

**ASSESSMENT OF NEEDS AND CONTENTS OF A CUSTOMIZED  
DIGITAL TOOL FOR RETENTION TO CARE AND MEDICATION  
ADHERENCE AMONG PREGNANT AND BREASTFEEDING WOMEN  
LIVING WITH HIV/AIDS IN KILIMANJARO**

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**A Dissertation Submitted in Partial Fulfilment of the Requirements for the Degree  
of Master of Science in Public Health Research of the Nelson Mandela African  
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## ABSTRACT

Retention in care and adherence to medication among pregnant and breastfeeding women living with HIV (PBWLH) are crucial for prevention of mother to child transmission (PMTCT) of HIV. Wide coverage of mobile phones, digital tools, including the use of 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. A mixed-methods study was conducted from September 2021 to March 2022 at five health facilities in Kilimanjaro region. Pregnant and breastfeeding women receiving PMTCT services were included in a survey 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 a period of one month and feedback on their adherence patterns was received after one month using adherence graph from the Wisepill digital tool. Later, exit interviews, in-depth interviews were conducted to explore needs and contents for a future customized digital adherence tool. Descriptive analyses for quantitative data and thematic content analyses for qualitative data were also done. Among 142 women interviewed, 42(30%) were pregnant and 100 (70%) were breastfeeding. A majority of 136 (95%) had access to mobile phones and used SMS daily, while 90% were interested in receiving reminder messages. Qualitative findings revealed more insights on 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 helpful to remind clients on medication time and the medication dispenser provided them with privacy and safe storage for their medication. Findings from this study will help to construct useful content for future digital adherence tools to support the health of pregnant and breastfeeding women living with HIV.

**Keywords:** HIV, PMTCT, Digital Adherence Tools, Retention, RTMM, ART

## DECLARATION

I, Rehema Anenmose Maro do hereby declare to the senate of the Nelson Mandela African Institution of Science and Technology that this dissertation titled “*Predation efficacy of Anopheles funestus larvae by aquatic predators in rural south-eastern –Tanzania*” is my original work and has never been or intending to be submitted for a degree award in any other institution.

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## CERTIFICATION

The undersigned certifies that they have read and hereby recommend for acceptance by the Nelson Mandela African Institution of Science and Technology a dissertation titled “Needs and contents of a customized digital tool for retention in care among breast-feeding and pregnant women living with HIV in Kilimanjaro” in partial fulfilment of the requirements for the Degree of Master of Science in Public Health Research at the Nelson Mandela African Institution of Science and Technology Arusha, Tanzania.



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## TABLE OF CONTENTS

ABSTRACT.....	i
DECLARATION .....	ii
COPYRIGHT.....	iii
CERTIFICATION .....	iv
ACKNOWLEDGEMENTS .....	v
TABLE OF CONTENTS.....	vi
LIST OF TABLES .....	ix
LIST OF FIGURES .....	x
LIST OF ABBREVIATION AND SYMBOLS .....	xi
CHAPTER ONE .....	1
INTRODUCTION .....	1
1.1 Background of the Problem.....	1
1.2 Statement of the Problem .....	2
1.3 Rationale of the Study .....	3
1.4 Research Objectives .....	3
1.4.1 General Objectives.....	3
1.4.2 Specific Objectives .....	3
1.6 Significance of the Study.....	4
1.7 Delineation of the Study .....	4
CHAPTER TWO .....	5
LITERATURE REVIEW .....	5
2.1 Adherence to Treatment among Pregnant and Breastfeeding Women Living with HIV ...	5
2.2 Retention in care among Pregnant and Breastfeeding Women living with HIV .....	6
2.3 Application of Digital Adherence Tools .....	6
2.4 Introduction to Wisepill Digital Adherence Device in Tanzania.....	7

CHAPTER THREE .....	9
MATERIALS AND METHODS.....	9
3.1 Study Area.....	9
3.2 Study Design .....	9
3.3 Sample Size.....	10
3.4 Inclusion and Exclusion Criteria.....	10
3.5 Application of DAT and Tailored Feedback.....	11
3.6 Study Procedures.....	11
3.7 Theoretical Framework on Needs, Contents and Barriers for Digital Tools Application	12
3.8 Data Collection Tools .....	13
3.8.1 Survey with Semi-Structured Questionnaires.....	13
3.8.2 Exit Interviews .....	13
3.8.3 In-depth Interviews.....	14
3.9 Data Analysis .....	14
3.10 Ethical Clearance .....	15
CHAPTER FOUR.....	16
RESULTS AND DISCUSSION .....	16
4.1 Results.....	16
4.1.1 Participants Characteristics.....	16
4.1.2 Themes related to needs.....	18
4.1.3 Themes Related to Barriers.....	21
4.1.4 Themes related to content .....	22
4.2 Discussion .....	24
CHAPTER FIVE .....	27
CONCLUSION AND RECOMMENDATIONS .....	27
5.1 Conclusion.....	27



5.2	Recommendations .....	27
	REFERENCE.....	28
	RESEARCH OUTPUT .....	35

## LIST OF TABLES

Table 1:	Demographic characteristics of 142 participants.....	16
Table 2:	Mobile phone use.....	17
Table 3:	Demographic and adherence characteristics of in-depth interview participants .....	17

## LIST OF FIGURES

Figure 1:	The Wisepill device functions in the real-time medication monitoring intervention	8
Figure 2:	Map of the study area: Tanzania (left) and Kilimanjaro region (right) .....	9
Figure 3:	The overall study flow design.....	10
Figure 4:	TFA model and HBM model .....	13

## **LIST OF ABBREVIATION AND SYMBOLS**

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
CTC	Care and Treatment Centre
CRERC	College Research and Review Committee
DAT	Digital Adherence Technology
FGD	Focus group discussion
GCP	Good Clinical Practice
HBM	Health Believe Model
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
IDI	In-depth Interviews
KCMC	Kilimanjaro Christian Medical Centre
KCRI	Kilimanjaro Clinical Research Institute
NACP	National Aids Control Program
NIMR	National Institute for Medical Research
NM-AIST	Nelson Mandela African Institution of Science and Technology
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
WHO	World Health Organization

# CHAPTER ONE

## INTRODUCTION

### 1.1 Background of the Problem

HIV/AIDS is still a major cause of death globally. About 38 million people globally were living with HIV in 2020 (UNAIDS, 2020). Approximately, more than half of the world's population affected with HIV live in Sub-Saharan Africa (Kharsany & Karim, 2016). The Eastern and Southern African region is the most affected region by HIV in the world and is the home to about 20.7 million people living with HIV (AVERT, 2021). In Tanzania, nearly 1.7 million were said to be diagnosed with HIV in 2019 (UNAIDS, 2020). From 2010 to 2019, the number of people living with HIV in the country has increased from 1.3 million to 1.9 million (UNAIDS, 2020). The prevalence of HIV among female individuals aged between 15-49 years is higher compared to males with 6.3% and 3.4% respectively (THIS, 2018.). 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). 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).

