Experiences Using an SMS Service for ART Adherence Among Pregnant and Postpartum Women Living with HIV in Kenya: A Qualitative Analysis

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Abstract

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Purpose: Understanding the experiences of pregnant and postpartum women living with HIV (WLWH) receiving standard text messages (SMS) to encourage ART adherence can help elucidate the benefits and limitations of SMS for adherence in this population. We aimed to understand the experiences of pregnant and postpartum women living with HIV (WLWH) in Kenya during their experience with the Mobile WAChX trial.

Methods: Semi structured individual interviews were conducted among women (n=44) who received bidirectional or unidirectional SMS and were exiting the Mobile WAChX trial. This trial was an unblinded, three-arm randomized controlled trial examining the effect of unidirectional and bidirectional combined HIV and maternal child health (MCH) text messages on ART adherence during pregnancy and up to 2 years postpartum. Participants were recruited via purposive stratified sampling. Transcripts were coded by two investigators and analyzed

using the Information-Motivation-Behavioral Skills (IMB) framework. Deductive thematic analysis was also performed to understand the challenges experienced by the women during the intervention.

Results: Women overall reported a positive experience with the SMS intervention. There were 5 key themes that emerged. First, SMS provided reminders and skills for medication adherence and clinic appointments. Second, SMS served as a significant source of social support and motivation for adherence-related behaviors. Third, SMS provided hope for living a normal life. Fourth, SMS reduced feelings of internalized and anticipated stigma and increased feelings of courage and self-acceptance. Lastly, participants experienced technical, financial, and logistical challenges to the intervention.

Conclusion: Combined HIV/MCH messaging was well received by participants and provided them informational and psychosocial support. Challenges experienced by participants that could not be overcome with SMS included the daily financial stressors that participants faced as well as technical challenges. Our study highlights the potential for mHealth to intervene on stigma related barriers to adherence and retention in care. Further research is needed to understand the challenges that impede consistent ART adherence among pregnant and postpartum women living in Kenya.

BACKGROUND AND SIGNIFICANCE

In 2012 the WHO released guidelines for Option B+, recommending initiation of life-long antiretroviral therapy (ART) for all pregnant and postpartum women living with HIV (WLWH), as a means of preventing mother to child transmission (PMTCT) (World Health Organization, 2012). However, peripartum women face many obstacles to long-term ART adherence particularly in low-middle-income-countries (LMICs) (Omonaiye, Nicholson, et al., 2018). These obstacles to ART adherence are complex and span multiple socio-behavioral domains at the individual, interpersonal, community, and structural levels. At the individual level, some lack complete understanding about how the medication can improve their lives and prevent MTCT. Furthermore, competing interests, such as caring for their children and food insecurity, particularly in the pregnancy and the neonatal period, can impair adherence(Omonaiye, Kusljic, et al., 2018). At an individual and community level, WLWH are often stigmatized in their community and may have internalized stigma making it difficult to accept their diagnosis and incorporate adherence into their lives (Hodgson et al., 2014). This may lead to behaviors such as missing clinic appointments and medication refills due to fear of involuntary disclosure to the community at large while standing in clinic lines, ultimately reducing effectiveness of treatments for HIV related health needs (Hodgson et al., 2014; Omonaiye, Kusljic, et al., 2018). At the interpersonal level, nondisclosure to a partner and/or lack of social support around the HIV diagnosis can negatively influence behaviors related to adherence (Hodgson et al., 2014). At the structural level, WLWH may experience significant financial barriers due to reduced financial opportunities or their economic dependence on their partners (Omonaiye, Kusljic, et al., 2018). This may cause competing household financial priorities between paying for transportation to health facilities and paying for basic needs such as food, resulting in nonadherence (Croome et al., 2017; Hodgson et al., 2014; Omonaiye, Kusljic, et al., 2018). Furthermore, negative interactions with healthcare workers or the healthcare system may further discourage women from accessing HIV-related services (Hodgson et al., 2014; Omonaiye, Kusljic, et al., 2018).

A variety of interventions have shown promise in overcoming obstacles to ART adherence across the various stages of a person's life ranging from adolescence to adulthood, including pregnancy and postpartum. A recent study in Uganda evaluated the effect of an economic empowerment intervention on ART adherence among adolescents living with HIV and showed significant improvement in viral load suppression compared to control (Ssewamala et al., 2019, 2020). Among postpartum women, interventions such as conditional cash transfer incentives have increased retention in care but have not demonstrated a meaningful improvement in viral suppression (Yotebieng et al., 2016). Smart-pill bottle devices used in conjunction with text message reminders also have been evaluated to target non-adherence and have been found to improve ART levels despite negligible effects on viral load (Ellsworth et al., 2021).

Several studies have shown that short messaging service (SMS) between patients and healthcare providers has the potential to improve ART adherence and virologic suppression among adults in LMICs (Demena et al., 2020; Haberer et al., 2016; Lester et al., 2010; Odeny et al., 2019; Pop-Eleches et al., 2011). However, SMS interventions among pregnant and postpartum WLWH have yielded mixed results. While qualitative studies demonstrate that SMS interventions are a viewed as a significant source of social support for people living with HIV, including in the perinatal period, (Fairbanks et al., 2018; Geldof et al., 2020; Ware et al., 2016, 2020), quantitative results from short-term SMS interventions have shown modest to no improvement in viral load suppression (Geldof et al., 2020) or retention in care (Geldof et al., 2020; Odeny et al., 2019; Schwartz et al., 2015). Because of the mixed findings among on SMS interventions, further understanding and evaluation of these tools is needed. Evaluation of user experiences with SMS trials and programs is needed to better define how they are used and the mechanisms by which interventions are effective or why they are ineffective. This is particularly true for tools aimed at the pregnant and post-partum periods, which have been rolled out despite a paucity of rigorous data. Despite limited data, mobile health (mHealth) interventions such as SMS have been increasingly adopted as affordable tools in improving maternal child health and ART adherence among pregnant and post-partum women (Barron et al., 2018; Chen et al., 2020; Peter et al., 2018; Unger et al., 2018).

The Mobile WAChX study was a randomized controlled trial that evaluated the use of tailored one-way and two-way (interactive) combined HIV/MCH text messaging to improve ART adherence, viral suppression, retention in care, and PMTCT in Kenyan women from pregnancy until 2 years postpartum. Women were randomized into three study arms: the one-way text message arm only received push messages, the two-way arm both received and were able to respond to text messages and freely text the nurse, and the control arm received no text messages. Quantitative results of the study found no significant differences in maternal viral load, visit attendance, ART adherence, or infant HIV free survival outcomes between the intervention and control groups (Kinuthia et al., 2021).

