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Needs and contents of a customized digital tool for retention in care and medication adherence among pregnant and breastfeeding women living with HIV in Kilimanjaro

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Abstract

Background Retention in care and adherence to medication among pregnant and breastfeeding women living with HIV (PBWLH) are crucial for preventing mother-to-child transmission (PMTCT) of HIV. Wide coverage of mobile phones, digital tools, including internet-enabled medication dispensers and short message service (SMS), have been recommended as potential interventions to improve adherence to medication by PBWLH. The main objective of the study was to understand the needs and contents for a customized digital tool for retention in care and medication adherence among PBWLH.

Method A mixed-methods study was conducted from September 2021 to March 2022 at five health facilities in the Kilimanjaro region. We interviewed 142 pregnant and breastfeeding women, receiving PMTCT services, using a semi-structured questionnaire. Among the interviewed, twenty breastfeeding women were purposively selected and enrolled to use an internet-enabled Wisepill medication dispenser for one month. They received different types of SMS reminders for one month, and feedback on their adherence patterns was received after one month using an adherence graph from the Wisepill digital tool. Later, exit and in-depth interviews were conducted to explore the needs and contents of a future customized digital adherence tool. Descriptive analyses for quantitative data and thematic content analyses for qualitative data were also done.

Results Among 142 women interviewed, 42(30%) were pregnant and 100 (70%) were breastfeeding. Most 136 (95%) had access to mobile phones and used SMS daily, while 90% were interested in receiving reminder messages. Qualitative findings revealed more insights into reminders' content and educational SMS. Most people preferred neutral SMS, which does not contain the word "medication". Health educational SMS content was preferred to be on breastfeeding, opportunistic diseases, nutrition and entrepreneurship education. Overall, SMSs were regarded as helpful to remind clients of medication time and the medication dispenser provided them with privacy and safe storage for their medication.

Conclusions This study's findings will help construct useful content for future digital adherence tools to support the health of pregnant and breastfeeding women living with HIV.

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Keywords Antiretroviral therapy (ART), HIV/PMTCT, Retention, Digital adherence tools (DAT), Real time medication monitoring (RTMM)

Background

HIV/AIDS is still a major cause of death globally. Globally there are 38.4 million people living with HIV in 2021 (UNAIDS 2022). In Tanzania, the HIV prevalence is 4.6 and nearly 1.7 million were said to be diagnosed with HIV in 2019 (UNAIDS 2020; THIS 2018). From 2010 to 2019, the number of people living with HIV in the country increased from 1.3 million to 1.9 million (UNAIDS 2020). Despite the implementation of option B+ in 2014, 8600 children aged 0–14 were newly infected with HIV through mother-to-child transmission during delivery or breastfeeding in 2019 (UNAIDS 2020). Without antiretroviral treatment, the risk of mother-to-child infection is 15–45% in Sub-Saharan Africa (Points 2018). A systematic review of cohort studies done in East Africa shows that the average prevalence of mother-to-child transmission is 7.68% (Belachew et al. 2020). Despite the fact that most people living with HIV have access to antiretrovirals (ARVs), maintaining adherence to lifelong treatment has been a major challenge (Dzansi et al. 2020). From the UNAIDS report of 2020 shows that among 67% of people living with HIV, who are on treatment in Tanzania, only 59% are virally suppressed (UNAIDS 2020). Non-adherence to treatment contributes to failure in viral load suppression (Knettel et al. 2018).

In Tanzania, the percentage of pregnant women enrolled in prevention of mother-to-child transmission (PMTCT) services reached 92% in 2019 (UNAIDS 2020). However, poor retention and adherence to medication among pregnant and breastfeeding women remain a challenge, contributing to the mother-to-child HIV infection rate of 11% in 2020, which is higher than the global target of 5% (UNAIDS 2020). Retention in care is required for treatment adherence, as visiting a clinic is needed for medication dispensing. A systematic review done in Africa, including 35 articles, showed that retention in care after the first appointment was estimated to be 76.4% at 12 months after ART initiation (Knettel et al. 2018). A cohort study in Tanzania shows that among women living with HIV during the postpartum period, the loss to follow-up was about 69.5% (Cichowitz et al. 2019). Lack of social support and stigma have been linked to poor adherence and low retention in care (Knettel et al. 2018; Buregyeya et al. 2017). Poor retention and non-adherence to medication among breastfeeding women threaten the progress towards eliminating HIV in children.

Interventions to improve adherence, such as reminder cues, counselling, extensive education, and clinical care retention, have been done. However, still, there is a lack of enough evidence on effective intervention to improve retention in care and medication adherence (Ritchie et al. 2019). Several review studies have shown a positive effect of SMS on retention in care and adherence to treatment, though all recommend that more robust intervention studies are needed (Geldsetzer et al. 2016; Kanters et al. 2017; Mayer and Fontelo 2017; Sarna et al. 2019).