Over 90% of new infections among infants and young children occurs through mother to child transmission which is during pregnancy, labour and breastfeeding (WHO, 2007). In absence of interventions during breastfeeding, 5-20% of infants are at risk of acquiring HIV (UNAIDS, 2020). In Africa, the risk of mother to child infection is higher with 15-45% without antiretrovirals treatment (Points, 2018). A systematic review of cohort studies done in East Africa shows that the prevalence of mother to child transmission is 7.68% (Belachew *et al.*, 2020). 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 rates among pregnant and breastfeeding women remain a challenge contributing towards the mother to child HIV infection rate of 11% in 2019 which is higher than the global target of 5% (UNAIDS, 2020). A systematic review study which was done in Africa and included 35 articles, showed that, retention in care after 12 month of follow up is 69% (Knettel *et al.*, 2018). The WHO guideline recommends that, regardless of immunity (CD4 count) of the pregnant women living with HIV, they should immediately initiate ARV treatment (World Health Organization, 2006). Adherence to ARVs during pregnancy, labour and breastfeeding contributes largely to reducing the risk of transmission to the child from 35% to 2% in low middle-income countries (Lozada, 2012). Poor retention and

non-adherence to medication among breastfeeding women threaten the progress towards elimination of HIV in children. Various factors have been identified as barriers for women to adhere to ART or be retained in care, such as lack of correct information on how to use ARVs, low awareness on HIV infection and mother to child prevention of HIV, stigma, disclosure to a spouse, regime fatigue, physical and depressive symptoms and lack of social support (Hodgson *et al.*, 2014). Lack of social support has been linked to poor adherence and low retainment in care (Buregyeya *et al.*, 2017; Knettel *et al.*, 2018). Therefore, both increase the possibility of developing drug resistance and treatment failure and contribute to failure in viral load suppression and increase rate of HIV transmission (Ngarina *et al.*, 2013).

Adherence to treatment and retention in care are among the most important factors for success of the UNAIDS “start free-stay free-AIDS free” framework. High levels of adherence are needed to prevent treatment failure (defined as viral load becoming detectable, development of opportunistic infections or mortality), to prevent development of drug resistance and to prevent vertical transmission of HIV to the new-born child (UNAIDS, 2015). Retention in care is a requirement for adherence to treatment as visiting a clinic is needed for medication dispensing (Stricker & Fox, 2014). Adherence can be measured and monitored directly through measuring drug levels in serum. As this method is expensive, indirect measures can be used such as self-reported adherence, pharmacy refill counts and medication monitoring through digital adherence tools (Stricker & Fox, 2014).

## **1.2 Statement of the Problem**

Adherence to medication and retention in care are still major challenges among people living with HIV. A cohort study done in Tanzania shows that among women living with HIV during postpartum period, the lost to follow up in care was about 69.5% (Cichowitz *et al.*, 2019). In Tanzania, despite that option B+ has been implemented since 2014, 8,600 children below 14 years of age were newly infected with HIV through mother to child transmission during delivery or breastfeeding in 2020 (UNAIDS, 2020). Several studies have been done on interventions to improve adherence such as reminder cues, counselling, extensive education, and clinical care retention (Geldsetzer *et al.*, 2016; Mayer & Fontelo, 2017), but still there is lack of evidence on improved adherence effect (Ritchie *et al.*, 2019). The penetration of mobile technology in Tanzania was more than 89% by 2021 (TCRA, 2020). However, mobile phone communication has not been used yet for improving retention and adherence to medical care and treatment. Also, no robust research has been conducted using mobile technology interventions to improve adherence and retention in care among breastfeeding and pregnant women living with HIV, especially in resource limited settings. Given the high coverage of mobile technology in the country, digital health tools

are feasible to be implemented. This study therefore aimed to identify the needs and contents of a customized digital tool for retention in care of breastfeeding and pregnant women living with HIV.

### **1.3 Rationale of the Study**

Digital technology for health is increasingly used to overcome challenges in providing standard health services and health information systems. Several studies around the world have shown that, digital technology has been used to link antenatal clinics and pregnant or breastfeeding women in maternal and child health care (Ambia & Mandala, 2016; Geldsetzer *et al.*, 2016; Tamrat & Kachnowski, 2012). Also, there is evidence on the positive effect of SMS on retention in care and adherence to treatment in low to middle income countries (Geldsetzer *et al.*, 2016; Gurman *et al.*, 2012; Kanters *et al.*, 2017; Mayer & Fontelo, 2017), though these studies recommend that, more research is needed for better intervention. This study aimed to identify the needs of breastfeeding and pregnant women living with HIV, as contents for a digital tool for improving adherence to medications and retention in care, in order to customize an existing tool as preparation for its clinical trial.

### **1.4 Research Objectives**

#### **1.4.1 General Objectives**

To identify the needs and contents for a customized digital tool among pregnant and breastfeeding women living with HIV in Kilimanjaro region.

#### **1.4.2 Specific Objectives**

- (i) To investigate needed contents for short message service texts to remind taking their medication, facilitate education and clinic attendance among pregnant and breastfeeding women living
- (ii) To determine barriers in using digital tools among breastfeeding and pregnant women living with HIV.
- (iii) To investigate the needed contents of tailored feedback on adherence patterns during clinic visits.

### **1.5 Research Questions**

- (ii) What are the needed contents for short message service texts to remind taking medications, educating and clinic attendance among pregnant and breastfeeding women living with HIV?

- (iii) What are the barriers in using digital tools among breastfeeding women living with HIV?
- (iiii) What are needed contents for tailored feedback on adherence patterns during clinic visits?

## **1.6 Significance of the Study**

Researchers, the government, policy makers, and other stakeholders will be made aware of the study's findings in order to advocate for the need of digital tools and the content to be used for the digital tools such as the correct reminder content of the SMS, retention and educational SMS. However, this study will contribute in improving existing digital adherence tools which are being used to remind people living with HIV on their medication intakes and clinic visits. Furthermore, findings from this study will be used in a trial as a base in improving and customizing digital tools. Also, this study will help government and stakeholders to understand and start to use digital tools in standard of care as it has already been recommended by WHO, to improve adherence to medications.

## **1.7 Delineation of the Study**

The mixed method study design intended to understand needs and contents of a customized digital tool among pregnant and breastfeeding women living with HIV. Moreover, this study aimed to identify barriers in using digital tools.



## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 Adherence to Treatment among Pregnant and Breastfeeding Women Living with HIV

Targets to eradicate AIDS pandemic and attaining universal health coverage by 2030 were outlined in the Sustainable Development Goals in 2015. The intention was to stop the transmission of new HIV infections to children by 2018. Yet, in 2019, a total of 150 000 children were newly infected with HIV globally, mainly due to vertical transmission (UNAIDS, 2020). In Eastern and Southern Africa, 95% of pregnant women living with HIV had access to treatment through prevention of transmission of mother to child (PMTCT) programs in 2019 (UNAIDS, 2020). Despite these levels of access to treatment, the rate of transmission through mother to child was more than 8% in 2019 and viral suppression was only 69% among women in Eastern and Southern Africa (UNAIDS, 2020). Due to the gap in prevention of vertical transmission, there were 40 000 new HIV infections among children in 2019 in Eastern and Southern Africa (UNAIDS, 2020).

The option B+-program has been implemented in Tanzania since 2014. It involves lifelong treatment for pregnant women diagnosed with HIV and six weeks daily single dose nevirapine for the infant after birth. In Tanzania, despite option B+ having been implemented for several years, 8600 children aged less than fourteen years were newly infected with HIV through mother to child transmission during delivery or breastfeeding in 2019 (UNAIDS, 2020). Uninfected new-borns and infants until 12 months of mothers living with HIV depend on treatment adherence by their mothers. In addition, breastfeeding practices by mothers determine the chance of the infant to become HIV-positive. In Tanzania, the rate of vertical transmission including during breastfeeding was 11% in 2019 (UNAIDS, 2020).

