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Electronic Adherence Monitoring May Facilitate Intentional HIV Status Disclosure Among People Living with HIV in Rural Southwestern Uganda

Angella Musiimenta[1,2], **Jeffrey I. Campbell**[3], **Wilson Tumuhimbise**[1], **Bridget Burns**[4], **Esther C. Atukunda**[1], **Nir Eyal**[5], **Jessica E. Haberer**[4]

[1]Mbarara University of Science and Technology, P.O. Box 653, Mbarara, Uganda

[2]Angels Compassion Organisation (ACO), Mbarara, Uganda

[3]Boston Medical Center and Boston Children's Hospital, Boston, MA, USA

[4]Center for Global Health, Massachusetts General Hospital, Boston, MA, USA

[5]School of Public Health and Philosophy, Rutgers University, New Brunswick, NJ, USA

Abstract

HIV status disclosure remains one of the major challenges to effective HIV prevention. Given the complexities and low rates of disclosure, new innovative strategies are needed. Since electronic adherence monitoring (EAM) are unique mobile devices that light up when transmitting data, those who see them often want to know more about them, which can potentially result in HIV status disclosure. We conducted a qualitative study to explore patient experiences with EAM for antiretroviral therapy (ART) in Uganda with a goal of understanding potential ethical concerns, including disclosure. Unexpectedly, several participants reported intentionally using EAM to facilitate HIV status disclosure to others in order to get social support, encourage HIV testing, and create awareness about HIV. Although researchers and clinicians need to be mindful of the potential for unintended HIV status disclosure through the use of EAM, they should also recognize the potential of this approach to support intended disclosure.

Keywords

HIV intentional disclosure; Electronic; Adherence; Uganda

✉Angella Musiimenta, amusiimenta@must.ac.ug.

Author Contributions JIC and BB collected and analyzed data. AM, JEH, ECA, WT, and NE reviewed the transcripts and codebook. AM wrote the first draft of the manuscript and all authors reviewed the drafted and refined versions of the manuscript. All authors read, reviewed and approved the final version of the manuscript.

Conflict of interest The authors declare that they have no competing interests.

Ethical Approval The institutional review committees of Mbarara University of Science and Technology, the Uganda National Council for Science and Technology, and the Partners Healthcare/Massachusetts General Hospital approved this study.

Consent to Participate All participants provided signed informed consent before study participation.

Introduction

Adherence to antiretroviral therapy (ART) is important for individual and public health, as it optimizes patients' response to therapy and prevents spread of HIV [1]. Non-adherence to ART increases the risks of medication failure, drug resistance, and death [2]. Traditional approaches to adherence monitoring (such as self-report, pill counts, and pharmacy refills) do not report non-adherence in real-time and may be susceptible to social desirability and recall biases. Electronic adherence monitoring (EAM) technologies are wireless alternative approaches to adherence monitoring and may provide more accurate data on underlying adherence that could allow timely detection of adherence lapses prior to the resumption of viral replication [3]. EAMs transmit objective adherence data through a cellular network to a web portal in real-time. Patients' opening of EAM is taken as a proxy for taking medication, although accuracy may be limited by openings without dosing or removal of multiple doses at one time. EAM enable a variety of intervention strategies to support adherence. Medication reminders in the form of alarms, text messages, or automated voice calls can be integrated into the EAM to remind the patient about medication dosing or engage social networks to provide emotional or structural support. EAM technologies have been shown to improve ART adherence in Uganda [4] and in China [5], as well as in a recent systematic review that included studies from diverse settings in both developed and developing countries [6]. Importantly, studies have also found high levels of acceptability and feasibility of using wireless EAMs for ART adherence monitoring in these settings [7, 8]. These technologies have additionally been reported to improve tuberculosis (TB) medication adherence in China [9] and are acceptable and feasible in TB medication monitoring in Uganda [10].