As the percentage of loss to follow-up is high in Tanzania, interventions are highly needed. Using digital tools, including reminder cues through short message service (SMS), which contain neutral preferred content and tailored feedback on adherence reports, can overcome stigma and fear of disclosure. The penetration of mobile phones in Tanzania was 89% in 2021 (TCRA 2020). Using the common way of communication through SMS at an affordable price of nearly 54 Tanzania shillings (\$0.02) has high potential for disease management. In previous Tanzanian pilot studies, it was found that using digital adherence tools (DATs), including SMS to remind about medication intake among adults living with HIV, was feasible (Ngowi et al. 2020; Sumari-de Boer et al. 2016). A trial was successfully implemented using a DAT (Wisepill) combined with SMS reminders. It showed a positive effect of both the DAT and SMS on adherence to treatment among participants with viral load below 1000 copies/ml. Furthermore, the proportion of participants reaching 90% was higher among the intervention groups (Sumari-de Boer et al. 2021). Results of a mixed-method study among participants of the same trial have shown that real-time medication monitoring is highly acceptable and has the potential to improve adherence (Ngowi et al. 2021).

Despite these positive results, the authors also encountered concerns about unwanted disclosure and stigma due to the contents of SMS asking directly if the medication was taken (Ngowi et al. 2020). These could be overcome by using more neutral messages, (colour) symbols, multimedia SMS or a joke as a code for reminding people to take their pills. Given the high coverage of mobile technology in the country, digital health tools are feasible to implement. Based on the previous studies done, there is a need for a formative study to understand better the contents of digital tools, which may help to improve adherence to medications.

Therefore, this study aims to understand the needs and contents of customized digital tools among pregnant and breastfeeding women living with HIV. We explored contents for short message service texts to take medication and contents for reminder short messages to facilitate clinic attendance. Furthermore, we investigated educational needs to design messages and identified barriers to using digital tools.

Methods

Study design

This was a parallel formative mixed-methods study, including quantitative and qualitative data collection methods. We conducted a survey among pregnant and breastfeeding women. A selection of women was then using a digital adherence tool (DAT) for a month, followed by feedback from a nurse counsellor on their adherence to medication patterns. After this, we conducted in-depth interviews (IDI) among Breastfeeding women. We obtained ethical clearance from the local institutional review board, Kilimanjaro Christian Medical College Research Ethics and Review Committee (CRERC) and the National Medical Research Institute (NIMR) of Tanzania. We followed Good Clinical Practice (GCP) guidelines in all study procedures.

Study area

This study was conducted in the Kilimanjaro region in the Northern part of Tanzania. We conducted the study in five HIV care clinics, including care and treatment centres (CTC), antenatal care (ANC) and PMTCT clinics in Kilimanjaro, Tanzania. Participants were recruited from Kilimanjaro Christian Medical Centre (KCMC), Pasua Health Centre, Mawenzi Regional Hospital and Majengo Health Centre, all located in Moshi Urban. We also involved a peripheral site, which was Kibosho Hospital.

Study population and inclusion and exclusion criteria

This study involved pregnant and breastfeeding women living with HIV in Kilimanjaro region. Data collection took place from September 2021 to March 2022.

Inclusion criteria: Pregnant and breastfeeding women who are HIV-positive: Pregnant women were only included in the survey, and breastfeeding women were included in both survey and digital adherence tools study; Attending Care and Treatment Centres (CTC) or postnatal clinics in Kilimanjaro; Age between 18 and 50 years. Breastfeeding women willing to use digital tools; Pregnant or breastfeeding women willing to sign and able to understand the informed consent.

Exclusion criteria: Admitted to hospital, participating in other trials related to adherence and retention into care.

Sample size calculation

To our knowledge, there is no information on how many participants experience barriers to using Digital Adherence Tools (DAT). Selecting the arbitrary percentage of 50% experiencing barriers to using a DAT with a standard error of 0.05 and power of 80% (estimation of single proportion sample calculation), we needed 142 pregnant and breastfeeding women.

Intervention (DAT and tailored feedback)



The Wisepill device (RT2000 dispenser) is a pocket-sized dispenser designed by the Wisepill company. It contains a global SIM card that communicates through cellular networks to synchronize with the Wisepill Cloud service each time the device is opened. At any point that the device is opened, the exact opening time, its identification number, and technical information of the battery and signal strength are recorded in the database. We registered the user's agreed intake time on the Wisepill Web Server. A reminder SMS is sent to their mobile phones whenever a participant forgets to take medication at the prescribed time. The health care workers and researchers can monitor medication intakes through access to online adherence reports and graphs generated.