Despite high access to ART treatment of 92% in Tanzania, the percentage of infected infants has not decreased much since 2010 (UNAIDS, 2020). Preventing the risk of HIV-infection to the infant and monitoring of treatment progression are very crucial. Unfortunately, the potential of ART in preventing HIV in new-borns and young children has not been completely accomplished due to non-adherence to ART treatment. Adherence to ART medications does contribute to a reduced risk of transmission, increased life expectancy and stable viral load suppression (Bor *et al.*, 2013; Filippo *et al.*, 2017; Tanser *et al.*, 2013). Moreover, poor adherence to treatment contributes to drug resistance, treatment failure and decline in CD4 count (Hoffmann *et al.*, 2016). Studies have shown that, adherence to ART in PMTCT programs is very crucial in reducing HIV transmission from mother to child (Gamell *et al.*, 2017; Mirambo *et al.*, 2015; Okonji *et al.*, 2012). Only 69%

of pregnant women in a mixed-method study conducted in South Africa adhered perfectly to their medication (Adeniyi *et al.*, 2018). Another study which was done in Zimbabwe among pregnant and breastfeeding women living with HIV reported that, only 67.7% were retained in care and less than half of them (39.1%) were adherent to ART after one year of ART initiation (Erlwanger *et al.*, 2017). Among factors identified as contributing to non-adherence were marital status, use of tobacco or alcohol, failure to disclose, absence from home, forgetfulness, stigma and demands from the workplace (Adeniyi *et al.*, 2018; Mellins *et al.*, 2008).

## **2.2 Retention in care among Pregnant and Breastfeeding Women living with HIV**

Missed clinic visits have contributed to increased rates of mortality among people who are in HIV treatment care (Mugavero *et al.*, 2009). Despite of improved access to ART and high ART uptake among pregnant and breastfeeding women living with HIV, retaining them in care is still a major challenge (Hodgson *et al.*, 2014; Knettel *et al.*, 2018; Sakyi *et al.*, 2020). A study, which was done in Ghana to assess retention in care among women in the postpartum period, reported only two-third of women were retained in care (Reece *et al.*, 2016).

The National Aids Control Program (NACP) of Tanzania encourages monthly antenatal visits for pregnant and breastfeeding women living with HIV but yet there is challenge. A retrospective cohort study in Kilimanjaro, Tanzania, which had 650 participants, showed that loss to follow up during pregnancy was 11.5% and after delivery the risk increased to 69.5% (Cichowitz *et al.*, 2019). Reasons for non-retention are stigma, fear of disclosure to HIV status, lack of information, depressive symptoms, lack of transport to the clinic, low income and lack of social support (Knettel *et al.*, 2018; Sakyi *et al.*, 2020). Retention in HIV care was associated with achieving high viral load suppression (Mugavero *et al.*, 2012). As the percentage of lost 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 content and tailored feedback on adherence reports, can overcome stigma and fear of disclosure. For example, if a patient thinks he or she is stigmatized and this lowers adherence, this may be the point for discussion during feedback on the reports. Moreover, by giving education during visit clinics on how to cope with such factors and others creates a form of social support.

## **2.3 Application of Digital Adherence Tools**

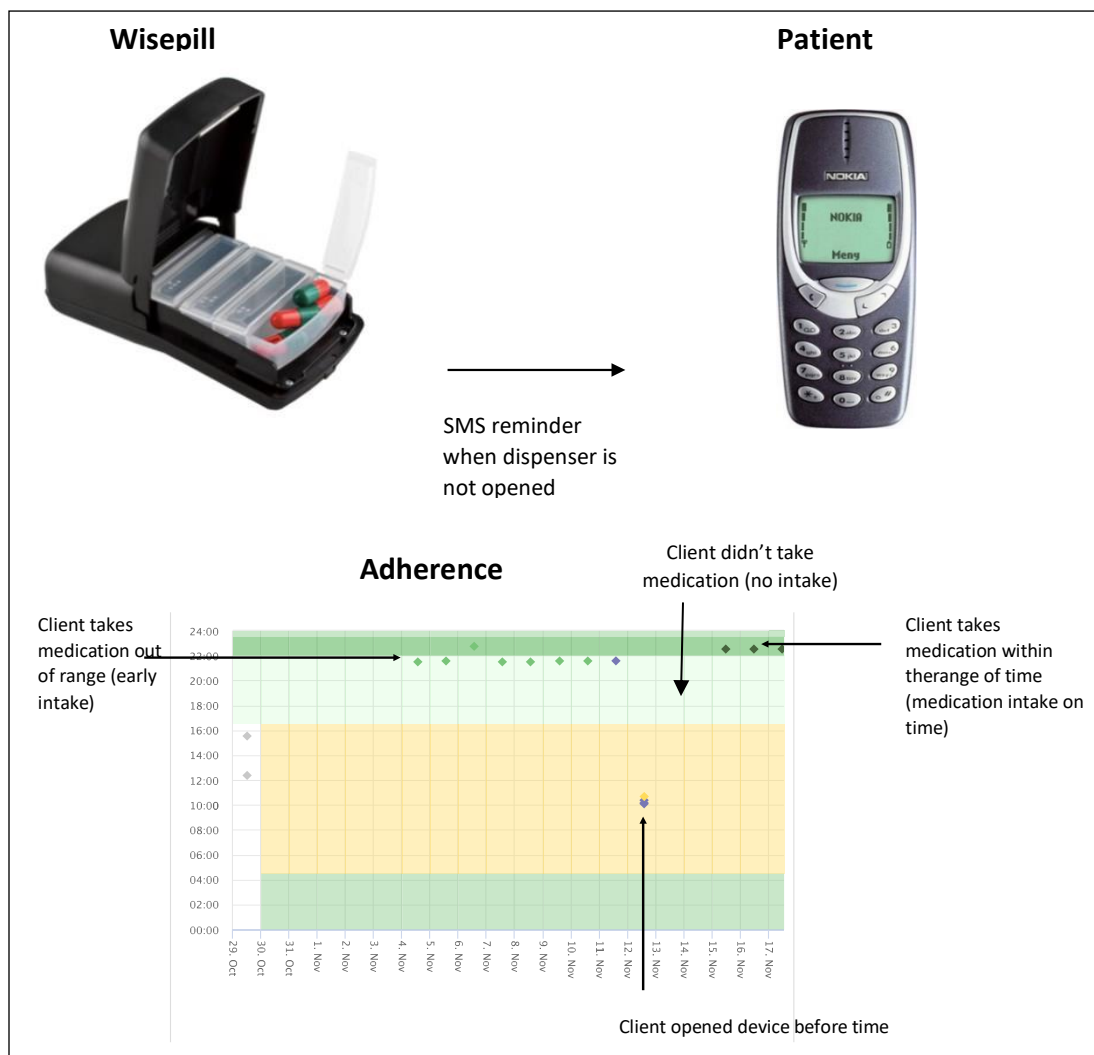
Several review studies have shown a positive effect of SMS on retention in care and adherence to treatment, though all recommend that more robust intervention studies are needed (Geldsetzer *et al.*, 2016; Gurman *et al.*, 2012; Kanters *et al.*, 2017; Mayer & Fontelo, 2017; Sarna *et al.*, 2019). Most studies on the use of SMS in PLHIV in SSA are conducted in Kenya. There is one trial that

sends a weekly message asking, ‘How are you?’ to pregnant women, in Western Kenya (Awiti *et al.*, 2016). Another study sends weekly motivational and educational SMS and visit reminders (Drake *et al.*, 2018). The intervention used in this last trial was designed through formative research, in which results showed that, SMS may improve outcomes. Messages should be customized according to the context and users have different needs considering the contents of SMS (Fairbanks *et al.*, 2018). Another study in Kenya, which sent SMS informed by constructs of the Health-Belief-Model, showed a significant effect on maternal postpartum clinic attendance (Odeny *et al.*, 2014). This intervention was also informed through qualitative research and has led to a currently ongoing trial (Odeny *et al.*, 2018). The penetration of mobile phones in Tanzania was 89% in 2020. Additionally, 32 billion SMS were sent in the first quarter of 2020 (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. However, optimization of existing and previously investigated strategies is needed. In Tanzanian previous pilot studies, it was found that, using RTMM and SMS for reminding about medication intake among adults in Moshi, Tanzania was feasible (de Sumari-de Boer *et al.*, 2016; Ngowi *et al.*, 2020). Furthermore, a trial has successfully been implemented using the Real Time Medication Monitoring intervention (Wisepill) combined with SMS reminders. It showed a positive effect of both RTMM and SMS on adherence to treatment among participants with viral load below 1000 copies/ml. Furthermore, the proportion of participants reaching 90% adherence to medications was higher among the intervention groups (Sumari-de Boer *et al.*, 2021).

