before deciding to switch to LA-ART. The findings are in agreement with a study that showed that women have limited decision making capacity regarding health related decisions[33]. The study findings align with what other scholars in Uganda have observed, as well as results from a survey, which showed that HIV patients tend to be poorer than the general population[34,35]. While we agree that socio-cultural factors can still influence women's decision-making to some extent, we don't believe this is still the prevailing norm. Times have changed, and many women today are increasingly empowered and able to make independent choices about their health and well-being Future research should examine uptake after its implementation in Uganda to establish LA-ART coverage, barriers and facilitators and how to address them as well as the role played by socio-cultural factors on women's decision-making capacity. Perceptions about LA-ART should also be examined in additional community settings and populations, where challenges to ART adherence persist, including among youth, key populations and other stakeholders engaged in ART.

Strengths

Our study aimed to raise awareness and hope for future LA-ART. We ensured inter-rater reliability by involving multiple coders during the analysis. Additionally, we utilized data triangulation from both FGDs and in-depth interviews, which allowed for comparison of engaged and disengaged women's perspectives. The findings are generalizable to women outside Kampala who share similar concerns and fears around accidental disclosure, stigma, shame, and isolation.

Limitations
All participants were female, and future research could involve the general population to gather a wider range of perspectives. Raising the required numbers for the FGDs was challenging, especially among the disengaged women. Nevertheless, we conducted in-depth interviews with women who disengaged from the clinic, and they provided detailed views and opinions on LA-ART and loss to follow up.

Conclusions
Most women in the PVT clinics appeared to have a positive attitude towards the rollout of the LA-ART because of its likely impact in improving adherence, reducing stigma and discrimination. LA-ART offers a potential solution to LTFU and could improve retention in care for women living with HIV. To optimize women acceptability of LA-ART, health programs should ensure strengthening counseling, create awareness and understanding of LA-ART. Policymakers should consider using peer-to-peer approaches by involving mentor mothers in the regular visit schedules of PVT programs. This would give women the chance to connect with and learn from others who have walked a similar path. Through these trusted relationships, mentor mothers can help raise awareness about LA-ART, answer questions, and offer encouragement in a way that feels supportive and relatable.

Data availability
Data is provided within the mauscript and as supplementary information.

Received: 7 November 2024; Accepted: 4 July 2025
Published online: 16 July 2025

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Acknowledgements

The IDI is thanked for hosting the research, along with study participants and research assistants who helped: Patience Nantume, Kalisa Patricia Kelly and Mercy Nankoma. Deborah Ekusai-Sebatta, a doctoral student, has received support from the Fogarty International Center under Award Number D43TW010892. We are grateful for the program's training and mentorship in her journey as a researcher.

Author contributions

DES: Led the writing, contributed to conceptualization, analysis and critically reviewed and provided feedback on drafts and final approvalEL: Contributed to conceptualization, critically reviewed, and provided feedback on drafts and final approvalAK: Contributed to project conceptualization, critically reviewed, and provided feedback on drafts and final approvalPBK: Contributed to conceptualization, critically reviewed, and provided feedback on drafts and final approvalRK: Oversaw the writing, contributed to conceptualization, critically reviewed, and provided feedback on drafts and final approval.

Funding

This research was supported by the NIH CFAR P30A1027763, Booster award BO-1122, BO-0423.

Declarations

Competing interests

The authors declare no competing interests.

Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki. Ethics approval was obtained from the Infectious Diseases Institute (IDIREC) on 3 November 2021 (**IDIREC 032/2021**). Additional approvals were obtained from the Uganda National Council for Science and Technology (**SS1095ES**) on 8/12 2021. UCSF approval (**Ref 327715**) in 05/04/2022. All participants signed an informed consent sheet either in English or Luganda and confidentiality was maintained by anonymizing participants' identifiers at all stages of data collection and reporting. All data were stored on encrypted computers. Filed notes and signed participant-informed consent forms were kept in a locked drawer at the study site. Participants' names were not recorded anywhere during data collection. Each participant was given a unique identifying number to ensure confidentiality. The research teams did not include any identifying information that could have harmful consequences for the participants.

Consent for publication

All authors reviewed approved the final manuscript and consented to submission for publication.

Additional information

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1038/s41598-025-10686-8.

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