Here, we present findings from qualitative analysis of Mobile WAChX participants' experiences in the study, to understand factors that may explain the null quantitative results and explore other utility of the intervention. Evaluation of end user experiences in mHealth provides a deeper understanding of the mechanisms by which digital interventions may work as well as their limitations (Coleman et al., 2020; Nelson et al., 2017). In addition, this type of investigation allows women to define what aspects of these programs are important and useful for them, which may differ from the hypothesized utility of the intervention. For this analysis we sought to evaluate women's perceptions of the effect of Mobile WAChX on their knowledge, self-efficacy, and motivation for ART adherence. Secondly, we sought to evaluate maternal perceptions of the limitations of the Mobile WAChX intervention.

METHODS

Study design

This study is a qualitative analysis of individual interviews conducted with participants exiting the Mobile WAChX trial, an unblinded, three-arm randomized controlled trial examining the effect of unidirectional and bidirectional combined HIV/MCH text messages on ART adherence during pregnancy and up to 2 years postpartum among WLWH (Kinuthia et al., 2021). Intervention text messages were designed to provide actionable information on topics ranging from maternal child health (MCH) to HIV prevention of mother to child transmission (PMTCT), as well as be supportive and encourage participants to ask questions (Drake et al., 2017; Fairbanks et al., 2018). Additionally, participants received messages 3 days before scheduled clinic appointments. The overall study was performed in 3 phases. The first phase consisted of focus group discussions with women and individual interviews with their spouses and health care providers to inform the content of the SMS intervention (Fairbanks et al., 2018; Ronen et al., 2018). The second phase consisted of a two-year RCT, to evaluate the impact of one-way versus two-way versus no SMS on long-term ART adherence in the PMTCT (Kinuthia et al., 2021). In the third phase we conducted post-RCT individual interviews with participants across study arms as well as questionnaires of their partners and interviews with health care providers. The semi-structured individual interviews (IDI) with participants were based in the Information – Motivation - Behavior Skills (IMB) framework for behavior change. This qualitative analysis focuses on interviews conducted with the women who participated in the study.

Study population:

Participants were selected from a subset of those enrolled in each of the intervention arms of the RCT. Inclusion criteria in the RCT were: pregnant WLWH, planning to live in the local area for at least 2 years postpartum, daily access to a mobile phone, and age ≥14 years. Women were either ART naïve or had a history of taking ART. RCT participants were invited to participate in IDIs via stratified purposive sampling based on participation in treatment arms (one-way vs. two-way), viral load trajectory during the study period (suppressed vs unsuppressed), and engagement with text messaging (high vs low). Figure 1 shows a summary of this sampling scheme; defining criteria and cutoff values are found in Table 1.

Data Collection:

Interviews were conducted by local staff trained in qualitative research methods in English, Kiswahili or Dholuo depending on participant preference. The conversations were semi-structured, audio-recorded, transcribed and translated into English if needed.

Data Analysis:

English language interview transcripts were uploaded to Dedoose (Seattle, 2021). An initial codebook was developed via deductive code creation using the Information-Motivation-Behavior skills framework (Fisher & Fisher, 1992) and inductive code creation based on reading of a subset of the transcripts. The IMB theory of behavior change posits that decision making regarding HIV risk reducing behaviors are influenced by a person's knowledge regarding HIV prevention and transmission, motivation to prevent infection or transmission, and the adoption of behavioral skills to facilitate risk reducing activities (Fisher & Fisher, 1992). This health behavioral framework has been frequently used within the intersection of HIV and mHealth. This researcher (GA) and a study nurse researcher (BW) coded the transcribed interviews. A preliminary codebook was created and iteratively refined upon further review of the transcripts and final codebook was agreed upon and used for consensus coding. Each transcript was first coded independently then reviewed by a secondary coder (GA or BW). Any conflicts with code application were resolved through group discussion. Codes were categorized into code categories and categories were aggregated to form themes. This thematic analytic framework explored emerging themes within the IMB framework regarding women's experiences within the intervention as well as potential challenges with the intervention.

Ethical approval

This study was approved by the ethical review boards of the University of Washington and Kenyatta National Hospital. Women exiting the Mobile WAChX RCT provided written informed consent for IDI participation.

RESULTS

Forty-four individual interviews were conducted among participants across all six study sites in the RCT. Participant characteristics are shown in Table 2. Over 80% of the participants were married or partnered and nearly 90% of those had disclosed their status to their partners. Approximately 40% (17/44) of the participants used a shared phone. Among participants in the two-way group (n=24), nearly 40% (n=9) were suppressed and highly interactive with the text messages, 25% (n=6) were suppressed with low interactions, 25% (n=6) were unsuppressed with high levels of interaction and 13% (n=3) were unsuppressed with low interaction. Among participants in the one-way group, 50% (n=10) were virally suppressed. Participants' median age was 27. Thematic analysis by sub-groups (viral load, one-way/two way, high/low engagement) showed no significant differences among themes between the interventional arms. Therefore, the following results reflect the aggregated experiences of participants.

We identified five themes that aligned with the Information – Motivation – Behavioral Skills Model and elucidate the mechanisms by which participants perceived the intervention's effect on

ART adherence (Figure 2). A sixth theme captured challenges associated with the intervention and possible reasons for the null quantitative results.

Information: SMS provided reminders and skills for medication adherence and clinic appointments

Participants reported that messages served as useful reminders for medication adherence and clinic appointments. These reminders contributed to the informational component of the IMB construct for behavioral change. Many women referenced these medication and appointment reminders to be among the most helpful components of the intervention.

> *What was most useful to me were the ones that were reminding me to adhere to my medication [and] clinic appointments (Participant 0436, Age 29, Suppressed, One-way)*

In addition to the reminders serving an informational role in the intervention, they led to adoption of new behavior skills. For example, SMS suggestions for adopting skills such as setting a pill alarm, led to participants taking up these suggestions.

> *Before, I used to take my medication any time at night with no knowledge that I should be taking the drugs at a specific time … but after receiving the message [from the nurse] I was now advised to have a specific time for my medication. I was therefore able to get an alarm clock to help me do this which has been useful to date. (Participant 0569, Age 30, Suppressed, One-way)*

Women also discussed other adherence related behavioral skills that they adopted due to prompting by SMS, such as storing drugs in accessible areas to reduce physical barriers to adherence. Other adopted behavioral skills included transportation planning for clinic appointments and negotiation of safer sexual practices.