Because they are cellphone-shaped and unique mobile devices that light up when transmitting data through the cellular network, EAM technologies, can easily attract people's attention, which can potentially result in HIV status disclosure [7, 11, 12]. HIV status disclosure is complex; reactions from friends, family, sexual partners, and the community may vary widely. In some cases, disclosure can lead to stigma and discrimination, which may result in social harms [13] and/or loss of retention in HIV care [14]. On the other hand, it also can have a number of potential benefits, such as increasing opportunities for social support and reducing stigma [15], motivating partners' HIV testing, enabling behavioral change that decreases HIV transmission, and improving access to medical care [16]. Much of the outcome of HIV status disclosure depends on how and when it is done. Face-to-face disclosure approaches (e.g. counsellor-supported disclosure [17]) may be beneficial, but they are restricted by geographical boundaries, are time consuming, involve transport costs, and may not be confidential. Overall, HIV status disclosure (especially to sexual partners and children) remains one of the major challenges to effective HIV prevention. Given the low rates of disclosure especially in areas with high HIV prevalence [18], coupled with complexities and challenges of HIV disclosure, new innovative strategies are needed to encourage and support individuals living with HIV to disclose their status.

We conducted a qualitative study to explore patient experiences with EAM for ART in southwestern Uganda with a goal of understanding potential ethical concerns, including

disclosure. Unexpectedly, several participants reported intentionally using EAM to facilitate HIV status disclosure. In this paper, we present an analysis of their actions, goals, and associated implications. We do not examine the process or experience of disclosure across all participants, but rather focus on this participant-initiated approach to facilitating communication of their HIV status to others.

Methods

Parent Study

Full details of the parent study—the Uganda AIDS Rural Treatment Outcomes (UARTO) study—have been described previously [19]. Briefly, UARTO, a longitudinal, observational study of 750 individuals initiating HIV ART, was carried out from 2005–2015 in Mbarara, Uganda. Participants received free ART through the Mbarara Regional Referral Hospital Immune Suppression Syndrome Clinic. Upon enrollment, all participants used an EAM. From 2005–2011, medication event monitoring system (MEMS; Aardex Group, Switzerland) caps were used to monitor ART adherence by tracking each time a participant's pill bottle was opened. Research staff downloaded adherence data during study visits. From 2011–2015, a real-time wireless EAM (Wisepill; Wisepill Technologies, South Africa) was used to monitor ART adherence. Interruptions in wireless EAM signal transmission lasting more than 48 h were investigated through a brief interview to determine the cause of the lapse. Following each interruption, blood draws were done to assess HIV RNA levels. Participants who subsequently declined to use either device or who moved out of the study catchment area (approximately 60 km from the research offices) continued participating in non-monitoring aspects of the study. Behavioral determinants and biological consequences of incomplete adherence were assessed from adherence data; in depth analyses are published elsewhere [20, 21]. The current study presented in this paper involved interviewing some participants and research assistants (RAs) from the UARTO study.

Qualitative Data Collection

Full details of our qualitative study have been described previously [19]. In brief, from August 2014 to June 2015, we performed two rounds of semi-structured interviews. First, to understand general impressions of wireless EAM use, we conducted exploratory interviews with UARTO participants who used the wireless EAM (n = 20) to assess their experience of using the device and participating in the study. Drawing from the results of the exploratory interviews, a second set of in-depth interviews (on which this paper is based) was conducted with three groups: (1) participants who used the wireless EAM (n = 40, distinct from exploratory interviewees), (2) participants who did not use the wireless EAM (n = 20), and (3) UARTO research assistants (RAs) (n = 6). We interviewed both EAM users and those who declined using the EAM in order to get a wide range of opinions surrounding EAM use. Using the research notebooks with the contact details of the all the EAM users and EAM-non users that were participants of the parent study, we contacted participants based on recommendations of the research assistants, purposively sampling for varied experiences in the study. We interviewed them until reaching thematic saturation when no new information arose from the interviews. Interviews with RAs were meant to contextualize participants' experiences. Research assistants who had worked for the UARTO study for at least three

months were interviewed. Prior to being interviewed, all participants had been enrolled in UARTO and had been taking ART for at least six months; all were ages 18 or older. We excluded participants who were unable or unwilling to provide consent.

Participants were asked about a range of potential ethical considerations (such as autonomy, trust, dependence, privacy and confidentiality) proposed in our prior theoretical work [11]. Depending on participants' preferences, interviews were conducted in the local language (Runyankole) or English.