## **2.4 Introduction to Wisepill Digital Adherence Device in Tanzania**

The Wisepill device (Wisepill RT2000®), also known as an internet enabled medication dispenser, enables remote medication monitoring on a real-time basis. The Wisepill device (RT2000 dispenser) is a pocket-sized dispenser designed by the Wisepill company. This device holds up to 30 large pills or 60 small pills in a two-partitioned container. It is manufactured by the Wisepill company in Cape Town, South Africa. The Wisepill device contains a global SIM card which communicates through cellular networks to automatically synchronize with the Wisepill Cloud service each time the device is opened. At any point 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. User’s agreed intake time is required to be registered on the Wisepill Web Server. If a participant forgets to take medication at the prescribed time, a reminder SMS is sent to their mobile phones. The health care workers can monitor medication intakes with access provided to online adherence reports and graphs generated.

The Wisepill device suit research and clinical trials on adherence (Haberer et al., 2010). This device was firstly introduced in Tanzania in 2018 among people living with HIV, and results from that study have shown that, real time medication monitoring is highly acceptable and has potential to improve adherence (Ngowi *et al.*, 2021). Despite these positive results, the investigators also encountered concerns about unwanted disclosure and stigma due to contents of SMS asking directly whether medications were taken or not. 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 pill. In addition, there have been technical challenges encountered, such as limited network availability, electricity and battery life resulting in SMS not being sent (Ngowi *et al.*, 2020). Furthermore, most studies have mainly focused on adults in general, while this study focused on understanding the digital tools and gaining the experience of the tools from pregnant and breastfeeding women.



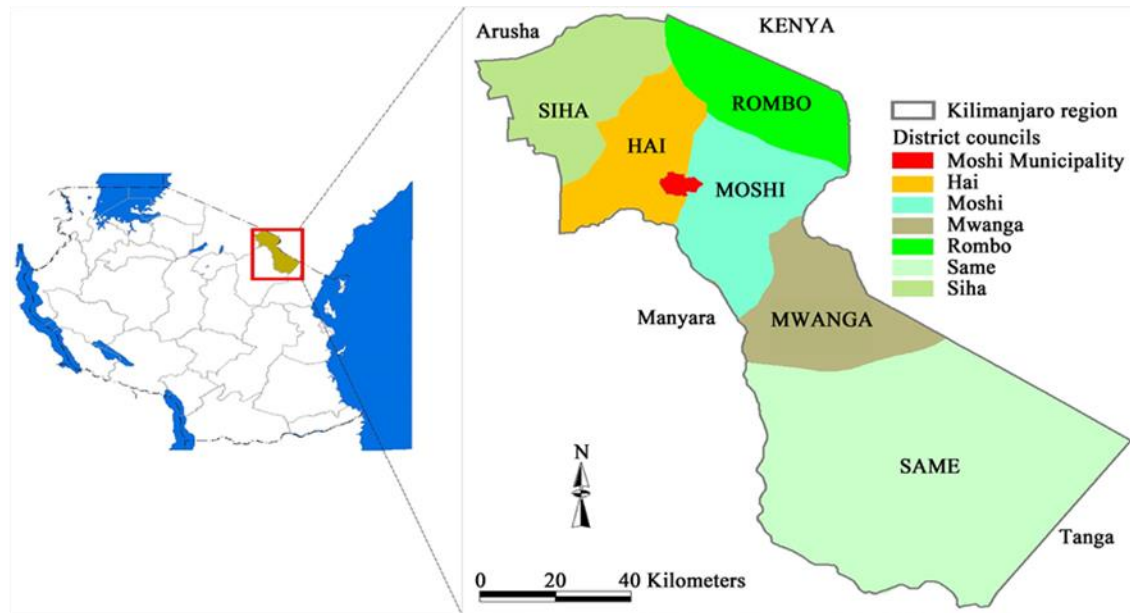
**Figure 1: The Wisepill device functions in the real-time medication monitoring intervention**

## CHAPTER THREE

### MATERIALS AND METHODS

#### 3.1 Study Area

This study was conducted in the Kilimanjaro region located in the Northern part of Tanzania. Kilimanjaro Region has an area of 13 250 km square. It has seven districts and the capital is Moshi. In the latest census of 2012, the region had a population of about 1.6 million with a sex ratio of 94. Seventy-six percent live in rural areas and 38% is below age 15.

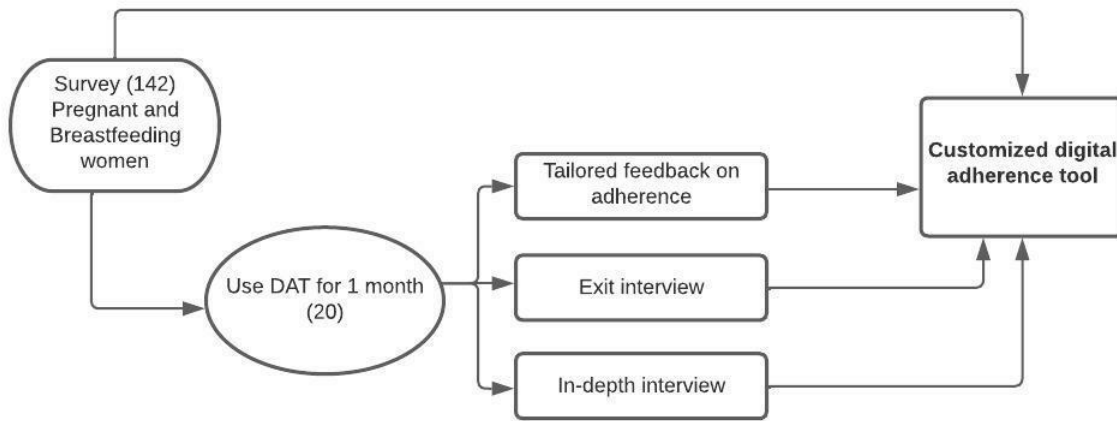


**Figure 2: Map of the study area: Tanzania (left) and Kilimanjaro region (right)**

The study was conducted in five HIV care clinics, which included 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. A peripheral site was also involved, which was Kibosho hospital.

#### 3.2 Study Design

This was a parallel formative mixed method study, which included both quantitative and qualitative data collection methods. A survey was conducted among pregnant and breastfeeding women. Selected women were then given a digital adherence tool (DAT) for a month, followed by feedback from a nurse counsellor on their adherence patterns. After this, in-depth interviews (IDI) were conducted.