> *You see we are being told so many times, like even when taking medicine, you never know of tomorrow because you can meet with someone and they tell you that they love [you]. You tell that person if they love you then you should go [get a] test. So, you go and test today because if you wait for tomorrow you may never know. [...] So, it has helped me to use condoms more. (Participant 0978, Age 25, Unsuppressed, High Engagement)*

Motivation: SMS served as a significant source of social support and motivation for adherence-related behaviors

Participants often described the messages as a source of care provision and social support, which motivated them to take better care of themselves, aligning with the motivational component of the IMB framework. At times, this social connection with the Mobile WAChX nurses directly motivated behavior changes, such as consistent adherence to medications.

…. Because the messages made me feel that the nurses really cared about me and that was the reason that they were sending me frequent messages. And that was the reason that I did all that the messages were instructing me to do. (Participant 2102, Age 28, Suppressed, Two-Way, High Engagement)

Participants also reported the supportive messages increased their motivation to provide daily ART to their infant and increased their sense of parental self-efficacy.

Initially when I was given the [antiretrovirals], I felt that it was too taxing to take them and even to give the baby her drugs daily. So the messages made me feel that it was not such a hard task and I could actually do that by the continuous support that I got from them. (Participant 2060, Age 25, Suppressed, One-Way)

In addition to fostering motivation, participants reported the messages acted synergistically with clinic visits, strengthening participants' trust in the healthcare system through an additional line of communication. One participant described the increased sense of freedom she felt through the SMS communication to talk about things she could not disclose in clinic.

The messages were encouraging because sometimes I could have a problem and suffer from a lot of fear that I could not even express to other providers what I was going through. But through the messages, I now gained a lot of courage that I could even freely tell the study nurse about and be sure that it was going to be kept as a secret. (Participant 2073, Age 30, Suppressed, Low Engagement)

Participants also reported that the messages expanded their sources of social support to include both spouses and study nurses. Several women spoke about the messages helping them feel "more free" to speak openly about HIV management with their partner. At times, this open communication stemmed from the couple having a shared phone. Participants reported that spouses expressed interest in the messages as they sought knowledge regarding HIV management for themselves. The resulting open communication with spouses led women to feel closer to their partner. This theme was more commonly described by participants who were virally suppressed by the end of the RCT, though one unsuppressed participant also experienced this.

…we were now able to support each other with my partner because the messages made us to be more free and open with each other. The encouragements and the reminders that I did receive from the hospital also made me to feel more supported unlike before when I never used to receive such messages. (Participant 2066, Age 23, Unsuppressed, One-way)

Motivation: SMS provided hope for living a normal life

Several women described how the messages they received increased their feelings of hopefulness about living a 'normal life,' often alluding to moving through life like an HIV negative person.

> *Before, I knew that once you are HIV positive then there was no hope and future for you, but from the messages that I received, I got to learn that one could still just live the same way as the negative people did. (Participant 0116, Age 34, Unsuppressed, Low Engagement)*

These thoughts and feelings centered around being able to give birth to HIV negative children and the ability to live a long life. They described that central to maintaining this normalcy was adherence to ART. They also discussed the risks of non-adherence including active illness, death, and transmission of HIV to the baby, as a direct challenge to their experience of normalcy. Therefore, the benefits of adherence and risks of non-adherence served as strong motivators for many participants.

> *I learned that HIV treatment helps us live healthy lives and those who default treatment [...] they die faster. So HIV treatment makes us live longer and we go on with our usual lives. (Participant 0073, Age 32, Suppressed, Two-Way, High Engagement)*

Many participants described feelings of hopelessness that accompanied learning their HIV status and alluded to these feelings as contributors to their non-adherence. However, knowledge gained from the messages alleviated these barriers to adherence by instilling hope for a long life, prompting strong motivation for adherence.

> *It made me feel that my life was important because each time that I was alone, I used to think that my life was not so important and it did not matter whether I took my medication or not because I thought that eventually I would die. So through the messages, I got encouraged and got to know that I could live longer and that was the reason I now decided to adhere to my medication as I was being told (Participant 0406, Age 20, Unsuppressed, One-way)*

Message topics describing steps to prevent mother to child transmission resulted in a strong motivation for adherence and adoption of behavioral skills to facilitate adherence (Table 3). Preventing HIV transmission to their baby appeared to be a significant motivator for many participants.

> *I wanted a way to prevent my child from getting HIV, and such messages came, how I can take care of her so that she can grow without being infected by HIV and how I can also take care of myself so that I don't infect my child. (Participant 1657, Age 30, Suppressed, Two-Way, High Engagement)*

Motivation: SMS reduced feelings of internalized and anticipated stigma and increased feelings of courage and self-acceptance

Many participants discussed experiencing and overcoming internalized and anticipated stigma. Effects of anticipated stigma included social withdrawal, fear of judgement, and fear of disclosure, which influenced adherence related behaviors such as going to the clinic for medication refills. Furthermore, internalized stigma led to self-devaluation and hopelessness in being able to live a full life, further reducing one's motivation for adherence. The messages intervened on these effects of stigma on adherence, weakening their influence on participants. Figure 3 displays the four main components of stigma mentioned in the transcripts and Figure 2 demonstrates the mechanisms by which messages contributed to the process of de-stigmatization.

Women spoke about how the SMS helped them overcome anticipated stigma, allowing them to go to the clinic for refills with less fear of judgement or scrutiny by others in the community who may see them there. Thus, the SMS helped reduce this barrier to ART treatment by facilitating courage to attend clinic or pharmacy appointments.

> *… before I was stigmatized to come to the clinic for my drugs because I thought that the people that I found there would be talking about me, but that changed as a result of the encouraging messages that I used to receive from the study. (Participant 2066, Age 23, Unsuppressed, High Engagement)*

Similarly, women spoke about messages increasing their social interactions and reducing anticipated stigma. Messages helped women have hope for the future, facilitating engagement in social interactions and "being free". One woman described the process of de-stigmatization leading to more free social interactions:

> *All the barriers I had before diminished and I never worried that maybe people judged me because I am HIV positive. They made me to feel free unlike before when I was even afraid to socialize with other people, but the messages offered me pieces of advice on how to live positively. (Participant 2060, Age 25, Suppressed, One-Way)*

The messages also normalized participants' experience of living with HIV, reducing their fear of disclosure.

> *I never wanted anybody to know my status in the first place because I didn't know how I got it, so I didn't know how to say it. Then after reading all the messages it became normal then I started talking about it. (Participant 0888, Age 36, Suppressed, Two-Way, High Engagement)*

Furthermore, the SMS intervention improved many participants' sense of self-worth. The process of reducing internalized stigma and increasing self-worth was evident as women spoke about the sense of self-love that the messages evoked in them.

> *...when I joined this study and started receiving these messages I felt loved and I started seeing my life in a positive way. Initially I used to hate myself. (Participant 1230, Age 22, Unsuppressed, One-way)*

One participant described how the messages altered her sense of self-worth, which motivated her to overcome obstacles to adherence, such traveling far distances to the clinic.

