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Lessons learned from a mobile technology-based intervention informed by behavioral economics to improve ART adherence among youth in Uganda

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ABSTRACT

Evidence suggests that simple text messaging interventions may not suffice to improve ART adherence among youth in low-resource settings. To address this shortcoming, we developed an intervention that shared weekly real-time adherence feedback to youth in Uganda using short message services (SMS), based on information tracked by an electronic device (Wisepill). We present results from 7 formative and 6 exit focus groups (FGs) in Mulago and Entebbe, Uganda with youth ages 15–24, providers, and Community Advisory Board members. Participants consistently conveyed positive impressions of Wisepill, noting that it helped store their medications, facilitated travel, served as a reminder, and motivated adherence. Participants raised phone-related issues before the study; most were addressed but some remained (e.g., limited network access, electricity for powering phones). Further, they highlighted the importance of carefully crafting text messages (e.g., use slang rather than potentially stigmatizing words) and viewed personalizing messages favorably but were divided on the desirability of including their name in study-related texts. Exit FGs confirmed that sharing group adherence levels with participants tapped into the competitive spirit common among youth. Our results suggest future mobile technology-based interventions can be improved by providing messages that go beyond simple reminders to provide individual and group-level adherence feedback.

Abbreviations: ART (Antiretroviral Therapy); CAB (community advisory board); FG (focus group); FGs (focus groups); RCT (randomized controlled trial); SITA (SMS as an Incentive To Adhere); SMS (short message services)

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Introduction

Researchers are exploring how technology such as mobile phones can help address problems with ART adherence among youth in sub Saharan Africa (Bikaako-Kajura et al., 2006; Inzaule, Hamers, Kityo, Rinke de Wit, & Roura, 2016; Nabukeera-Barungi et al., 2015). However, multiple studies suggest that simple SMS-based interventions may not motivate the desired behavior change (Bigna, Noubiap, Kouanfack, Plottel, & Koulla-Shiro, 2014; M. P. Fox & Kaufman, 2018; Lester et al., 2010; Linnemayr et al., 2017; Nagata, Ferguson, & Ross, 2016; van der Kop et al., 2018). To address limitations of SMS-based interventions, we developed SITA (**S**MS as an **I**ncentive **T**o **A**dhere) for Ugandan youth ages 15–24. We analyzed results from formative and exit focus groups (FGs) in the larger randomized controlled RCT (ClinicalTrails.gov) to capture initial impressions of SITA, to identity potential concerns, and to learn which concerns remained after the intervention.

Methods

The RCT included 7 formative focus groups (FGs) (conducted March-April 2015) to inform intervention design, and 6 exit FGs (conducted December 2016-March 2017) to identify areas for improvement. The qualitative methods are described in detail elsewhere;(MacCarthy et al., 2018 [Under Review]) here we provide a brief summary.

The intervention had two treatment groups and a control group. The first treatment group (T1) received text messages to their mobile phones every week informing them of their individual adherence as measured by Wisepill. The second group (T2) received not only their own adherence information but also that of a

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Table 1. Example text messages used in the intervention.

Sample Messages	Treatment
Good work dear [PARTICIPANT NAME]. You did 50%. There is light ahead!	T1
Hey [PARTICIPANT NAME] you scored 50%. Keep the move on!	T1
Dear [PARTICIPANT NAME], keep up the good work! You made 50%	T1
[PARTICIPANT NAME] you have made it to 50%! #SITA	T1
[PARTICIPANT NAME] you have made it to 50%. The rest of the team has a score of 80%. #SITA	T2
Good work dear [PARTICIPANT NAME]. 50% compared to many of your SITA buddies at 80%. There is light ahead!	T2
Hey [PARTICIPANT NAME] you scored 50%. Many guys at SITA scored 80%. Keep the move on!	T2
Dear [PARTICIPANT NAME], keep up the good work! You made 50%, others in SITA got 80%	T2
[PARTICIPANT NAME] you have made it to 50%. The rest of SITA has a score of 80%. Great job!	T2

peer group. The control group received the usual standard of care. Of note, participants received texts only from study staff and were not able to communicate with other participants via text. Table 1 gives examples of text messages.

The study population included community advisory board (CAB) members, providers and patients from Mulago and Entebbe (Table 2).

All CAB members and providers working with adolescents were invited to participate and given approximately $16 USD. A list of study-eligible youth attending the clinic was generated, 6–8 of whom then participated and were given approximately $8 USD. All who attended the FGs were given snacks and soft drinks.