**Figure 3: The overall study flow design**

### 3.3 Sample Size

The sample size for this descriptive study was determined based on practical considerations and the available resources. Since this was a formative study, I aimed to include sufficient number of participants to provide a representative of the pregnant and breastfeeding women living with HIV. After considering various factors, including time constraints and feasibility, a sample size of 142 breastfeeding women was selected. Although this sample size may not allow for generalizability to the entire population, it provides valuable insights into the characteristics and experiences of the participants in this study. The selection of 142 participants was based on our judgment and consideration of the available resources, without the use of formal power calculations or hypothesis testing.

### 3.4 Inclusion and Exclusion Criteria

This study involved pregnant and breastfeeding women living with HIV in Kilimanjaro region. Inclusion criteria were:

- (i) 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.
- (ii) Attending Care and Treatment Centres (CTC) or postnatal clinics in Kilimanjaro.
- (iii) Aged between 18-50 years and being <2 years breastfeeding.
- (iv) Breastfeeding women willing to use digital tools.
- (v) Pregnant or breastfeeding women willing to sign and able to understand the informed

consent.

Exclusion criteria are:

- (i) Admitted to hospital at study-entry.
- (ii) Participating in other trials related to adherence and retention into care.

### **3.5 Application of DAT and Tailored Feedback**

The Wisepill device (RT2000 dispenser) 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. Whenever a participant forgot to take medication at the prescribed time, a reminder SMS was sent to their mobile phones. The health care workers and researchers monitored medication intakes through access provided 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. The participants were firstly asked on how they felt about their medication intake behaviour. This was followed by showing a graph to the participant, so he or 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 possible solutions, such as "cues" in daily life to be coupled with medication intake. The third phase of the feedback session consisted of the participant taking making decisions concerning their behaviour. An adherence goal for the next clinic visit was set by the nurse and participant together (goal setting). The modified stage of change model was used developed by Prochaska *et al.* (1997).

### **3.6 Study Procedures**

Eligible individuals were asked to participate in the study by signing an informed consent form. After participants completed their clinic visits with health care 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.

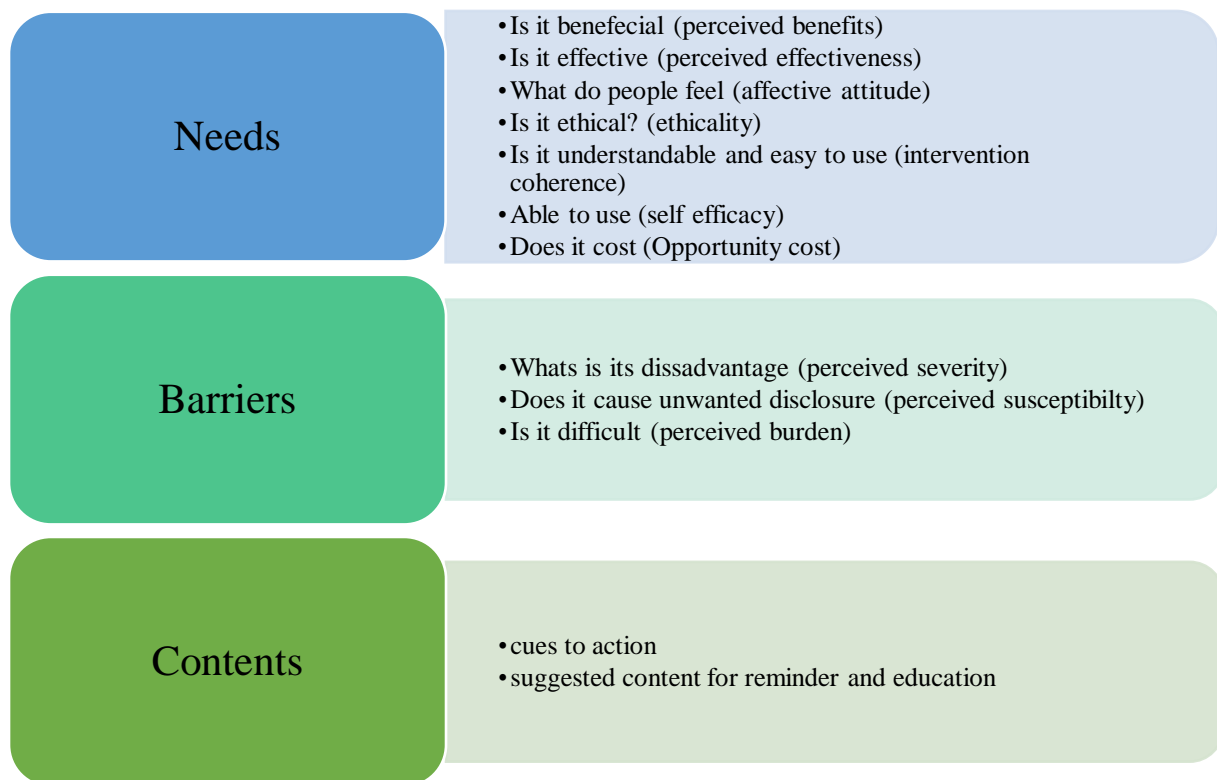
After informed consent was filled, a semi-structured questionnaire was administered face to face to breastfeeding and pregnant women as part of the survey.

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 in to use of digital tools. 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 its operation. 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. It was 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 were conducted 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.

### **3.7 Theoretical Framework on Needs, Contents and Barriers for Digital Tools Application**

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





**Figure 4: TFA model and HBM model**

The contents of the interview guide for IDI was informed by the Health Belief Model (HBM) (Karen *et al.*, 2008) and Theoretical Framework of Acceptability (TFA) (Sekhon *et al.*, 2017). Findings from prior research done in Kenya were used to develop contents for the mHealth intervention to promote postpartum retention in preventing mother to child HIV transmission with the use of the HBM (Odeny *et al.*, 2014). We used six domains of the HBM as summarized in Fig. 4.

### 3.8 Data Collection Tools

#### 3.8.1 Survey with Semi-Structured Questionnaires

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

#### 3.8.2 Exit Interviews

Exit interviews were conducted after participants completed one month of using DAT. Interviews were done face to face. A semi-structured questionnaire was based on previous studies (Ngowi *et al.*, 2021) and included all emerging issues during 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.

### **3.8.3 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 for 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. The interviews were conducted in the hospital clinic in a private doctor's room. The interviews lasted approximately 40 to 90 minutes. The topic guides were adapted during the study in an iterative process. Interviews were transcribed verbatim and translated to English.

All collected data were stored pseudonymously using patient identifier codes.

## **3.9 Data Analysis**

Descriptive analysis was used to summarize the participants characteristics, preference and use of mobile phones. In order to answer the objectives regarding needs and contents of SMS for reminding and education and content for tailored feedback on adherence patterns, thematic content analysis was conducted using data from in-depth interviews and descriptive analysis from survey and exit interviews.

Themes were developed from reading and re-reading of transcripts. Memos were developed based on the first six interviews by two research assistant and from there a preliminary codebook was developed. Translated transcripts and field notes were uploaded into NVivo software for data organization and the codebook was imported as well. Data was organized according to codes from where themes were derived. The listed themes were discussed 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 reliability and validity of the coded data together with compliance of the framework.

To answer objectives on the barriers of using digital tools, thematic content analysis was conducted from in-depth interviews as above. Descriptive analysis was done using data from survey and exit interviews.