> *The [messages gave me] motivation to continue with my medication. I came from [name of place] which is very far from here but I could walk to the clinic because I valued my life. (Participant 0569, Age 30, Suppressed, One-way)*

Theme: #5 Challenges with the SMS intervention and potential explanations for null quantitative results

The Mobile WAChX RCT found no significant differences in viral load suppression among women who received the SMS intervention and those receiving no SMS control (Kinuthia et al., 2021). We analyzed interviews to investigate potential explanations for these results, including challenges in engaging with the intervention that may have reduced its effectiveness, or limitations of the intervention that did not address salient barriers to women's HIV management.

Women spoke about challenges receiving the SMS due to lacking access to their phone for a variety of reasons including losing their phone, having a broken phone, lack of consistent access to a shared phone, and poor network coverage. One participant described difficulties with the intervention due to a shared phone, which was among the most common barriers to receiving SMS.

> *I don't have a phone of my own and it was not easy to respond to messages on somebody's phone. But there was a time [my husband] replied [to] some messages on my behalf. (Participant 2073, Age 28, Suppressed, Two- Way, Low Engagement)*

Other challenges with the intervention included fear of messages being read by others and involuntary disclosure of their status. Among some participants, maintaining privacy of the messages was a chief concern that resulted in heightened anxiety while engaging with the intervention. Although participants had choice about whether they wanted to receive explicitly HIV-related SMS content, a few women described staying at home to wait for the weekly messages to prevent involuntary disclosure to others. One participant describes this challenge in her effort to maintain privacy.

... for the last 2 years it has been a challenge because maybe the message is sent and someone else is with my phone. […] For that period I did not go anywhere, apart from staying at home. So this far, I can say that I did get many challenges. (Participant 1274, Age 24, Suppressed, One-way)

Despite there being few mentions of negative interactions with SMS content, a few participants described the messages evoking a negative feeling about themselves, such as reminding them about their HIV status.

...sometimes I could not respond because being reminded of your status every other time is not good, I could feel bad because once I think I am HIV positive it disturbed my mind. (Participant 1209, Age 25, Suppressed, Two-Way, High Engagement)

Some participants expressed a desire to have their HIV lab results available via SMS as a suggested improvement to the intervention. This addition of real-time feedback regarding their viral load status may have provided targeted motivation for individuals to adhere more consistently throughout the two-year period.

I also feel that they [SMS] should be able to give back the test results for viral load. (Participant 2067, Age 33, Suppressed, Two-Way, Low Engagement)

Women experienced several external hardships which may have impacted their adherence and were not addressed by the Mobile WAChX intervention. Women often indirectly mentioned experiencing financial difficulties during the interviews, highlighting the inability to have a personal phone, difficulty with maintaining a balanced diet and gathering funds for transport, as well as the challenge of hard labor jobs. Financial constraints affected the extent to which women could follow the instructions of the SMS and maintain retention in care. One participant below described her experience with skipping meals so that her children could eat fuller meals.

…I had issues that if I had some money I was to feed my kids. But me, I wasn't taking care of myself, so I just made sure my kids are well despite the fact that I am taking drugs… They don't know the little that might have remained was what I sorted myself with. (Participant 0888, Age 36, Suppressed, High Engagement)

Other women expressed a desire for financial opportunities and proposed the intervention should provide assistance. Requests ranged from asking for employment opportunities with the study team to requests for job skills training and creation of co-operatives where participants could meet each other and sell various goods together.

...the mothers who used to receive the messages, we can come up with a project whereby we can invest...even if it's selling kerosene we [can be] sure at the end of the month we have something. (Participant 0896, Age 24, Unsuppressed, Two- Way, High Engagement)

Lastly, participants commented on the barriers to healthcare caused by several health worker strikes during the study period. Though the messages could not overcome lack of clinical care provision during the strike period, some participants commented on the value of SMS communication in this time.

...when I went into labor, I sent a message because it [was] when the nurses were on strike. (Participant 0073, Age 32, Suppressed, Two-Way, High Engagement)

DISCUSSION

Principal Results

This qualitative analysis explored the experiences of women living with HIV during and after pregnancy in the Mobile WAChX SMS communication intervention designed to improve ART adherence and retention in care in the perinatal period. Although quantitative findings of the Mobile WAChX RCT did not demonstrate a significant intervention effect on ART adherence and viral suppression, participants reported the intervention had multifaceted utility and promoted knowledge, motivation, and behavioral skills to engage in HIV care, in alignment with the IMB framework of behavioral change (Figure 3). Women overwhelmingly responded positively to the intervention and expressed gratitude for participation. They reported that the informational components of the intervention, such as the clinic reminders and education regarding PMTCT, facilitated the adoption of behavioral skills such as setting an alarm for medication adherence. The SMS intervention also positively influenced women at a psychosocial level by helping them overcome HIV-related stigma, facilitate disclosure of their HIV status, and increase feelings of self-acceptance. Women felt encouraged through the social support the messages provided and altered their outlook of living with HIV, giving them hope of living a long healthy life. These informational and psychosocial impacts facilitated the behavior skills of taking medication, ensuring accessibility to medications, and negotiating safer sex.

Despite these positive effects, some women described the intervention's limitations, including technical barriers to consistently receiving the intervention. Participants also identified barriers to ART adherence that the mHealth intervention was unable to overcome, such as financial barriers and food insecurity. These limitations may have prevented the intervention from improving engagement in HIV care, despite participants' experiences of its benefits.

Comparison with prior work

Prior literature has shown that provision of information and social support by SMS is widely accepted by WLWH (Lewis et al., 2019; Skinner et al., 2018). Prior trials of SMS interventions to promote HIV care in Sub-Saharan Africa have reported that participants feel social support from receiving a reminder text message, even if the message content is not intended to be encouraging (Geldof et al., 2020; van der Kop et al., 2018). A qualitative evaluation of user experiences with Mom Connect, a similar SMS-based maternal health intervention among pregnant and postpartum women in South Africa, demonstrated positive user experiences including themes of heightened confidence in their roles as mothers, as well as trust in the knowledge gained through the message content (Skinner et al., 2018). Our data supports these observations, as women overwhelmingly reported positive experiences with the information and social support provided by the messages.