After one month, participants received feedback on adherence reports. In the first part of the feedback session, consciousness was being generated by providing tailored feedback on adherence performance. They were firstly asked how they felt about their medication intake behaviour. This was followed by showing a graph to the participant, so she could understand where adherence

could be improved. In addition, nurses gave basic education on the importance of adherence. After this phase in the session, participants considered changing their drug-taking behaviour. The possible pros and cons of changing behaviour and barriers to improving were discussed. Nurses offered potential solutions, such as “cues” in daily life to be coupled with medication intake. The third phase of the feedback session consists of the participant taking making decisions concerning their behaviour. The nurse and participant set an adherence goal for the next clinic visit (goal setting). We used a modified stage of change model developed by Prochaska et al. (Prochaska and Velicer 1997).

Study procedures

Eligible individuals were asked to participate in the study by signing an informed consent form. After participants completed their clinic visits with healthcare workers, they were brought to a private room where research assistants interviewed them. A thoroughly informed consent procedure was used whereby the aim of the study was explained using a patient information sheet. After informed consent was filled, a semi-structured questionnaire was administered face to face to breastfeeding and pregnant women as part of the survey.

A sub-sample of 20 participants was purposively selected from the study participants, with a variability in demographic characteristics, including rural or urban, facilities, clinic adherence patterns, and viral load to ensure heterogeneity. Another thoroughly informed consent procedure was done before enrolment in the DAT study. Participants used the device for a period of one month to understand the mechanism of operation of the device. In the first week, participants received a basic medication reminder SMS in Swahili, “Habari ndugu, muda wako wa kumeza dawa umekaribia unakumbushwa kumeza dawa zako kwa wakati kama ulivyoelekezwa na wataalamu wa afya”, which in English means “Hello dear, your time to take medications is near, you are reminded to take your medications as instructed by the health care professionals”, half an hour before usual time of intake. A second reminder was sent one hour after the agreed usual time of intake in case there was no signal of the box being opened. These types of SMS were derived from our previous REMIND study (Sumari-de Boer et al. 2021). More neutral SMS reminders were sent in the next three weeks, which did not mention the word medication. We decided not to use the word medication as the word could lead to unwanted disclosure of the HIV status to others who might, by accident, read the SMS. Over time, messages became more neutral; for instance, in the second week, we used SMS such as “you are reminded to drink” (unakumbushwa kunywa) or “your time to use is near” (muda

wako unakaribia) and in the third week were “your health is important” (afya yako ni muhimu) or “remember to care about your health” (kumbuka kulinda afya yako), and in the fourth week were “health!” (afya) or “use!” (tumia) or “value health” (thamini afya). After one month, study nurses shared and discussed adherence reports generated by the device, giving each participant tailored feedback on their adherence reports during clinic visits. Exit-interviews and in-depth interviews followed this to understand the context of adherence to treatment, use of the digital tools, contents and experience of DAT and SMS in breastfeeding women. Exit interviews and IDI were done in Kiswahili by trained research assistants who were not part of care of the participant.

Theoretical framework

In order to understand needs, contents and barriers, it would be best explained through the two theoretical frameworks. Figure 1 outlines how the theoretical framework construct helped to understand digital tools’ needs, contents and barriers.

The content of the interview guide for IDI was informed by the Health Belief Model (HBM) (Karen Glanz and Rimer 2008) and Theoretical Framework of Acceptability (TFA) (Sekhon et al. 2017). We also used findings of prior research done in Kenya on developing content for the SMS intervention to promote postpartum retention in preventing mother to child HIV transmission using the HBM (Odeny et al. 2014).

Data collection tools

Survey with semi-structured questionnaires

We used a semi-structured questionnaire using electronic data capture, RedCap (Research Electronic Data Capture) for the survey. In the survey, we collected demographics, treatment-related data, medication and clinic adherence, use of mobile phones and network availability, barriers to using DAT, stigma and depression related to HIV.

Exit interviews

Trained research assistants conducted exit interviews after participants completed one month of using DAT. Interviews were done face to face. A semi-structured questionnaire was used which was based on previous studies (Ngowi et al. 2021) and included all emerging issues during the formative study. Closed questions were first asked to understand participants’ perceptions, followed by open-ended questions for each item to allow further explanation. Data were entered in real-time using RedCap.