### **3.10 Ethical Clearance**

Ethical approval for this study was obtained from Kilimanjaro Christian Medical College Research Ethics and Review Committee (CRERC) (No.2518) and the Tanzania National Institute for Medical Research (NIMR/HQ/R.8a/Vol. IX/3825). Good Clinical Practice (GCP) guidelines were followed in all study procedures.

## CHAPTER FOUR

### RESULTS AND DISCUSSION

#### 4.1 Results

##### 4.1.1 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. Their mean age was 31.3 (SD 6.3) and ranged from 19 to 45 years. One hundred and two women (72%) had either primary or secondary education. Most women included were seeking health services from Pasua Health Centre. One hundred and thirty-four (95.7%) owned a mobile phone, of which 85 (60%) had a basic feature phone and 49 (35%) owned a smartphone. The details of the participants are shown in Table 1.

**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	28%
	Majengo health centre	41	32%
	Pasua health centre	45	39%
	Mawenzi regional hospital	14	10%
	Kibosho hospital	3	2.10%
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%

More than 90% of participants use and read SMS in their daily life. Among 142 participants, 23 (15%) reported to ever have skipped medications. Among 23 participants who skipped medications, 13 (56.5%) reported that they forgot. Only 64 (46%) were having someone in their environment to remind them to take medication. Among 42 pregnant women, 10 (24%) did not have knowledge on how to protect their child from HIV infection.

**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%

All 20 breastfeeding women who used the device for one month participated in an IDI. Characteristics of these 20 interviewees are shown in Table 2 above. There was considerable variability in demographic characteristics and adherence rates.

**Table 3: Demographic and adherence characteristics of in-depth interview participants**

No	Age of Breastfeeding women (years)	Religion	Marital status	Age of Child (months)	Adherence DAT	Medication time	Regimen
1	34	Christian	Married	3	96%	21:00	TDF+3TC+DTG
2	30	Christian	Single	3	100%	21:00	TDF+3TC+DTG
3	29	Christian	Married	5.5	100%	20:00	TDF+3TC+DTG
4	37	Christian	Single mother	9.5	96%	20:00	ATV/r+ABC+3TC
5	28	Christian	Married	9	96%	21:00	TDF+3TC+DTG
6	24	Christian	Single	2	90%	20:00	TDF+3TC+DTG
7	28	Muslim	Married	9	96.70%	22:00	TDF+3TC+DTG
8	32	Christian	Single	6	70%	18:00	TDF+3TC+DTG
9	45	Christian	Married	8	100%	20:00	TDF+3TC+DTG
10	41	Muslim	Married		100%	19:00	TDF+3TC+DTG
11	31	Muslim	Married	5	100%	21:00	TDF+3TC+DTG
12	30	Muslim	Single	6	96.50%	19:00	TDF+3TC+DTG
13	25	Muslim	Married	7	NIL*	22:00	TDF+3TC+DTG
14	38	Christian	Single	6	79.80%	21:00	TDF+3TC+DTG
15	30	Christian	Single	11	100%	21:00	TDF+3TC+DTG
16	33	Muslim	Married	11	100%	21:00	TDF+3TC+DTG
17	23	Christian	Single	18	100%	21:00	TDF+3TC+DTG
18	30	Christian	Single	4	NIL*	21:00	TDF+3TC+DTG
19	23	Christian	Married	5	100%	21:30	TDF+3TC+DTG
20	36	Christian	Married	8	100%	20:00	TDF+3TC+DTG

Note: There were two devices which didn't communicate (NIL\*)

Results are based on the two models and we categorized results in three major themes. Two categories of themes were: (a) Themes related to needs of DAT, (b) Themes related to barriers in using DAT and (c) Themes related to content of DAT.

#### 4.1.2 Themes related to needs

##### (i) Perceived Benefits

From the IDI, the majority of participants explained that using the DAT helped them with taking medications on time. Even before they receive 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 social support as participants felt like they are not alone.

*...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 years 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 years 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 single woman].*

##### (ii) Perceived Effectiveness

From the survey, we found that most women (105 (78%)) were interested to receive 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 the SMS made them to take their medications on time hence improve their adherence. Through IDI, we found that participants perceived that DAT helped to improve taking medication on time. A 32 years-old woman explained that after receiving the device, she had never missed or exceeded time for medications. She becomes more conscious with the time to take medications.

*After receiving the device, I have never exceeded the time for medication. When it is 9 o'clock or even before it reaches 9 o'clock, sometimes when it is 8:30, after the message, I waited about 15 minutes then I took medications*

Another one explained that:

*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 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 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 single woman].*

### **(iii) Affective Attitude**

In the follow-up interviews, 19(95%) participants reported to have good or very good experience with receiving reminder SMS and they thought the device was good. Twenty women (100%) said it has good appearance. Ninety five percent reported that the way the graphs displayed their adherence level was either good or very good. The IDI participants felt good and happy using the DAT, both the device and SMS. The majority of participants were satisfied with the graphs showing the 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 and others suggested that this intervention should be used by all people living with HIV. *“Actually, the way it's working, I see it is good, that is, I love it very much, very, very much” (34 years married woman).* *“.... we would like to be given (DAT) to all the people with this problem.” (31 years 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].*

### **(iv) 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. The 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 receiving 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 are using medications since the device almost looks like a phone. For participants who shared their phones with their husband or children, they did not report any domestic disputes or unwanted disclosure caused by reminder SMS. There was no issue which was raised that concerned religion or culture from participants.

*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 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 single woman).*

*“...it's not easy to know what is inside the device.” (32 years single woman)*

#### **(v) Intervention Coherence**

From the follow up interviews, 17 (85%) participants did not experience difficulties in opening of 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, but others had understood only that the device was for storing medication and it has no link to the reminders message which they receive. Though the majority of 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.

*“.... I don't know. I just know it's a thing to store medications” (45 years 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 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 married woman).*

#### **(vi) Opportunity Costs**

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



## **(vii) Self-efficacy**

Participants were confident in using the DAT as required and were able to use the intervention. IDI participants explained that it was easy for them to understand the SMS which they received. *“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 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 married woman)*

### **4.1.3 Themes Related to Barriers**

#### **(i) Perceived Burden**

In the survey, 31 (22%) reported to experience network challenges and in the follow-up interviews, 3(15%) experienced network challenges during the study period. For IDI participants, the mostly perceived barrier identified was to receive more than one SMS, which was 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 to receive the reminder SMS twice. Also, there were participants describing that in the beginning, opening of devices was a challenge. However, after some time they did understand and it was even easy to refill and take pills from the Wisepill device. *“About two times, I noticed I didn't receive SMS” (30 years single women).*

*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 married woman]*

*“I normally receive reminder SMS although I have already taken [pills]” (30 years single woman)*

#### **(ii) Perceived Susceptibility**

In the survey, 27(20%) of women reported to share their phone and 15 (56%) share their phone with their husband. In follow up interviews, no participant reported that the intervention caused any unwanted disclosure of their HIV status. Although, IDI participants perceived that they were having a risk of unwanted disclosure when someone uses their phone or for those 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 to be a consequence of using SMS reminders which contain the word “dawa” or “medication”. They said that if someone saw the reminder message with the word ‘medicines’, they will start to

ask questions and start to follow up with them on why they are taking medication or what the medication is for. This may create stigmatization and women may start to lose confidence that they are not normal people.

*...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].*

*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].*

### **(iii) Perceived Severity**

In follow-up interviews, 18(90%) participants reported to have no concern about being watched or monitored all time by healthcare providers. Perceived severity explained during the IDI was a fear created that there were being watched by someone.