Importantly, our data highlights the potential of mHealth as a tool to help WLWH combat internalized and anticipated stigma in the peripartum period. In recent years, there have been increasing calls for the use of mHealth to address the psychosocial impacts of stigma for PLWH (Mulawa et al., 2021; Rao et al., 2018). Previous studies have shown associations between internalized stigma and low rates of ART initiation and adherence (Katz et al., 2013; Rice et al., 2017; UNAIDS: Confronting discrimination & Overcoming HIV-related stigma and discrimination in healthcare settings and beyond, 2017). In addition, studies have demonstrated the effect of internalized and anticipated stigma on reduced health seeking behaviors such as avoidance of delivery at health facilities among pregnant women and overall poor clinic attendance due to fears of involuntary disclosure (Treves-Kagan et al., 2016; Turan et al., 2008). Our results suggest that combined HIV/MCH messaging helped decrease women's perceptions of internalized and anticipated stigma, building self-acceptance and facilitating disclosure of status to partners and family. This potential for combined HIV/MCH SMS messaging in reducing HIV related stigma among WLWH in the peripartum period is a critical finding for supporting women through lifelong ART adherence. This integrated MCH/ HIV SMS messaging approach may have normalized the experience of pregnancy and living with HIV for many women and ultimately facilitated self-acceptance.

Despite the benefits of Mobile WAChX reported by participants, the intervention was not found to improve HIV treatment outcomes (Kinuthia et al., 2021). This qualitative evidence suggests that participants perceived intervention effects in each of the IMB domains and women found great benefits from participating. We explored possible explanations for the null trial outcome in our interview data.

One potential explanation was that participants experienced barriers to intervention engagement that lessened the intervention's effects on clinical outcomes. Challenges highlighted in the interviews included technical challenges such as poor phone network coverage, lost phones, difficulties with using a shared phone, and broken phones. Other qualitative studies of participants in mHealth interventions for ART adherence also identified similar intervention limitations,

including lack of access to electricity, poor network signals, privacy concerns, and changes to sim cards or phone numbers (Addotey-Delove et al., 2020; Ames et al., 2019). Despite mention of these technical challenges in our data, less than half of participants described experiencing technical difficulties. Therefore, while technical challenges may be a contributing barrier to adherence, it is not the central explanation for nonadherence in our study.

Another potential explanation is that the intervention benefits reported by participants did not overcome critical barriers to ART adherence and engagement in HIV care. Interview participants alluded to financial barriers during the intervention including food insecurity and transportation related costs, that prevented them from consistently taking ART and engaging in care, and that Mobile WAChX did not address. Food insecurity was found to be associated with virologic non-suppression during baseline assessment in the Mobile WAChX trial – highlighting the importance of financial factors (Chohan et al., 2021).

Other explanations for null results included lack of individualized messaging tailored to participant viral load status, which may have provided real-time feedback and served as motivation for the women (Kinuthia et al., 2021). This targeted addition to the mHealth intervention may have provided more personalized information that, coupled with the encouraging messages, may have served as a strong motivator for supporting adherence-related behaviors. Though these interviews did not make significant mention of this degree of personalization in the interviews, this incorporation may be considered for further research.

Finally, the conflict between the null trial results and women's positive experiences raises the question of whether the benefits of SMS in the peripartum period can extend beyond psychosocial impact. Additional scholarly work is necessary to answer this question faced by mHealth researchers and implementors.

The conflict between Mobile WAChX trial's null quantitative findings and the overwhelmingly positive qualitative experiences is perplexing. Furthermore, the lack of significant differences between the subgroups (suppressed vs unsuppressed, high vs low interactors) also leaves us with further questions regarding intervention effect. Despite this disconnect, the substantial psychosocial impact participants reported cannot be ignored. Stigma reduction and social support are not only critical for improving PMTCT goals but are also important aspects of long-term HIV treatment and quality of life. Researchers have increasingly called for extension of the WHO's 95-95-95 goals for HIV treatment, to extend beyond the end goal from viral suppression and add a fourth goal - quality of life for PLWH (Heath et al., 2021; Lazarus et al., 2016). Our results support the use of SMS in improving the quality of life for peripartum WLWH. Furthermore, the sense of self-love and acceptance that participants reported, coupled with the strengthened provider–patient relationship, supports the WHO strategic goal of people-centered care in the healthcare setting (WHO Global Strategy on Integrated People-Centered Health Services 2016-2026, 2015).

Strengths

This paper is among a growing body of research exploring how user experiences of mHealth interventions explain the mechanism by which these interventions work or do not work and what additional benefit these programs may provide. Sample size was relatively large, and we purposively sampled a variety of participant experiences, including participants receiving one-way or two-way messages. While our intervention has unique attributes, this evaluation allows us to understand the ways in which pregnant and postpartum women experience SMS communication interventions in general. To date, there have been no studies that have used mHealth in the peripartum period as a tool for overcoming internalized and anticipated stigma among WLWH. Further research is needed to explore the use of mHealth in this field.

Limitations

There were limitations in our study. First, interview questions related to challenges experienced during the intervention were not a focus of the interviews and thus made it challenging to make final conclusions about barriers to intervention access and limitations of intervention impact. Second, social desirability bias may have influenced the responses we received, further limiting our ability to detect difficulties or concerns with the intervention that may have contributed to the null quantitative results. Lastly, the uniformity of the themes across all intervention subgroups, especially between viral load groups, may suggest a limitation in the interview questions as they were unable to differentiate the experiences that correlate to the intervention's end clinical outcomes.

Conclusion

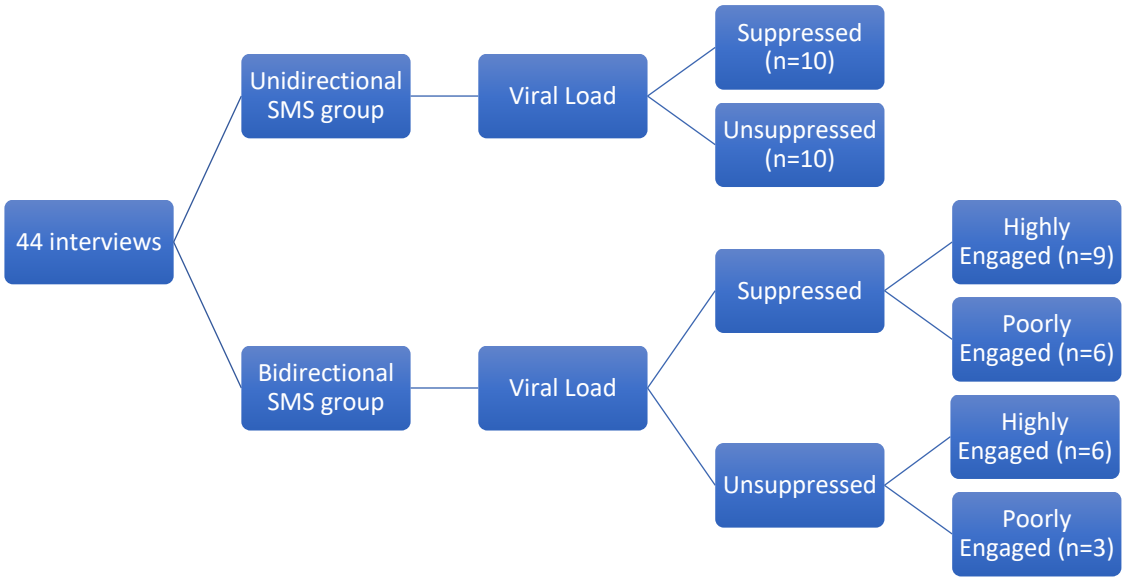
This study provides insight into the benefits and challenges of using SMS for PMTCT and retention in care among pregnant and post-partum WLWH in Kenya. Combined HIV/MCH messaging was well received by participants and provided them informational and psychosocial support. Challenges experienced by participants that could not be overcome with SMS included the daily financial stressors that participants faced, such as expenses related to food and transportation, as well as technical challenges. Furthermore, our study highlights the potential for mHealth to intervene on stigma related barriers to adherence and retention in care. Further research is needed to understand the challenges that impede consistent ART adherence among pregnant and postpartum women living in Kenya.