Study coordinators facilitated the FGs. They provided a general introduction; after receiving verbal consent from participants, the coordinators recorded the discussion. The FG guide was informed by our previous SMS-based interventions with youth in Uganda (Linnemayr et al., 2017; Rana et al., 2015). We asked about using Wisepill, acceptability of using phones to receive adherence information, and the content of potential text messages. We also probed on receiving individual and group adherence information. All FGs were transcribed, translated, and uploaded into Dedoose for thematic analysis. A codebook was developed and inter-rater reliability was established based on a pooled Cohen's Kappa of 0.79 and 0.80.

The study was approved by the RAND Human Subjects Protection Committee, the local IRB, and the Uganda National Council for Science and Technology.

Results

Table 3 summarizes the key themes and selected quotes for each theme.

Using Wisepill

Participants generally expressed enthusiasm about Wisepill, but some initial concerns persisted. Participants felt that the devices might trigger security systems. They were also worried about the (un)intentional impact of opening the box without a pill being taken. Other concerns included the potential that the device could be stolen, or broken if carried in their pocket.

In the exit FGs, participants consistently conveyed positive impressions of Wisepill, noting that it helped store their medications, facilitated travel, served as a reminder, and motivated adherence because they knew

Table 2. Characteristics of formative and exit focus groups.

Participant Type	Eligibility Criteria	Participants
FORMATIVE FOCUS GROUPS (Mulago)		
CAB ($n = 1$)	Requested attendance from existing CAB members.	9 participants: community representatives working with the HIV clinic and had diverse tasks including identifying and introducing new clients to HIV treatment and conducting home visits to support ART adherence.
Providers ($n = 2$)	Requested participation from all providers with frequent contact with youth clients.	Group A - 8 participants: 1 patient advocate, 2 clinic managers, 2 research managers, 1 psychologist, 1 dispensing staff, 1 receptionist Group B - 7 participants: 5 counselors and 2 dispensing staff
Youth & Minors ($n = 4$)	Primary eligibility confirmed by medical records: HIV-positive; age 15–24 (minors age 15–17 and youth ages 18+); on ART or co-trimoxazole; engaged in HIV care for at least 3 months; not currently pregnant or having any opportunistic infections.	Group A: 8 boys age 18+ Group B: 6 boys age <18 Group C: 6 girls age 18+ Group D: 5 girls age <18
EXIT FOCUS GROUPS (Mulago and Entebbe)		
Providers ($n = 1$)	Requested participation from all providers having frequent contact with youth enrolled in SITA.	7 participants: 3 counselors, 1 drug dispenser/pharmacist, 1 client representative, 2 study coordinators
Youth ($n = 4$)	Participants either participated in the first treatment group (T1 - text messages with individual adherence information measured by Wisepill) or the second treatment group (T2 - additionally received the adherence information of their peer group)	Entebbe T1: 5 youth age 18+ including 2 female, 3 male age 18+ and 3 minors age <18 including 2 female, 1 male Entebbe T2: 9 youth age 18+ including 4 male, 5 female Mulago T1: 9 youth age 18+ including 2 male, 7 female Mulago T2: 7 youth age 18+ including 1 male, 6 female
Minors ($n = 1$)	Either T1 or T2, but all below age 18	Mulago - minors only group: 5 minors age <18 including 2 male, 3 female

Table 3. Key themes and selected quotes.