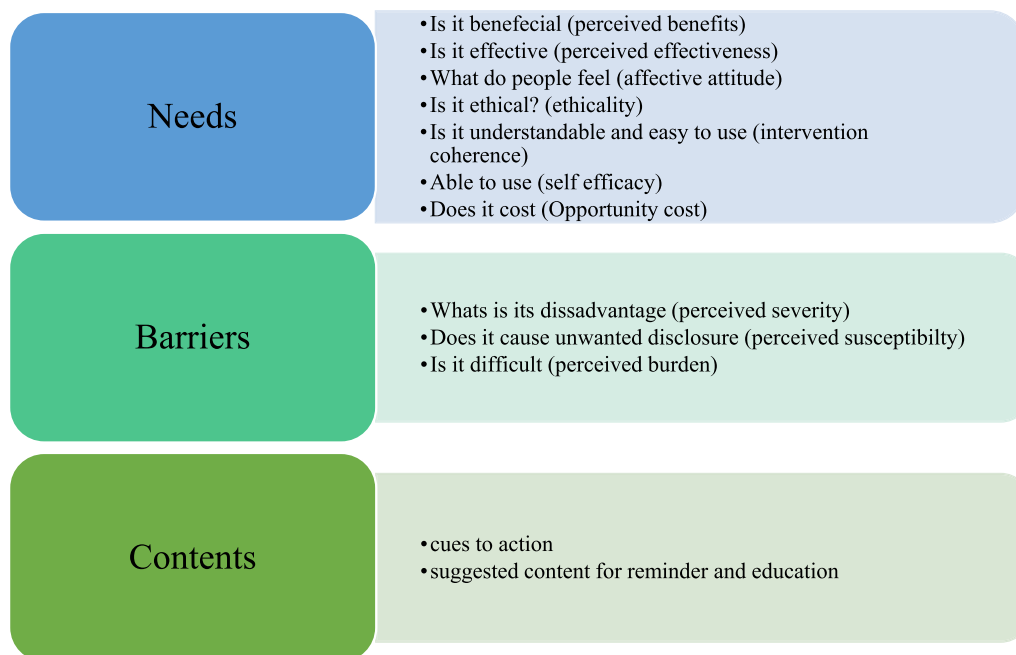


Fig. 1 TFA model and HBM model

In-depth interviews

The topic guide focused on the experience in using mobile phones, phone access, SMS use, network connectivity, barriers to using digital tools, needed content for reminder SMS, needs for educational SMS, needed content of tailored feedback on adherence patterns during clinic visits and preference in time, psychosocial factors (stigma, disclosure and social support), medication adherence and usage of graphs which were generated by the digital tools. Research assistants did the interviews face-to-face and were conducted in the hospital clinic in a private doctor's room. The interviews were audio recorded and lasted approximately 40 to 90 min. Research assistants also took notes during the interviews to expand later. The topic guides were adapted during the study in an iterative process. Interviews were transcribed verbatim and translated into English. All collected data were stored pseudonymously using patient identifier codes.

Data analysis

We used descriptive analysis to summarize the participant's characteristics, preference and use of mobile phones.

In order to answer the objectives regarding the needs and contents of SMS for reminding and education and content for tailored feedback on adherence patterns, we conducted thematic content analysis of data from

in-depth interviews and descriptive analysis from survey and follow-up interviews.

Themes were developed from reading and re-reading of transcripts. Memos were developed based on the first six interviews by RAM, and KWK, and an initial codebook was developed from there. Translated transcripts and field notes were uploaded into NVivo pro V12 software for data organization and the codebook was also imported. Data was organized according to codes from where themes were derived. We discussed the listed themes, and agreement was met on common subthemes. A coding framework was developed based on the themes. Themes were discussed with other research assistants who were in data collection together with other social scientists to ensure the reliability and validity of the coded data together with compliance of the framework.

To answer objectives on the barriers to using digital tools we conducted thematic content analysis from in-depth interviews as above. Descriptive analysis was done using data from survey and follow-up interviews.

Results

Participants characteristics

A total of 142 women were interviewed in the survey. Among those, 42 (30%) were pregnant women and 100 (70%) were breastfeeding women. Mean age was 31.3 (SD 6.3) and ranged from 19 to 45 years. One hundred and two women (72%) had primary or secondary education. Most women included were seeking health

Table 1 Demographic characteristics of 142 participants

Variable	Category	Frequency	Percentage
Participants	Breastfeeding	100	70
	Pregnant	42	30
Level of education	None	1	0.7
	Primary	51	36
	Secondary	51	36
	Tertiary	39	27
Inclusion site	KCMC referral hospital	39	27.5
	Majengo health centre	41	28.8
	Pasua health centre	45	31.7
	Mawenzi regional hospital	14	9.9
	Kibosho hospital	3	2.1
Own mobile phone		134	95.7
	Phone which have no access to Internet	85	60
	Phone which access to Internet	49	35
	Others	8	6

services from Pasua Health Centre. One hundred and thirty-four (95.7%) owned a mobile phone, 85 (60%) had a basic feature phone and 49 (35%) owned a smartphone. The details of the participants are shown in Table 1 below.

More than 90% of participants use and read SMS in their daily lives. Among 142 participants, 23 (15%) reported to ever have skipped medications. Among 23 participants who skipped pills, 13 (56.5%) reported that they forgot. Only 64 (46%) have people to remind them taking medications. Among 42 pregnant women, 10 (24%) did not know how to protect their child from HIV infection. The details about mobile phone use are shown on Table 2 below.