Qualitative Data Analysis

We used a content analysis approach [22] to explore the above-noted ethical concepts and to identify additional exploratory themes. With substantial input from authors JEH and AM, JIC and BB carried out initial analysis that involved review and discussion of 20% of interviews to identify relevant content. A code book was iteratively developed from the identified content. This process involved defining codes and identifying illustrative quotes from interview transcripts. After importing the final code book into NVivo version 11, JIC and BB used this software to code all interviews, with approximately 25% of interviews coded by both researchers to determine inter-rater reliability. Coding discrepancies were discussed to reach consensus. Results reported in this paper focus on the analysis of intentional EAM-related disclosure.

Quantitative Assessments

All participants completed a baseline demographic survey that was translated into Runyankole for non-English speakers. These quantitative data were entered into a secure electronic database, Research Electronic Data Capture (REDCap) version 6, and analyzed descriptively.

Ethical Reviews

All participants provided signed informed consent before study participation. The institutional review committees of Mbarara University of Science and Technology, the Uganda National Council for Science and Technology, and the Partners Healthcare/ Massachusetts General Hospital approved this study.

Results

Participant characteristics are shown in Table 1. The majority of the participants were illiterate. The majority of EAM non-users were females in their 40 s. The majority (n = 16, 80%) could not use the device due to logistical reasons (such as poor network connections, coming from or moved out of the study catchment area (approximately 60 km from the research offices), and the mobile nature of some participants which would complicate follow-up). Only 4 (20%) of the EAM-non users feared disclosure. At time of our interviews, 58/60 participants had disclosed to someone (39/40 EAM users, and 19/20 EAM non-users). We did not collect data that relates device use with intentions to disclose across all participants.

Interview Results

Overview—UARTO participants and RAs reported that the EAM device could facilitate intentional HIV status disclosure to people to whom disclosure would otherwise be challenging; disclosure was sought to alleviate the burden of hiding their status and to achieve social support. Some participants associated the EAM device with high social status, which gave them the confidence to disclose. These participants also encouraged their colleagues to test for HIV to have an opportunity to be given the device if the test reveals HIV infection. Other participants used the device to create awareness about HIV, encouraging their colleagues to learn from them and avoid HIV. They also used the device to reduce the prevailing stigma against individuals living with HIV. Despite these largely positive experiences, however, some participants feared disclosure through EAM use.

Facilitating Intentional HIV Status Disclosure

Some participants intentionally disclosed their status to members of their social networks using the EAM as a starting point for talking about their HIV status. A participant explained how she intentionally opened the device before her father to disclosure her status. She had previously struggled to disclose to him, but explaining the device to her father gave her an opportunity and to disclose her status.

> I: Have you ever gone with it [EAM device] and someone asks you about it?
>
> R: For me if someone asks, I tell them that it's a device that keeps my ARTs. For me I am free. For example, this device helped me to disclose to my father whom I had spent a long time figuring out how to tell him. I went home and I opened it and I explained how it works and why they gave it to me. So I liked the way it helped me disclose to my father.
>
> My father is very tough even if am now married I was worried of how I would tell him that am sick of HIV but it was easy to tell him while explaining the device.
>
> *~ Female, EAM user*

To facilitate HIV status disclosure using the device, another participant intentionally left the device on the bed where it could be easily seen by his wife. After she had seen the device and the drugs it contained, she asked the participant about the device. This scenario provided an opportunity for him to disclose his HIV status. An RA described the following story.

> I: You also mentioned disclosure and that there are people who would be afraid that it may lead to disclosure. Can you please tell me more about this?
>
> R: I will actually even give you an example; there is a participant of mine who had not disclosed to the wife although he knew it was good to disclose. He went and left the device on the bed and went away, so the wife came and saw the device on the bed, opened it, and saw the drugs. So, when the husband came, she asked him what it was and he explained everything. This was actually good for him since he had a chance to disclose to the wife, so it worked for him.
>
> *~ Male, UARTO RA*

For these participants, using the device to disclose their HIV status enabled them overcome the complexity of HIV status disclosure and thus created a sense of relief.