Appendix

Table 1 Interview participant group definitions

Outcome	Definition
Suppressed viral load	Has ≥4 VL results available ≥6mo post-ART initiation ≥2 latest VL results <1000copies/ml and ≥6mo post-ART initiation ≥1 earliest VL result ≥1000copies/ml and ≥6mo post-ART initiation
Unsuppressed viral load	Has ≥2 VL results available ≥ 4mo post-ART initiation ≥2 sequential VL results ≥1000copies/ml and ≥6mo post-ART initiation and span ≥1 year
Highly engaged participants	Among 2-way participants with more than 100 system messages and ≥ 90% of these system messages successfully delivered Participant's percent weeks active is ≥75th percentile of all participants' percent of weeks active.
Poorly engaged participants	Among 2-way participants with more than 100 system messages and ≥ 90% of these system messages successfully delivered Participant's percent weeks active is ≤25th percentile of all participants' percent weeks active.

Figure 1 Stratified sampling of interviewees from the intervention groups among the Mobile WAChX trial participants.



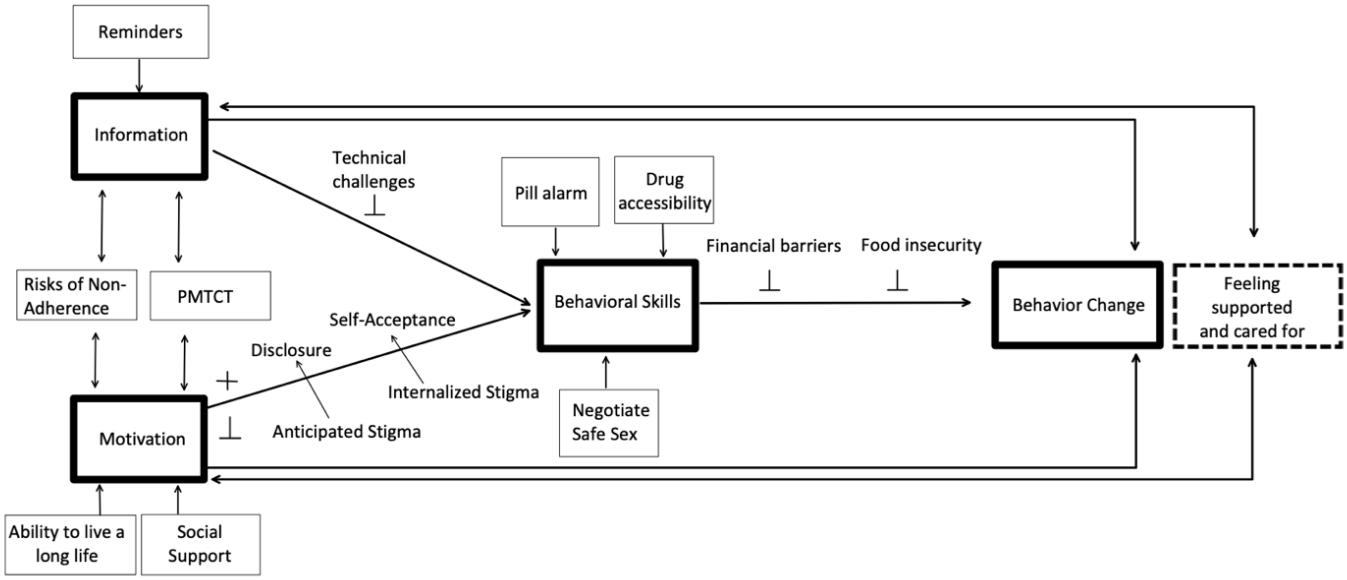


Figure 2: Conceptual framework for participant-identified effect of the Mobile WAChX intervention. Intervention effects reported by participants are displayed in black text and mapped onto domains of the Information-Motivation-Behavior Skills (IMB) behavioral change framework. Barriers to adherence are identified with the symbol⊥. Stigma related facilitators to adherence are shown with a plus sign. Arrows represent the flow of participant experiences that map onto the IMB. Text within the thin black boxes represent participant identified effects of the intervention within the IMB. Text within black dashed lines represent an alternative outcome of the intervention that maps outside the IMB framework.

Figure 3: Components of internalized and anticipated stigma mentioned in the interviews.

Table 2: Female IDI participant characteristics

Number of participants interviewed			44
Number of participants with suppressed viral load			25 (56.8%)
Number in two – way group			24 (54.5%)
	Suppressed among two-way		15 (62.5%)
		Suppressed with High Interactions	9 (37.5%)
		Suppressed with Low interactions	6 (25.0%)
	Unsuppressed among two-way		9 (37.5%)
		Unsuppressed with High Interactions	6 (25%)
		Unsuppressed with Low Interactions	3 (12.5%)
Number in one-way group			20 (45.5%)
	Number Suppressed among one-way		10 (50%)
	Number Unsuppressed among one-way		10 (50%)
Age			27.7 (20 – 43)
Completed primary education			37 (84.1%)
Able to read SMS unassisted			42 (95.5%)
Able to write SMS unassisted			42 (95.5%)
Married/Cohabiting			36 (81.8%)
Employed			27 (61.4%)
Primigravid			9 (20.5%)
Shared phone			17 (38.6%)
On ART at enrollment			39 (88.6%)

Disclosed to partner	39 (88.6%)

Table 3: Themes and illustrative quotes, organized in relation to the IMB framework and intervention limitations.