The 20 breastfeeding women who used the device for one month were included in the IDI. Their age ranged from 23 to 45 years old, and they had an average of 95.5% adherence rate (based on the Wisepill dashboard results). Almost all women (95%) were on first line medication

and their intake medication time ranged from 19:00 to 22:00 h.

We present results based on the two models, and we categorized results into three major themes. Two categories of themes were: (i) themes related to the needs of DAT and (ii) themes related to barriers in using DAT and (iii) themes related to the content of DAT.

Themes related to needs

Perceived benefits

From the IDI, most participants explained that using the DAT helped them take medications on time. Even before they receive an SMS, just seeing the device triggers them to remember to take medications. Participants explained they were busy taking care of the family and, therefore, easily forget the time for medications. The device also gave them privacy while taking medication, because the device does not make a sound when taking out the pill like the usual medication containers. The DAT provided

Table 2 Mobile phone use

Variable	Frequency	Percentage
Use and read SMS	134	96
Good experience with SMS	129	90.8
Participants who reported ever skipped taking medications	23	15
Forgetting among people who skip medications	13	56.5
Willing to be reminded for those who skipped	20	95
Having people to remind them taking medication	65	46

social support as participants felt like they were not alone.

Perceived effectiveness

From the survey, we found that most women (105 (78%)) were interested in receiving reminder SMS to support them in adherence to medications. In the follow-up interviews, 19 (95%) said they received SMS on time and they did not have difficulties in receiving SMS. Participants agreed that the interventions made them to take their medications on time every day. Out of 20 participants, 18 (90%) mentioned that the SMS made them to take their medications on time, hence improving their adherence. Through IDI, we found that participants perceived that DAT helped to improve their ability to take medication on time. A 32-year-old woman explained that after receiving the device, she had never missed or exceeded the time for medications. She becomes more conscious with the time to take medications.

Affective attitude

In the follow-up interviews, 19(95%) participants reported having a good or very good experience with receiving reminder SMS and they thought the device was good. Twenty women (100%) said it has a good appearance. Ninety-five per cent reported that the way the graphs displayed their adherence level was either good or very good. IDI participants felt good and happy using the DAT, both the device and SMS. The majority of participants were satisfied with the graphs showing their adherence status, especially the percentage that indicated their adherence. Participants elaborated that they wished to continue using the DAT, even for the rest of their lives. Others suggested that this intervention should be used by all people living with HIV.

Ethicality

From the survey, 128 (93%) participants were comfortable receiving reminder SMS, and 105(78%) were ready to receive reminder SMS and to use the device. Even 96 (69%) participants were willing to pay to receive medication reminder SMS. In the follow-up interviews, 18 (90%) of participants said it was appropriate to receive reminder SMS. IDI Participants did not have concerns or ethical issues with using DAT or receiving tailored feedback from the nurse. Most of them explained that it was appropriate to receive reminders, and they were comfortable using the device in front of their family members. Furthermore, the device protected their privacy because it was not easy for someone to know if they were using medications since the device almost looked like a phone. For participants who shared their phones with their husbands or children. They did not report any domestic

disputes or unwanted disclosure caused by reminder SMS. There was no issue that concerned participants' religion or culture.

Intervention coherence

From the follow-up interviews, 17 (85%) participants did not experience difficulties in opening the device and 18 (90%) did not have any issue with refilling medications to the device. Some of the participants in the IDI understood how the intervention works. Still, others had understood only that the device was for storing medication and it had no link to the reminder message that they received. Though, most participants understood at the end of the intervention, after receiving the one-month feedback, how the device generated the adherence graph. Also, all of them understood how to open and refill the device.

Opportunity costs

No participants mentioned that they had incurred any extra cost in terms of finance or time during the study period.

Self-efficacy

Participants were confident in using the DAT as required and could use the intervention. IDI participants explained that it was easy to understand the SMS they received.

Themes related to barriers

Perceived burden

In the survey, 31 (22%) reported experiencing network challenges, and in the follow-up interviews, 3(15%) experienced network challenges during the study period. For IDI participants, the most perceived barrier identified was receiving more than one SMS due to network challenges. They explain that they took medications on time, and yet they receive the second reminder SMS stating that they did not take medications. One participant reported not receiving the reminder SMS twice. Also, participants were describing that in the beginning, opening of devices was a challenge. However, after some time, they understood and it was easy to refill and take pills from the Wisepill device.

Perceived susceptibility

In the survey, 27(20%) of women reported sharing their phones and 15 (56%) shared their phones with their husbands. In follow-up interviews, no participant reported that the intervention caused any unwanted disclosure of their HIV status. However, IDI participants perceived that they were having a risk of unwanted disclosure when someone used their phone or who were sharing their phone with family or friends.