Disclosing to Access Social Support

Some participants reported using the device to intentionally disclose to people who they felt would be helpful in supporting them. Although she later stopped her medication (due to fear of disclosing to her husband) and brought back the EAM device, one woman selectively used the device to disclose to her colleagues and boss at work. Her goal was to obtain job-related permission to go to clinic for treatment and coverage for her regular duties when she was attending the clinic for treatment.

> I: What if it was at around 10:00 am when you are all in the staff room may be for break tea. Do you think it would have influenced your decision to refuse the device?
>
> R: No. It would not, because I told most of the staff members about the device. Even my head teacher knows about it.
>
> I: Why did you tell them?
>
> R: I told them because I know that they can help me. For example, if I need to come to the clinic, my fellow teachers can help me control my class and even the head teacher can give me permission without questioning me a lot…
>
> ~ *Female, EAM non-user*

The device was a focal point for disclosure and thus facilitated the participant's access to much needed social support.

Device-Related Disclosure Encouraged HIV Testing

In addition to seeking support for themselves, some participants reported using the EAM to disclose their HIV status and encourage their colleagues to go for HIV testing. These participants associated the EAM device with social status and bragged about being monitored remotely by the "computer", which notifies "even the whites in America", when opened to take medication. It was reported that those who were encouraged to test for HIV were driven by the desire to have the technology in case the test reveals HIV infection.

> I: Interesting, tell me one time when you opened the device and someone saw it and what happened?
>
> R: We had gone to my sister's burial, so my relatives saw it [EAM device] and they asked me what it is. I told them that for me, I found out that I have HIV and they gave me this computer to help me take my pills. So, I told them to all go and take an HIV test and they asked me if they can also get this device. I told them not everyone gets it; it's the lucky ones. I told them you see this one is a serious thing it has a battery inside and a line for MTN [cellular service provider], so when I open it even the whites in America see it, so I am a very special person. They were so amazed and they were all eager to go and take HIV tests so that they may get a chance of getting this device in case they find out that they are HIV positive.

~ Female, EAM user.

The EAM device played a unique role of generating prestige in this resource limited setting. Consequently, participants independently used the EAM to promote HIV testing in their communities.

Disclosing to Create HIV Awareness and Prevention

Some participants reported using the device to disclose their HIV status to create awareness about HIV and enable others to learn from them to avoid HIV. These participants reported freely using the device in public and explaining its purpose when asked by their colleagues. They believed that such awareness could reduce prevailing HIV-related stigma.

> I: This device can at times cause tension from other people when they see it. Tell me about a time when someone saw it or you using it and what happened?
>
> R: Sometimes I go somewhere. Like recently when you called me, I was in a seminar and it was residential. So I was sleeping in a room with my colleagues and I would open it [device] and I take my medication. Of course they saw the light and they asked me and I explained that it is a device for my HIV medication and I told them how it works and they were surprised. For me I am free to talk about it because I know that I can help another person who has stigma to also feel free about it.
>
> I: So how did all that make you feel?
>
> R: I felt okay because I am not hiding my HIV status I know that I am not the only one and my friends can learn from me to avoid HIV.

~ Male, EAM user

The EAM device created a tangible opportunity to disclose status, while at the same time creating HIV awareness, and facilitating learning to prevent HIV/AIDS.

Fear of HIV Disclosure Through EAM Use

Despite the reported benefits of EAM-facilitated HIV status disclosure, other participants had disclosure concerns and were not comfortable being seen using the device to take their medication.

> “For me I liked my device a lot and I was using it well but of course I thought if I shift to stay in my husband’s family it can disclose me so I cannot deny that is the reason why I brought it back.

~ Female, EAM non-user

When explaining their worries about potential unwanted disclosure, participants expressed anxiety about potential negative effects of disclosure such as fear of stigma and discrimination, family breakdown, partner violence, as well as concerns about job loss. Other participants recognized the potential for unintended disclosure, but felt the device was unlikely to do so because of its phone-like shape, black color, and lack of HIV-related labels.