*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 married woman].*

No participants reported to have difficulties in carrying the device around with them. In fact, they were happy to travel with it because no one could notice what is inside. *“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 married woman).*

#### **4.1.4 Themes related to content**

##### **(i) Cues to Action**

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

*..... 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 single woman].*

*“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 single woman).*

*“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 married woman]*

## **(ii) Participants’ Recommendation on the Content of the Message Content**

IDI participants preferred neutral messages and 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 that anyone could understand what its meaning.

*There is a message which has irritated me. It is the one of “use medication on time”, that word “medication. 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 single woman]*

*“For me, the solution is the word medicines to be removed, because someone might know that am taking medication” (29 years married woman).*

Several participants suggested other reminders which they preferred such as:

*... they should probably be, “remember to eat fruit for your health” .... “eat fruit”, “drink water”, “remember to drink water” (33 years married woman)*

Considering educational topics, women suggested they want education about business, breastfeeding, taking medication, mental health issues, nutrition, sexual issues and other opportunistic disease. *“I would like to know, for example, for a mother with such a disease, how long she should breastfeed” (33 years married woman). “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 single woman).*

*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 married woman]*

*“Education should be about how to avoid overthinking” (30 years single woman)*

*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 single woman]*

Women suggested on the frequency for clinic visit reminders to be at least monthly, a day before their appointment day. *“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 married woman). Also, women preferred educational messages that should be sent each week. *“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 single woman)

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 to receive reminders daily. *“For me I like to receive the reminders every day”* (30 years single woman)

## **4.2 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. The use of theoretical frameworks helped to understand needs, content and barriers of DAT and constructs from TFA and HBM were identified as themes within this data.

In terms of the overall findings, it was observed that the DAT had a significant impact on participants' medication adherence, with the majority reporting that it effectively reminded them to take their medications on time. Additionally, the study revealed a high need for the device, who expressed comfort and ease in extracting medication from the device. Consequently, they expressed a strong desire to continue using the DAT. Reminding people taking medication is a valued opportunity as it helps preventing instances of forgetfulness (Holender *et al.*, 2018).

Moreover, the ethicality of using the device was supported by several factors. Firstly, its appealing appearance and small size were regarded positively by the participants. Additionally, unlike usual ART's containers, the device operated silently when taking out the pills. However, it is important to note that while our study indicated ethical considerations, contrasting results have been reported in other studies. Some of these studies raised concerns regarding data security, potential dependence on technology, and worrying about the consequence of technological failures (Chevance *et al.*, 2022; Holender *et al.*, 2018)

The findings are in line with other studies, which were done in Kenya and South Africa among HIV infected women showing that neutral text message content provides confidentiality, minimize fear and provide self-confidence to women (Nachega *et al.*, 2016; Odeny *et al.*, 2014).

Educational messages preferred by women were about entrepreneurship, breastfeeding, advantage of taking medication, consequences of not taking medication, mental health issues, nutrition, sexual issues and other opportunistic disease. Interestingly, our findings showed that participants preferred to receive reminder SMS daily, which is different from the study done among women in South Africa who preferred to receive weekly SMS (Nachega *et al.*, 2016). Also, a Cochrane review, which included clinical trials from Kenya, reported that receiving weekly messages improved adherence to ART medication compared to daily messaging (Horvath *et al.*, 2012).

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

It was found that 15% of women reported to skip medication and more than half mentioned it was due to forgetting. From in-depth interviews, they explained that sometimes they were busy with other activities, therefore, receiving a reminder helped them to remember. Forgetting is a complex multi-faceted phenomenon (Freeman *et al.*, 2021). Studies suggest that, sending reminder SMS helps against forgetting (Nsagha *et al.*, 2016). Regarding tailored feedback, most women were happy to receive feedback and were mostly satisfied when they were shown adherence graphs generated by the RTMM device. During feedback sessions, women were able to have time to receive education from health care provider.

There were several limitations in my study, Firstly, the sample size for participants who used DAT is small, as this was a formative study in which a small number of participants were selected to use the DAT for one month. The aim of this study was to gain insight and develop SMS content for future trials using customized tool and not to generalize study findings. Secondly, participants used the device for only one month which is a short period of time therefore using the digital tools for a longer period of time might give different results on acceptability. Though, doing a formative study is an innovative step to explore feasibility of the study.

The major strength of our study is the use of mixed methods, which helped to provide quantification and insights leading to better understanding of the needed content for digital adherence tools among breastfeeding women. Also, triangulation of the data from different data sources helped to strengthen our study. These important findings will help to design better tools to improve adherence to ART among pregnant and breastfeeding women so as to prevent mother-to-

child transmission. Another strength is the use of two theoretical frameworks that offered inclusive insights in study participants' perceptions on the needs and contents for digital adherence tools which can be considered for future interventions.

## **CHAPTER FIVE**

### **CONCLUSION AND RECOMMENDATIONS**

#### **5.1 Conclusion**

The mixed methods used in this study help with construction of useful contents for future digital adherence tools, to support the health of pregnant and breastfeeding women living with HIV. Digital tools showed to be useful in this study when the content and feedback were tailored to the needs of pregnant and breastfeeding women living with HIV. From each construct, it was found that digital tools are highly needed as most women were happy to use the digital device and receive reminder message. In this study, participants reported 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.

#### **5.2 Recommendations**

Future research on digital tools should address these issues before implementation. These findings also create ways for customization of the digital tool in preparation of a clinical trial to evaluate effectiveness on improving retention to care among pregnant and breastfeeding women living with HIV.

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

Rehema Anenmose Maro; Kennedy Ngowi; Haikael Martin; Angel Dillip; Lydia Masika; Alan Mtenga; Benson Mtesha; Marion Sumari-de Boer

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Dear Ms Maro,

I am pleased to inform you that your manuscript "Needs and contents of a customized digital tool for retention in care and medication adherence among pregnant and breast-feeding women living with HIV in Kilimanjaro" (BNRC-D-23-00649R2) has been accepted for publication in Bulletin of the National Research Centre.

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# Needs and contents of a customized digital tool for retention in care and medication adherence among pregnant and breast-feeding 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.



Keywords: Antiretroviral therapy (ART); HIV/PMTCT; Retention; Digital Adherence Tools (DAT); Real Time Medication Monitoring (RTMM)

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## Background

HIV/AIDS is still a major cause of death globally. Globally there are 38.4 million people living with HIV in 2021 (1). In Tanzania, the HIV prevalence is 4.6 and nearly 1.7 million were said to be diagnosed with HIV in 2019 (2,3). From 2010 to 2019, the number of people living with HIV in the country increased from 1.3 million to 1.9 million (2). Despite the implementation of option B+ in 2014, 8,600 children aged 0-14 were newly infected with HIV through mother-to-child transmission during delivery or breastfeeding in 2019 (2). Without antiretroviral treatment, the risk of mother-to-child infection is 15-45% in Sub-Saharan Africa (4). A systematic review of cohort studies done in East Africa shows that the average prevalence of mother-to-child transmission is 7.68% (5). Despite the fact that most people living with HIV have access to antiretrovirals (ARVs), maintaining adherence to lifelong treatment has been a major challenge (6). 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 (2). Non-adherence to treatment contributes to failure in viral load suppression (7).

In Tanzania, the percentage of pregnant women enrolled in prevention of mother-to-child transmission (PMTCT) services reached 92% in 2019 (2). 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% (2). 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 (7). 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% (8). Lack of social support and stigma have been linked to poor adherence and low retention in care (7,9). Poor retention and non-adherence to medication among breastfeeding women threaten the progress toward 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 (10). 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 (11–14).