Using a feature phone made them susceptible to unwanted disclosure. This is because those phones have no password. Participants noted unwanted disclosure because of using SMS reminders that contain the word “dawa” or “medication”. They said that if someone saw the reminder message with the word ‘medicines,’ they would start to ask questions and follow up with them on why they are taking medication or what the medication is for. This may create stigmatization and women may lose confidence that they are not normal people.

Perceived severity

In follow-up interviews, 18(90%) participants reported having no concern about being watched or monitored all the time by healthcare providers. Perceived severity explained during the IDI was a fear created that someone was watching them. No participants reported having difficulties carrying the device around with them. They were happy to travel with it because no one could notice what is inside.

Themes related to content

Cues to action

The majority of IDI participants identified that they wished to receive reminder messages for medication and clinical attendance and educational messages. Participants felt cared for and satisfied after receiving feedback on how they had taken their medications.

Participants’ recommendation on the content of the message content

IDI participants preferred neutral messages, which do not directly mention words like ‘medication’ or ‘drink’ or ‘swallow’. Furthermore, they mention that reminder SMS should be short at least and not very open or obvious so that anyone could understand its meaning. Several participants suggested reminders with words like “remember to eat your fruit”, “remember to drink water” or “eat fruit”. Considering educational topics, women suggested they want education about business, breastfeeding, taking medication, mental health issues, nutrition, sexual issues and other opportunistic disease. In the survey, women suggested wanting to receive reminder SMS for their medication daily 82 (58%). This was the same for IDI results in which women also suggested receiving reminders daily. Also, women preferred educational messages that should be sent each week. Women suggested that the frequency of clinic visit reminders be at least monthly, a day before their appointment day (Table 3).

Discussion

This mixed-method study describes the needs and content of customized digital tools for retention in care and medication adherence among pregnant and breastfeeding women living with HIV. This study contributes to improving existing digital adherence tools, which are used to remind people living with HIV on their medication intakes and clinic visits. The use of theoretical frameworks helped to understand the needs, content and barriers of DAT and constructs from TFA and HBM were identified as themes within this data.

Overall findings were that most participants described that using the DAT triggered them to take medications on time. Also, we found that the device was highly needed as most of the women said that taking medication out of the device was comfortable and easy, and they wished to continue using the device. Furthermore, the use of the device was found to be ethical because of its good appearance, size and the fact that it does not make a sound when taking out the pills compared to the usual medication containers. The effectiveness of DAT in sending SMS was perceived to be high as most participants pointed out that SMS reminders were received daily and on time, and more surprisingly, we found that having a device at home motivated them to take medications. In addition, our results illustrate that the majority of women were able to understand how DAT works.

Despite the positive results, few participants reported concerns such as that the device did not capture the opening signal due to poor network availability. It led them to have low adherence graphs and receive a second reminder telling them they did not take their medication. Another issue was the word “dawa” or “medication” in the reminder SMS content, which was described as a potential for unwanted disclosure. In line with this, those with a simple feature phone described that the SMS content containing the word “medication” made them susceptible to unwanted disclosure as those phones have no security features as smartphones. Moreover, during the discussion with participants, we found there was a fear in use as they felt as if they were being monitored. Though, during the exit interviews, more than 90% of participants reported to have no concern about being monitored all the time.

Participants reported preferring SMS, which were more neutral so that even if someone else reads the SMS from their phone, they will not understand that she is reminded to take medications. Neutral messages are those that do not mention words like ‘medication’ or ‘drink’ or ‘swallow’. Also, they say that neutral SMS gave them self-confidence and having the advantage of being reminded. However, we saw that 20% of women shared their mobile phone with relatives, husband and their