Parent theme	Child Theme	Exemplary Quotes
Using Wisepill	Impressions of Wisepill device	Convenient for keeping medication: " … that device was portable, it was good to move with, it kept medication very well, it would push you, because every time you opened it … you would say", "they are seeing me" "that make you see to it that you never miss a day. It was really good" (T2 Participant from Entebbe, Exit FG).
		Provided helpful reminder: "good, generally, especially to us who used to not take our drugs well, so it reminded us … because skipping drugs, does not necessarily mean that you don't want the drugs. Most times, you may forget since you come back tired, but you remember it if you have the device in the bag … Whenever I opened my bag and saw, I always recalled that I had to take the drugs" (T1 Participant from Entebbe, Formative FG).
	Confidentiality	Triggers security systems: "It has been good but, on the other hand, bad for us who go to the bank. When they pass a detector at the bank, the detector sounds, until you show the guards the bank and that it is a power bank and it has a battery inside it. You have to explain to them about the medicine" (T1 Participant from Mulago, Exit FG).
		Helps maintain privacy: "I feel good because it reduces your own anxiety or temptation. No one knows what you have. Sometimes someone may think you have a phone or something else, and your medication is safe and sound" (T2 Participant from Entebbe, Exit FG).
	Manipulation of Wisepill device	Purposefully opening Wisepill device: "My boyfriend, he is a tricky guy, he knows that maybe the SITA program was following us and what he did he was so clever. He would go and open the device and close it without taking any pill from it, but then at the end of the week they bring 100. So, I would request that they modify it so that they can see that now someone has taken a pill out not only opened it" (T1 Participant from Entebbe, Exit FG).
	Logistical concerns with Wisepill device	Reported wrong information: "There was that time when the pill device had a problem." I [would] take my drugs on time, but they gave me a zero, and sometimes I would even burst out and cry, "why?" I thought these people were cheating me because I was taking the drugs on time, I was doing the right things, and my boyfriend would laugh at me and even family members all looking, and they were like "eeeeeeeh, you are a loser" (T1 Participant from Entebbe, Exit FG).
		Difficulty charging Wisepill device: "There are places without electricity. The problem is [when] [the Wisepill] goes off, I don't know how this person is going to solve the problem since they are deep in the villages and the battery is low. Some people come from villages where there is no power, and it's expensive to charge a phone and the machine at the same time" (Control Group Participant from Entebbe, Exit FG).
	Sustainability	Lack of motivation without Wisepill device: "When we entered this program I really had expectations, and the first expectation was I didn't expect it to end because of the way it changed my life. I wouldn't allow myself to go back in the life I was in, but now that I don't have a device, nothing to motivate me … I might continue to take my medicine like I have been but not everyone. Some people have been motivated because of the device" (T1 Participant from Entebbe, Exit FG).
		Desire to keep using the Wisepill device: "Let the device be brought back because it has been keeping the medicine safe" (Mulago Minors, Exit FG).
Phone-Related Concerns	Confidentiality	Concerns about having to disclose to others: " … .my only fear [is] at times you find that these adolescents do share phones with people they haven't disclosed to" (Provider from Mulago, Formative FG).
		Confidentiality concerns for illiterate patients: "Actually, there are even those who cannot read and when you send the message it will be a boyfriend to read it for her because she cannot tell what the message is about" (Member of the Community Advisory Board from Mulago, Formative FG).
	Technological issues	Issues with network coverage: " … there was a time I was going to [town name] and a week ended, and I didn't get the message. Then I called SITA and SITA told me that where I was there was no network coverage" (T1 Participant from Entebbe, Exit FG).
	Wording of messages	Careful word choice of text messages: " … maybe if we could have other words that would represent pills or drugs." I have heard clients call it "the daily bread or something" things like that replace the words pills and medication" (Providers from Mulago, Formative FG).
Treatment Group One (T1): Receiving Individual Adherence Information	Impressions about receiving individual adherence information	Useful reminder to take medication: " … [the] messages energized me because whenever I saw them, I was always motivated to take drugs" (T1 Participant from Mulago, Exit FG).
		Information encouraged some competition: "what I most liked about it, when I had it, I had my friend and we would be like in a competition. If he gets like 90, I would like to get above him. It always made me happy. We even used to call each other asking for what the other has gotten. On our side it was like a game" (T1 Participant from Entebbe, Exit FG).

(*Continued*)

Table 3. Continued.

Parent theme	Child Theme	Exemplary Quotes
Treatment Group Two (T2): Receiving Group Adherence Information	Impression about receiving group adherence information	Information on low scores encouraged better performance for some: "If I get low marks I would say 'aaaaah'". When I went back, [my provider] would ask me why? Yet she told me how everything has to move, so what I liked most where the messages because they would encourage me" (T1 Participant from Entebbe, Exit FG). Helped reflect on improving adherence: " … for me when I receive that message, when I asked for 100 and they did not give it me, I ask myself what going on? This motivates me, and I tell to myself that I have to add more effort so that I can get the 100" (T2 Participant from Mulago, Exit FG). The competition encouraged better adherence: "Now with this project, there was competition, I was competing with the rest of my colleagues and I always wanted good marks from the SITA program and so it really encouraged me with all friends, it really changed our lives. It was very wonderful" (T2 Participant from Entebbe, Exit FG).

that if they missed a dose, study staff monitoring Wisepill data would know. Respondents felt the device protected the privacy of their HIV status: even when they had to take ART in public, nothing indicated the nature of the drugs. Several participants mentioned that the device set off security detectors in some public buildings and shopping malls, but saying it was a cell phone power bank often dismissed security concerns.

Few participants reported intentionally manipulating Wisepill. However, several said that the device sometimes reported the wrong information or stopped working. Many participants asked if they could keep Wisepill to support ART adherence after the study ended.

Phone-related concerns

Most initial phone-related concerns were addressed, but some remained. Participants in the formative FGs feared that their HIV status could be unintentionally disclosed. This concern was amplified among illiterate patients who asked friends or family to read messages. Respondents also raised technical concerns such as limited network access, power sources, or having phones shut off temporarily or permanently. Participants in the exit FGs did not raise confidentiality as a concern, since the messages did not include any content that would suggest their HIV status; however; technical concerns – mainly limited network access and access to electricity - persisted.