Discussion

In this qualitative study, individuals living with HIV reported using an electronic adherence monitor to intentionally disclose their HIV status to others whom they would otherwise find it difficult to disclose. This disclosure enabled them to receive social support, such as getting permission to go to the clinic. Some participants reported associating the electronic monitoring component of the technology with high social status—these participants described using the technology to disclose their status in order to encourage their colleagues test for HIV. In turn these participants reported that their colleagues felt motivated to test for HIV to have the opportunity to access the prestigious technology if the test reveals HIV infection. Other participants reported intentionally using the technology in public and explaining its purpose to others to create awareness about HIV in attempt to encourage their colleagues to "learn from them and avoid HIV". These participants believed that such awareness could reduce the prevailing stigma in the community by minimizing the existing silence and denial.

For people living with HIV, disclosure, especially to others with whom they have a significant relationship, is a major challenge. The scenario of a participant who used the EAM device to disclose her status in order to get work-related social support, but worried about the possibilities of EAM-based disclosure to her husband, shows the complexity of the concept of disclosure and suggests that disclosure to one person does not necessarily mean disclosure to all. If desired, EAMs may be used to facilitate disclosure and thereby confer its benefits to a population of individuals who otherwise struggle with disclosure. As a unique appearing physical object, the EAM devices provide tangible opportunities for participants to disclose HIV status by strategically positioning or using them where they can be seen by others. Additionally, EAMs have unique characteristics that can potentially attract people's attention while at the same time creating a basis for disclosure. For example, they flash out light when sending signals, so they can easily attract other people's attention. Since they are rare devices, particularly in a resource-limited setting, those who see them often want to know more about them, which in the process creates an opportunity for wanted disclosure. These characteristics were particularly important for participants who wanted to disclose their status but lacked the confidence to do so. For these participants, the benefits of disclosing seemed to out-weigh the potential negative consequences. EAM created the basis for them to disclose in order to get social support and prevent further transmissions. This pathway to disclosure enabled them take active roles in their health.

For people who do not want to disclose their status, EAM can potentially threaten their privacy, or result in unwanted status disclosure [7, 12]. The same features that served to support disclosure for some (e.g., the flashing lights), functioned as a source of vulnerability for others. Importantly, only a small minority of participants declined to use the EAMs in the parent UARTO study (n = 5/750, 0.7%) due to fear of unwanted disclosure. We included all of these participants in our study, thus reducing the risk of bias towards an intention to disclose. For such participants, counselling sessions or other disclosure interventions could be utilized especially those that utilize behavioral theories (such as social cognitive theory [23], and consequence theory [24]) that focus on increasing disclosure self-efficacy, highlighting the benefits of disclosure, and assisting assessment of disclosure risk [25].

These interventions could be supplemented with electronic approaches to facilitate HIV status disclosure for those open to using them. Electronic approaches to disclosure can minimize the time and financial burdens that would otherwise be involved to travel to the clinic for face-to-face-based HIV disclosure interventions. This is particularly important given the socioeconomic vulnerability of most persons living with HIV/AIDS in settings like Uganda [26]. However, because EAM-facilitated disclosure may have positive or negative effects for a given individual, the role, use, and potential consequences of EAM-facilitated disclosure should be carefully discussed during adherence counseling.

For participants who are looking for opportunities to disclose their status, EAM could be one of the options that can serve both as an electronic disclosure intervention and a medication adherence monitor. Although studies utilizing electronic interventions to facilitate HIV status disclosure are uncommon, the modest number of studies that have been carried out, mainly in high income countries, report some positive benefits. For example, in North Carolina, United States, an intervention that utilized virtual reality (i.e. simulations) enabled men who have sex with men to practice disclosure using virtual characters; participants reported that the technology was easy to use, confidential, and acceptable [27]. The use of online-based HIV disclosure counselling among men who have sex with men in New York increased HIV disclosure [28]. In four cities in the Midwest and Northeast of the US, the use of photovoice (i.e. telling stories about one's HIV through photographs) facilitated HIV status disclosure even among those who would otherwise find it disturbing to disclose their status [29]. Although none of these studies utilized a technology similar to the EAMs assessed in the current study, the positive results reported suggest that electronic interventions can be innovative tools that can potentially empower individuals living with HIV/AIDS disclose their status.