Table 3 Participants quotes related to each construct of acceptability

Themes related to	Theoretical framework construct	Example of quotation
Needs	Perceived benefits	"...because it reminds me, you find that mothers, like we, are very busy. But, when you see the message, ohoo, you say 'let me count some few minutes'. It reminds you that its time." 45-year-old married woman
		"Firstly, the device stores well the medications. Secondly, you get motivation of taking medications because you know that you have something (device) and third, it is not easy for someone to recognize it even if someone sees it..." 32-year-old single woman
		"This device does not make a sound while using it. If you just take the pills out of the usual medication containers, the person in the second room will hear, it does 'karakaka'. 30 years-old single woman
	Perceived effectiveness	"SMS reminders helped a lot because they made me to take medications on time or they would remind me to take my pills when I forgot." 28 years old married woman
		"I think it has made me to take my medication on time. Because I never miss a pill, but it's just I don't take them on time. Few times I take them correctly on time." 34 years old married woman
		"Another thing, it makes me to not be forgetful, since I keep remembering that there is a device that I have to open to take my drugs." 23 years old single woman
	Affective attitude	"Actually, the way it's working, I see it is good, that is, I love it very much, very, very much." 34 years old married woman
"... we would like to be given (DAT) to all the people with this problem." 31 years old married woman		
"It would be nice to receive reminder message, because most people right now use the phone. So, if someone got a reminder text that you have to take your medication at certain time. It would be very helpful, because someone would know... if I didn't take the medication they will know (health care people)." 31 years married woman		
Ethicality	"The device is acceptable, because you are at peace when you are with it, as you can bring it with you when you go out or travel with it without someone else noticing what you have." 23 years old married woman	
	"I share my phone with my child. Even though my child knows this problem and I have no problem with it and he also keep my secret." 37 years old single woman	
	"...it's not easy to know what is inside the device." 32 years old single woman	
Intervention coherence	"... I don't know. I just know it's a thing to store medications." 45 years old married woman	
	"... for this device, when I open it, it turns on the lights. It sends information that I took the medication. So, health care providers or researchers, will really know that, I follow what I have been taught in the clinic." 31 years old married woman	
	"It is this way, I open and take the cartridge out. I take my pills and then I close it and return it inside." 23 years old married woman	
Self-efficacy	"I felt good using the device, because I told to myself: 'they gave it to me because they think I was capable of using it.'" 29 years old married woman	
	"... it didn't last even a few seconds, because after I received the SMS I knew it's for my health." 29 years old married woman	
Barriers	Perceived severity	"These people are watching me. My child refused to give me medicine from the device. He said 'mother, they will see me there'. My husband also said: 'you will use yourself that device because they will see us, we will not touch your device.'" – 28 years old married woman
		"But this device, even if you place it in your handbag you can go anywhere but it's difficult for someone to know." 29 years old married woman
	Perceived susceptibility	"...Eeeh medicine... someone might ask what medicine you are taking?..... For me, a solution is that the word medicines should be removed, because someone will know that." – 29 years old married woman

Table 3 (continued)

Themes related to	Theoretical framework construct	Example of quotation
	Perceived burden	<p>"The issue of the message is good. But the challenge was at the very beginning when I was used to be reminded with the message to take "medication". Now it made me worried to think where I left my phone on the table, while I am outside or am taking bath."—29 years old married woman</p> <p>"About two times, I noticed I didn't receive SMS." 30 years old single women</p> <p>"I felt bad the first time before getting the advice because you can find I took medications on time and then I receive SMS that you haven't taken on time, that's where it confused me." 25 years old married woman</p> <p>"I normally receive reminder SMS although I have already taken [pills]." 30 years old single woman</p>
Contents	Cues to action	<p>".... I feel like education which is related to HIV is important to me, because I didn't even know how to give medication to my child, which I was given for 42 days after I gave birth." 30 years old single woman</p> <p>"I also bought Septrin without knowing its function. I was just following the instruction which was given to me by the health provider." 30 years old single woman</p> <p>"Mmmm...my opinion is that there should be a system people would be sent a medication reminder message from the clinic. This would help our fellows to remember the time to take medication, as there was our neighbour who died, because he stayed three months without taking medication." 31 years old married woman</p>
	Suggested content for reminder and education	<p>"There is a message which has irritated me. It is the one of "use medication on time", that word "medication." 30 years old single woman</p> <p>"I would choose SMS that even when someone else get to see it he/she will not understand the meaning of that SMS." 30 years old single woman</p> <p>"For me, the solution is the word medicines to be removed, because someone might know that am taking medication." 29 years old married woman</p> <p>... they should probably be, "remember to eat fruit for your health" "eat fruit", "drink water", "remember to drink water." 33 years old married woman</p> <p>"I would like to know, for example, for a mother with such a disease, how long she should breastfeed." 33 years old married woman</p> <p>"Why do they say that a child is at danger of getting infected after a year while they grow tooth after six months?" 30 years old single woman</p> <p>"I would like to receive education about taking medications, because it will help me remember well and I will know very well that if I don't take medications, I will get this and this, I will be like this." 45 years old married woman</p> <p>"Education should be about how to avoid overthinking." 30 years old single woman</p> <p>"Other education to receive, I think, should be about food/nutrition meaning balanced diet for other people like us. When I say other people, it does not mean I am not among of them aa- no but it is only that for me I do really care about my health." 23 years old single woman</p> <p>"Then you (research team/health care workers) can also take note of maybe the person's clinics visit dates and call her maybe the day before visit to remind." 29 years old married woman</p> <p>"Interviewer: And what about educative ones, after how long should they be sent?" "Responder: I think educational message should be sent each week." 30 years old single woman</p> <p>"For me I like to receive the reminders every day." 30 years old single woman</p>

children. Despite that, no one reported that the intervention caused unwanted disclosure. However, during in-depth interviews, participants explained that the first week's SMS placed them at risk for unwanted disclosure.