The formative FGs also highlighted the importance of carefully crafting text messages –e.g., use slang rather than potentially stigmatizing words like *clinic* or *pill*. For example: youth often referred to pills as "daily bread" so messages asked youth if they had taken their daily bread. Additionally, participants recommended messages that did not use potentially problematic words such as *ART*. One participant suggested a reminder that simply read, "Thank you [name], it is time." Participants seemed to view personalizing messages in this way favorably but were divided on the desirability of including their name in study-related texts.

Receiving individual or group adherence information

Before the intervention started, none of the participants raised concerns about receiving their adherence information on their phone. In the exit FGs, participants noted that receiving adherence information reminded them to take their medication. Some participants who received only their own information reported asking their friends about their scores, turning scores into a competition. For some participants, getting a low score discouraged them; others thought low scores motivated them to improve. Further, in the formative FGs, participants anticipated that receiving group adherence information would motivate youth, creating a sense of community and mutual recognition. In the exit FGs, respondents who received group adherence information reported that it prompted them to reflect on how they could improve their own adherence.

Discussion

Many studies have described the adherence information produced by Wisepill devices in high (Blashill et al., 2017; Koss et al., 2017; Pellowski, Kalichman, Kalichman, & Cherry, 2016) and low-income settings (Bionghi et al., 2018; Haberer et al., 2010; Sabin et al., 2015); however, few have considered the logistics of using Wisepill (Bachman DeSilva et al., 2013). Our results support continued Wisepill use, but also suggest ways to maximize the device's potential. For example, study staff can conduct random data checks to ask participants how well they feel reported Wisepill results map to their self-reported adherence. These checks can ensure that Wisepill's adherence information is generally consistent with participants' self-reported adherence. Further, participants need ways

to describe Wisepill devices if they raise security concerns —for example, calling the device a cellphone power bank. Our results also highlight the need for adherence tracking devices that have extended battery life and can use alternative energy sources (e.g., solar charging).

Several phone-related concerns raised in the literature (Eze, Gleasure, & Heavin, 2018; Giguere et al., 2017; Nhavoto, Grönlund, & Klein, 2017) were echoed in our study. Formative FG participants feared having their HIV status disclosed, but no exit FG participants reported this happening. Such concerns must be addressed so they do not deter study enrollment—for example, clearly detailing steps to protect confidentiality during recruitment and again during the consent process.

Receiving information about group adherence appeared to harness the power of social influence to shape medication adherence (Patel et al., 2016). Behavioral economists use social comparison feedback in health interventions to influence behavior (e.g., to increase physical activity (Klein, Manzoor, & Mollee, 2017; Patel et al., 2016; Yun & Silk, 2011), reduce alcohol use, (Neighbors et al., 2016), reduce risky sexual behaviors, (Chernoff & Davison, 2005; Lewis et al., 2014), and improve food choice (Mummah et al., 2017; Thorndike, Riis, & Levy, 2016; Yun & Silk, 2011). Feedback from exit FG respondents suggests that receiving information about group adherence prompted participants to reflect on their own adherence and motivated them to outperform their peers. The FGs suggest that using social comparison to incentivize adherence may be an effective tool to improve adherence among youth.

Limitations and strengths

The study has both limitations and strengths. The FG data are not representative or generalizable to other youth living with HIV in Uganda. Further, the FGs were not conducted equally between sites: formative FGs were conducted only in Mulago, whereas exit FGs were also conducted in Entebbe. Our previous research identified distinct differences between youth versus provider and CAB perspectives on barriers to ART adherence (MacCarthy et al., 2018). We did not detect differences between participants; however, more FGs may help determine if more nuance exists. Finally, formative FGs among youth were single sex and age-restricted (e.g., 15–17 and 18–24) whereas exit FGs combined female and male youth and minors.

These limitations are balanced by significant strengths. Our study assessed both pre- and post-intervention implementation issues and clarified which persisted at the study's end. In addition, our results suggest ways to improve future mobile technology-based interventions by providing messages that go beyond simple reminders and offer value to the participant (e.g., feedback on individual and group level adherence).

Conclusion

SITA used SMS in a novel way that provided valuable information to recipients. Youth specific concerns (e.g., increased likelihood of phones being lost, stolen, or broken and difference in messaging for youth vs. adults)(S. Fox, November 8 2010) must be addressed to maximize the potential impact of future interventions. Continued attention to the ways in which current interventions can be improved will be critical to improving ART adherence among Ugandan youth.

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