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 (16). 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 (17,18). 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 (19). 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 (20).

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 (21). 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 18-50 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 (22).

### 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.

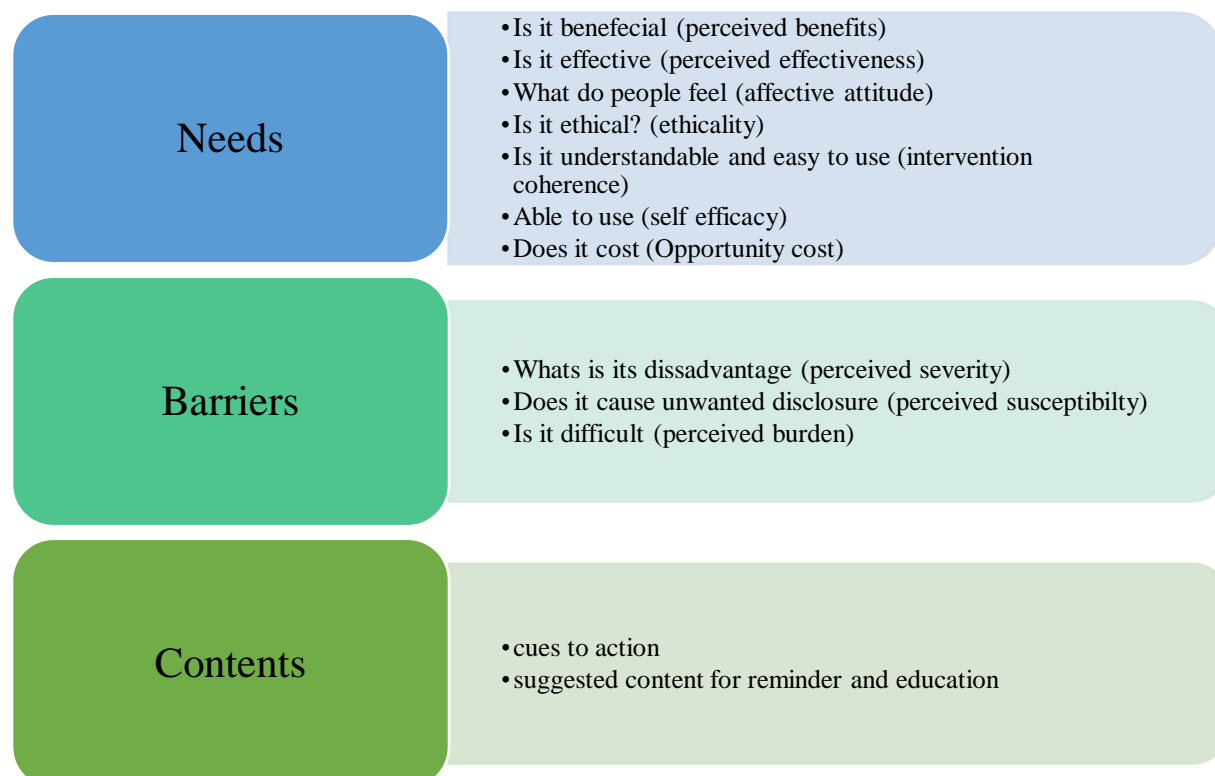
A sub-sample of 20 participants was purposively selected from the study participants, with a variability in demographic characteristics, including rural or urban, facilities, clinic adherence patterns, and viral load to ensure heterogeneity. Another thoroughly informed consent procedure was done before 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 (19). 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.

Figure 1: TFA model and HBM model



The content of the interview guide for IDI was informed by the Health Belief Model (HBM) (23) and Theoretical Framework of Acceptability (TFA) (24). 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 (25).

## 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 (20) 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.

### 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 minutes. 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 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.

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%

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 the Table 2 below.

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%

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 – 22:00 hours.

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 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 percent 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: Participants quotes related to each construct of acceptability

Themes related to	Theoretical framework construct	Example of quotation
Needs	Perceived benefits	<p>“...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</p> <p>“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</p> <p>“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</p>
	Perceived effectiveness	<p>“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</p> <p>“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</p> <p>“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</p>
	Affective attitude	<p>“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</p> <p>“.... we would like to be given (DAT) to all the people with this problem.” 31 years old married woman</p> <p>“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</p>
	Ethicality	<p>“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</p>

		<p>without someone else noticing what you have.” 23 years old married woman</p> <p>“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</p> <p>“...it's not easy to know what is inside the device.” 32 years old single woman</p>
	Intervention coherence	<p>“.... I don’t know. I just know it’s a thing to store medications.” 45 years old married woman</p> <p>“... 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</p> <p>“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</p>
	Self-efficacy	<p>“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</p> <p>“.... 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</p>
Barriers	Perceived severity	<p>“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</p> <p>“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</p>
	Perceived susceptibility	<p>“...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</p>

		<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>
	Perceived burden	<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>
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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 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 (26).

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 (20,27). 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 (17,28). 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 (29).

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 (30). 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 customise 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.

## List of 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

## 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

### Availability of data and material

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

### Competing interests

The authors have no competing interest to declare

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The European and Developing Countries Clinical Trials Partnership (EDCTP) supported this study. The funder had no role in the design of the study, execution, analysis or interpretation of data.

### Authors' 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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## Needs and contents of a customized digital tool to improve retention in care: A mixed methods study among pregnant and breastfeeding women living with HIV in Tanzania

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### BACKGROUND

Retention in care and adherence to medication among pregnant and breastfeeding women living with HIV (PBWLH) is crucial for prevention of mother to child transmission (PMTCT) of HIV. Due to the wide coverage of mobile phones, digital tools are the promising potential intervention to improve adherence to medication and retention in care. 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.



### METHODS

- Parallel formative mixed method study
- A survey was done among pregnant and breastfeeding women and we purposively selected women were then using the digital tools for a month followed by semi structure interview and in-depth interview and Focus Group Discussion
- We did descriptive analyses for quantitative data and thematic content analyses for qualitative data

### RESULTS

#### Quantitative Results

Among 142 women interviewed, 42(29.5%) were pregnant and 100(70.5%) were breastfeeding and mean age was 31.4(6.4); 136(95.8%) had access to mobile phones and used SMS daily; 132(96%) were interested in receiving reminder messages; 30(22%) reported to have network challenges; 86(61%) preferred to be reminded daily before medication intake time

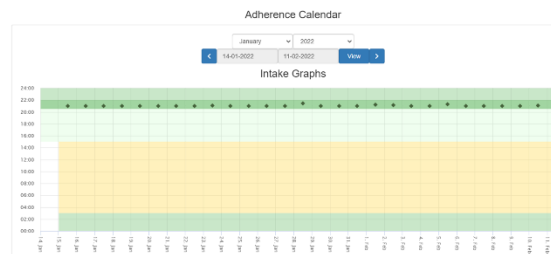
#### Qualitative Results

- DAT improved their medication intake, provide them privacy in storing medications and useful during travel
- Women preferred neutral reminder SMS and educational SMS contents preferred was how to breastfeed, alcohol use, other opportunistic diseases such as candidiasis, proper nutrition and self employment or entrepreneurship education were preferred

- During feedback sessions, participants mostly were satisfied and were happy to see their adherence graphs

*"To me, I feel very comforted, I wish I could continue to have the device because the SMS inspired me"*

Figure1: graphs which were used during feedback session



### CONCLUSIONS

- Tailored digital tools seem to be feasible and acceptable in this group
- This study helps to construct useful content for future digital adherence tools to support the health of pregnant and breastfeeding women living with HIV



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