Another potential benefit of EAM-enabled disclosure is its focus on the individual's choice and needs. Provider-initiated HIV disclosure and testing may be constrained by fear of stigmatizing patients [30, 31] and may infringe on patient autonomy in some contexts, which could lead to disengagement from care [32]. If desired, EAM-enabled disclosure is autonomous and may be confidential. It is important to note that the choice to use EAMs described in this analysis was made independently by the participants; the UARTO study only intended for the EAMs to monitor medication adherence. Additionally, associating this technology with high social status could minimize the shame that is often attached to living with HIV/AIDS. We found, for some participants, EAM-related disclosure was accompanied by a display of prestige, wealth, and social connectedness (e.g. to "whites in America"), potentially offsetting stigma that may have otherwise been associated with HIV.

Because EAMs utilize the existing cellular network, their application is particularly suitable in low resource settings where cellular network coverage is often widespread. EAM technologies can also be used together with other forms of mobile technologies to support HIV disclosure. For example, mobile phones can be used to send confidential and tailored disclosure-related information using voice calls, SMS texting or video/audio messages. Given the limited studies in this area, more efforts are needed to test the feasibility, acceptability and effectiveness of electronic approaches to support HIV disclosure especially in low resource settings.

This study is limited in that it reflects the views of a small number of participants in one setting and should be interpreted accordingly. We also did not collect data that relates EAM use with intentions to disclose across all participants and cannot comment on it quantitatively. Also, importantly, unintended disclosure through use of EAM can be a serious problem with resulting stigma, loss of relationships, and other hardships [7]. However, when appropriate for a given participant, the potential utility of EAM for facilitating disclosure should not be overlooked. The discovery of this finding through exploratory qualitative research speaks to the strength of this analysis. Further dedicated study of the use of EAMs for disclosure will be needed to fully understand its potential and any negative consequences.

In conclusion, our findings provide a novel understanding of how EAM fit into the lives of people living with HIV in this setting and provides insight into how participants view EAM-related disclosure. In this way, our report differs from other reports of unintended HIV status disclosure through EAM and associated negative consequences. Although researchers and clinicians need to be mindful of the potential for unintended HIV status disclosure through the use of EAM, they should also recognize the potential of this approach to support intended disclosure. The benefits of stigma reduction, increased social support, and/or HIV testing may be considerable. Overall, EAM technologies could be innovative approaches that can be used to supplement the current approaches to disclosing HIV status.

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Data Availability

Data are available upon request to the Corresponding author at amusiimenta@must.ac.ug.

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Table 1

Participant characteristics

UARTO Participants	**EAM users (n = 40)**	**EAM non-users (n = 20)**
Age in years (median [IQR])	41 [35–46]	45 [42–50]
Female (n [%])	41 [70%]	13 (65%)
Literate (n [%])		
Education level (n [%])		
Never attended school	4 [10]	2 [10%]
Primary	23 [57.5]	11 [55%]
O-level[a]	9 [22.5]	3 [15%]
A-level[a]	1 [2.5]	3 [15%]
University/vocational	3 [7.5]	1 [5%]
Post-graduate	0 [0]	0 [0%]
Socioeconomic status		
Earns a salary? (n [%])	8 [20%]	5 [25%]
Monthly salary (median [IQR]) (USD)[b]	$65 [$44–$130]	$116 [$87–$116]
Monthly non-salaried income (median [IQR]) (USD)[b]	$12 [$4–$36]	$63 [$24–$81]
Monthly household expenditures (median [IQR]) (USD)[b]	$75 [$39–$148]	$87 [$22–$171]
Time from UARTO enrollment to interview (years, mean [SD])	5.5 [2.7]	8.0 [1.1]
UARTO RA's	n = 6	
Age in years (median, [IQR])	36 [34–38]	
Female (n [%])	4 [66%]	

UARTO Uganda AIDS rural treatment outcomes study, *EAM* electronic adherence monitor, *IQR* interquartile range, *USD* United States dollar, *SD* standard deviation, *RA* research assistant

[a]In the Ugandan education system, O-Level is a four-year secondary school (often attended by 13–16 year olds). A-Level is a two-year pre-university schooling (often attended by 17–18-year olds)

[b]Monetary conversion calculated at 1 US Dollar = 3445 Ugandan Shillings (as of January 12, 2020)