IMB FRAMEWORK	Themes	Subthemes	Representative Quotes
INFORMATION	Reminders		*Yes they reminded me not to miss taking my medication, and to keep my pill time. (Participant 2024, Age 29, Unsuppressed, One-Way)* *What I like most about these messages was that, it was encouraging me by reminding me of when to take my drugs and the date of the next visit to the clinic… (Participant 0925, Age 35, Unsuppressed, One Way)*
INFORMATION & MOTIVATION	PMTCT		*Yes, hope in life in that although I found myself positive it is not a must that my baby will be positive also, I had the courage that my baby is okay, if I take my drugs well my baby will be okay. (Participant 1274, Age 24, Suppressed, One-way)* *Yes, hope in life in that although I found myself positive it is not a must that my baby will be positive also, I had the courage that my baby is okay, if I take my drugs well my baby will be okay. (Participant 1274, Age 24, Suppressed, One-way)*
	Risks of non-adherence		*Because now I got to know what would happen to me if I did not adhere to my medication or if I did not give the baby her drugs as I was supposed to […] I could get sick or even infect my baby with HIV. (Participant 2060, Age 25, Suppressed, One-Way)* *…I realized that if I don't take my drugs well my health will deteriorate and then what will happen to my child, up to now I do not skip (Participant 1273, Age 22, Unsuppressed, Two-Way High Engagement)*

			…you must take your drugs every day, if you don't you might have side effects and even get sick. (Participant 0824, Age 21, Suppressed, Two-Way, Low Engagement)
MOTIVATION	Belief in ability to live a long and normal life		*I learned that taking ARVs well will make me live a long life like anyone else who is HIV negative. (Participant 1260, Age 43, Suppressed, Two-Way High Engagement)* *It helped me because I realized that despite my status I could still live a normal life. (Participant 0813, Age 27, Suppressed, One-Way)* *I was also able to accept my status the way I am because sometimes when you are told about your status and you were not expecting to be that way, then you feel ashamed. But through the study, I came to realize that in fact we could live our lives well, like other people, with courage. (Participant 0813, Age 27, Suppressed, One-way)*
	Social Support		*Those messages were good because I felt that they encouraged me and therefore reduced my fear of taking my ART and then they also motivated me to do so. (Participant 0569, Age 30, Suppressed, One-Way)* *When I was receiving the messages, it made me think the people who are sending the messages care for me, that made me want to use my medication well and care for my life…So, when it was time to use my medicines or time for clinic, I pushed myself to do it. (Participant 0827, Age 31, Unsuppressed, One-Way)*
		Partner Support	

			Yes, [my husband] ensured that he read all the messages to me and that made us so close to each other than before. (Participant 2073, Age 28, Suppressed, Two-Way, Low Engagement) *Yes they did because we were now able to support each other with my partner because the messages made us to be more free and open with each other. (Participant 2066, Age 23, Unsuppressed, One-Way)*
		Healthcare system	*…the messages made me feel that I had a lot of support especially from the providers. (Participant 0116, Age 34, Unsuppressed, Two-Way, Low Engagement)* *I was happy because it made me realized that even the doctors loves me despite my status. (Participant 1027, Age 22, Unsuppressed, Two-Way, High Engagement)*
	Self-worth		*Because I learned that, the most important thing is love yourself despite your status and by doing so, the public will also see you as still important to them (Participant 1260, Age 43, Suppressed, Two-Way, High Engagement)* *Yeah, they taught me that the key thing is to love myself without self-love out there nobody can love me… so it influenced me so much on self-love then I can be able to love others. (Participant 0803, Age 23, Unsuppressed, Two-Way, High Engagement)* *Before, I felt stigmatized, but through the messages, I got to learn that my life was still important despite the fact that I was HIV positive. (Participant 2026, Age 33, Suppressed, One-way)*
	Disclosure		*I was now able to disclose to my family members because previously I was so stigmatized to be seen to the hospital when I had gone for my drugs. But*

		through the messages that I received, I got encouraged and that even made me to interact freely with others who had also come for their drugs knowing that I was not the only one who was doing this. (Participant 0436, Age 29, Suppressed, One-way) *Before, I was very afraid to even talk about HIV when with other people but now I fear nothing because nowadays cancer is all over and people fear cancer more than HIV, so with HIV you can live long on condition that you take your ARVs drugs as prescribed. That is why I can stand today with a lot of courage to even tell those who are around me that this is not the end of life. (Participant 1260, Age 43, Suppressed, Two-Way, High Engagement)* *It was good because through the messages that I received, I was now able to share with another person who was also on ART about the importance of adhering to them and having courage to go to the clinic for the medication. (Participant 2102, Age 28, Suppressed, Two-Way, High Engagement)* *Yes, they did because I was now open with my partner about my status and about my HIV medication, and that made us to now adhere well in order for both of us to have a healthy life. (Participant 2066, Age 23, Unsuppressed, One-way)*
BEHAVIOR SKILLS	Setting a pill alarm	*Before, I used to take my medication any time at night with no knowledge that I should be taking the drugs at a specific time…but after receiving the message from Y, I was now advised to have a specific time for my medication. I was therefore able to get an alarm clock to help me do this which has been useful to date. (Participant 0569, Age 30, Suppressed, One-way)* *I was now able to set my alarm so that I could take my drugs at the right time unlike before. (Participant 0436, Age 29, Suppressed, One-way)*

		I used to set alarm but now days I no longer set the alarm because I am used to, when it is the time I just know it, my mind is now well set to it. (Participant 1027, Age 22, Unsuppressed, Two-Way, High Engagement)
	Modifying medication placement	*They also made me to be able to store my drugs well in a more accessible area so that I could adhere well unlike before. (Participant 2000, Age 29, Unsuppressed, One-way)*
	Safe sex negotiation	*You see we are being told so many times, like even when taking medicine, you never know of tomorrow because you can meet with someone and they tell you that they love [you]. You tell that person if they love you then you should go [get a] test. So, you go and test today because if you wait for tomorrow you may never know. [...] So, it has helped me to use condoms more. (Participant 0978, Age 25, Unsuppressed, High Engagement)* *I learned how to use protection such as condoms. (Participant 2073, Age 28, Suppressed, Two- Way, Low Engagement)*
	Transportation preparation for clinic visits	*They were quite helpful to me because sometimes they could remind me for my next clinic appointments. You know sometimes they could do this two days to my clinic visit and maybe at that time I did not have money for transport, so it reminded me and gave me enough time to look for money for transport. (Participant 0044, Age 25, Suppressed, Two -way, Low engagement)* *I liked the fact that they encouraged me to take my medication and they also reminded me of when to go to the clinic…you know sometimes you can forget when you should be going for your next clinic appointment. So the messages reminded me about that because sometimes they could even send me a message two days to my clinic so I was able to plan. (Participant 1644, Age 33, Suppressed, Two-way, Low engagement)* *…there was an impact because financially I was not stable whenever I read the message, I got encouraged whether you have money or you don't have…You*