Women preferred educational messages about entrepreneurship, breastfeeding, advantages of taking

medication, the consequences of not taking medication, mental health issues, nutrition, sexual issues and opportunistic diseases. Our findings showed that participants preferred to receive reminder SMS daily, which differs from the study done among women in South Africa who preferred to receive weekly SMS (Nachegea et al. 2016).

In similar studies among people living with HIV done in Kenya and Tanzania, a high level of satisfaction with using digital technology interventions was found (Ngowi et al. 2021; Ronen et al. 2018). In our previous study, which was done in Kilimanjaro using the same RTMM device, participants reported that the device was easy to use and feasible (Ngowi et al. 2020; Boer et al. 2016). A meta-analysis, which was done to design better ART medications, showed that those receiving reminder SMS were more likely to adhere to medication than those not receiving reminders (Abdul Wahab et al. 2021).

We found that 15% of women reported skipping medication, and more than half mentioned it was due to forgetting. From in-depth interviews, they explained that sometimes they were busy with household activities and other income-generating activities; therefore, receiving a reminder helped them to remember. Forgetting is a complex, multi-faceted phenomenon (Freeman et al. 2021). Regarding tailored feedback, most women were happy to receive feedback and were mostly satisfied when shown adherence graphs generated by the RTMM device. During feedback sessions, women could have time to receive education from health care providers.

There are several limitations of our study. Firstly, the sample size for participants who used DAT is small, as this was a formative study in which we selected a small number of participants to use DAT for one month. Our study aimed to gain insight and build SMS content for future trials and not generalize study findings. Secondly, participants used the device for only one month, which is a short period; therefore, using the digital tools for a more extended period might give different results on acceptability, though doing a formative study is an innovative step to explore the feasibility of the tool.

The major strength of our study is the use of mixed methods, which helped to provide quantification and insights, leading to a better understanding of the needed content of digital adherence tools among breastfeeding women. Also, triangulation of the data from different sources helped strengthen our study. These important findings will help design better tools to improve adherence to ART among pregnant and breastfeeding women to prevent mother-to-child transmission. Another strength is the use of two theoretical frameworks that offered inclusive insights into study participants' perceptions of which digital adherence tools' needs and contents, which can be considered for future interventions.

Conclusions

Our mixed methods study helps construct useful content for future digital adherence tools to support the health of pregnant and breastfeeding women living

with HIV. Digital tools seem to be highly needed. However, the content and feedback should be tailored to the needs of pregnant and breastfeeding women living with HIV. We found that digital tools are highly needed from each construct as most women were satisfied with the intervention. However, participants reported a few challenges, such as network availability, issues related to fear of being monitored and the use of particular words in SMS leading to unwanted disclosure. Future research using digital tools should address these issues before implementation. These findings also create ways to customize the digital tool in preparation for a clinical trial to evaluate effectiveness in improving retention to care among pregnant and breastfeeding women living with HIV.

Abbreviations

AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
ART	Antiretroviral therapy
CTC	Care and treatment centre
CRERC	College research and review committee
DAT	Digital adherence tool
GCP	Good clinical practice
HBM	Health belief model
HCW	Health care workers
HIV	Human immunodeficiency virus
IDI	In-depth Interviews
KCMC	Kilimanjaro Christian medical centre
KCRI	Kilimanjaro clinical research institute
NIMR	The National Institute for Medical Research
PBWLH	Pregnant and breastfeeding women living with HIV
PLHIV	People living with HIV
PMTCT	Prevention of mother to child transmission of HIV
RTMM	Real time medication monitoring
SMS	Short message service
SSA	Sub-Saharan Africa
TFA	Theoretical framework of acceptability
UNAIDS	The joint united nations programme on HIV/AIDS

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Author contributions

RM: Wrote the main manuscript text and analysis. KN, AM: Involved in qualitative analysis. LM, BM: Involved in quantitative analysis, HM, AD: Contributed to proposal designing and drafting manuscript, MSB: Is a principal investigator of the study and was involved in study design and review of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

All data generated and analysed during this study are included in this article.

Declarations

Ethics approval and consent to participate

We obtained ethical clearance from the local institutional review board, which is Kilimanjaro Christian Medical College Research Ethics and Review Committee (CRERC) No.2519 and the National Medical Research Institute of Tanzania (NatHREC) with reference number NIMR/HQ/R.8a/Vol. IX/3825. We followed Good Clinical Practice (GCP) guidelines in all study procedures, including informed consent. All study methods were carried out in accordance with the guidelines and regulations of Tanzania ethical review boards. All interventions in the protocol were approved by local and national ethical review boards. We obtained informed consent from all participants.

Consent for publication

Not applicable.

Competing interests

The authors have no competing interest to declare.

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