		just have to plan and go [to the clinic] (Participant 0888, Age 36, Suppressed, High Engagement) *…they also reminded me, because I am somebody who is coming from far…I am living in Kuria, so through their reminder, I could know that in two days time I am supposed to go for the clinic. So, even if I had forgotten, then they would send me the message. The moment I saw the message I would know, "oh it is my clinic time in two days" so I had to prepare. Even if I didn't have things to put together, I would make sure that I put them together so that by the time that time reaches, I was here. So they really helped me in reminding me about the date I was supposed to come to the clinic. (Participant 2049, Age 27, Suppressed, One-Way)*
	Giving ART to baby	*When I was bringing my baby to the clinic, I was given drugs like septrine and nevirapine and it really helped because whenever I came for checkups I was always told, my baby is well and I should continue giving the same drugs to the baby. (Participant 1230, Age 22, Unsuppressed, One-Way)*
BEHAVIOR CHANGE	Socialize with others	*…I remember there was a time they told me that I should not be staying lonely but rather to interact with others, and when I did so I became relived. (Participant 1230, Age 22, Unsuppressed, One-Way)* *Yes, all the barriers I had before diminished and I never worried that maybe people judged me because I am HIV positive. They made me to feel free unlike before when I was even afraid to socialize with other people… (Participant 2026, Age 33, Suppressed, One-way)*
	Attend clinic appointments	*…they did affect positively because I was now able to honor my clinic appointments unlike before when I used to forget the days. ((Participant 2000, Age 29, Unsuppressed, One-way)*

		Yes, they encouraged me and that made me to be strong while taking my drugs. I don't miss my clinic appointments (Participant 0517, Age 30, Suppressed, High Engagement)
	Adherence	*I started taking my drugs on time unlike before when I had not joined this program.* *(Participant 0925, Age 35, Unsuppressed, One-Way)* *I now adhered to my medication as I was supposed to. (Participant 2066, Age 23, Unsuppressed, One-Way)*
CHALLENGES		
	Technical Challenges	*For example, I do not have a phone, I was borrowing in order for me to reply, lets say they should distribute some phones to the less privilege. Because some of us cannot even afford a phone, maybe only the husband has and borrowing him every other time will be hard. (Participant 1027, Age 22, Unsuppressed, Two-Way, High Engagement)* *…[there] were days that I did not have access to my phone because it had gotten lost. So they would send me messages but they were never successfully delivered. (Participant 2000, Age 29, Unsuppressed, One-way)* *…I was upcountry and it reached a time I didn't have a phone my phone got spoilt so I was off air for some time…almost like 2 to 3 months (Participant 0896, Age 24, Unsuppressed, Two- Way, High Engagement)*
	Privacy Concerns	*I used to worry about if someone from outside would take my phone and read the messages, So I used to wait for the messages and as soon as they hit my inbox I would read and hide it away from the inbox. (Participant 0931, Age 27, Suppressed, Two-Way, High Engagement)*

			To some extend I was afraid about it, because I thought it will be threating messages because naturally as human we do not like exposing our status like HIV status, so I was thinking that at the course of receiving those messages somebody else like my friend or my neighbor was with my phone without my consent, what will happen, so those were my worries. (Participant 0813, Age 27, Suppressed, One-way)
	Financial limitations		*Coming to take your medication, at times you have 50 ksh which is meant for food and you want to come to the hospital and you have no means but when you think about being reimbursed you can borrow 20ksh then you refund after reimbursement…(Participant 0931, Age 27, Suppressed, High Engagement)*
		Seeking financial opportunities	*youth services [would be helpful for], pregnant mothers especially…introducing careers to them. (Participant 1209, Age 25, Suppressed, Two-Way, High Engagement)* *I think because we are many here, I propose we form a group were we can start a business such that others are selling things like soap and others selling clothes and by doing so, we will support each other more and becoming important people in the society. (Participant 1230, Age 22, Unsuppressed, One-way)* *So I would like to know if I may be able to get any support from you [interviewer] since these drugs are powerful and should not be taken before eating something. I would appreciate if I could be offered something to do in order to earn a living instead of the hard labor that I have been doing all this time. (Participant 2102, Age 28, Suppressed, Two-Way, High Engagement)*
	Domestic Violence		*… I was sent a text on how to keep time on taking my drugs and at that time I had domestic issues and so I wasn't keen on [taking the drugs on] time [because] I felt low. And I told myself if [the study nurses] can be this caring why can't I be keen on [taking the drugs on] time so this made me rise and say*

		let come what may I will always keep [my pill] time. (Participant 0803, Age 23, Unsuppressed, Two-way, Low Engagement) *I also learned if am beaten by my husband and I have an injury my baby can be affected. (Participant 0803, Age 23, Unsuppressed, Two-way, Low Engagement)*
	Food insecurity	*It really helped me, but to some extend there was some, which were not useful, for example, balanced diet is hard to get, at time, I could get and sometimes miss. (Participant 1230, Age 22, Unsuppressed, One-way)*
	Nurses Strike	*Sometimes the nurses could go on a strike and so I could not be able to take the baby for PCR. So through the messages I was able to communicate with them and book appointments and each time that I came I just found them still working. (Participant 2067, Age 33, Suppressed, Two-Way, Low Engagement)* *...when I went into labor, I sent a message because it found when the nurses were on strike. (Participant 0073, Age 32, Suppressed, Two-Way, High Engagement)*
	Fear of taking ART	*It changed because as I have said I never used to like this medicine. In fact, when I saw this medicine for the first time, I was surprised because they are so big in size and they had side effects like; bad dreams, Dizziness and Vomiting. Therefore, I did not see the need of taking these medicines but when I started receiving these messages from [name of study nurse] it really helped me. In addition, I realized that I could take these medicines and be okay, up to now I have become used to it. (Participant 1273, Age 22, Unsuppressed, Two-Way, High Engagement)*
	Negative interactions with intervention	*The only thing that I did not like is the word 'Ayaki' [meaning AIDS] that they [SMS messages] kept on using all the time. I felt that it did not sound so good… I do feel that the word is insulting a bit. (Participant 0116, Age 34, Unsuppressed, Low engagement)*

	Preference for SMS provided lab results	*At first I did expect the message to inform me about my CD4 results after they had performed blood draw. (Participant 1644, Age 33, Suppressed, Two-way, Low engagement)*

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