

Experiences of Wisepill-facilitated HIV disclosure in rural southwestern Uganda

Emily E. Pisarski, MSc

Harvard Medical School, Boston, MA, USA

Disclosures

- No conflicts of interest to report

Background: Wisepill Device

- Real-time wireless ART adherence monitoring



Background: Wisepill Device

- High rates of device acceptability.
- Researcher and participant concerns remain about risk of HIV disclosure while using electronic adherence monitoring devices.
- We examined participant experiences and consequences of device-related disclosure.

Methods: Study Design

- Pilot randomized controlled trial in rural southwest Uganda.
- The aim was to assess the impact of SMS reminders and SMS-triggered social support on adherence, as measured through real-time electronic monitoring with Wisepill.



Mbarara, Uganda

Methods: Data Collection

- 63 participants took part in individual qualitative interviews covering:
 - Experiences with the Wisepill device
 - Acceptability and use of SMS reminders
 - Social support received

Methods: Data Analysis

- Transcribed interview data were coded using Atlas.ti software.
- Device-related HIV disclosure was identified as an emergent theme.
- Data were re-examined to understand fears, experiences, and consequences of disclosure for participants.

Findings: Demographics

	N (%) or Median (IQR)
Gender (female)	40 (65%)
Median age (years)	25 (30-35)
Education	
None	5 (8%)
Primary	36 (58%)
Greater than Primary	21 (34%)
Median CD4 count (cells/mm ³)	309 (231-397)

Findings: Outline

- The unique characteristics of the adherence monitoring device generated questions from others.
- Being asked questions about the device made participants feel at risk for HIV disclosure.
- Fearing negative consequences of device-related disclosure, participants developed strategies to avoid disclosure.
- Despite these efforts, experiences of disclosure did occur.
- Often, disclosure did not result in the anticipated negative consequences.
- Instead, it led some participants to feel that they had an expanded network of adherence support.

Questions about the Device

- The unique characteristics of the device generated questions from others.
 - Noise
 - Size and appearance
 - Lights

“...I have to visit my home in the village. When they [family members] saw it, they asked me what kind of thing it was that it was lighting that much...” Female, 33

Questions and Risk of Disclosure

- “Being seen with” and “asked questions about” the device made participants feel at risk for disclosure of HIV status.

“...The truth is that even the people that I had gone [travelled] with do not know my HIV status, so I did not want to carry a lot of drugs so that they do not get to know that I am positive. I did not want them to see the device and start asking me what it is for...” Female, 29

Anticipated Negative Consequences of Disclosure

- Participants feared device-related disclosure would result in isolation, discrimination, and gossip.

“You know people are funny. They may see you with it [the device] so they ask themselves many questions ...I don’t want people I work with to know my status because if they got to know they will discriminate against me. [They] will even not want to share anything with me.” Male, 50

Strategies to Avoid Disclosure

- Some participants went to great lengths to avoid being seen with the device.
- Strategies to avoid disclosure included:
 - Refusing to travel with the device
 - Hiding the device
 - Lying about the device's purpose

“...I was explaining to my brothers but I did not want to disclose to them...I lied to them that I was given the device because I was checked and my weight was high...” Female, 33

Experiences of Disclosure

- Despite efforts to avoid disclosure, experiences of disclosure did happen.
- Some participants used the device as a tool to initiate a conversation about HIV status.
- Often, disclosure did not result in isolation and discrimination, as feared.

Positive Consequences of Disclosure

- Device-related disclosure led some participants to feel they had an expanded network of adherence support:
 - Dosing reminders
 - Financial assistance
 - Prescription pick-up

“I told her and even showed her [the device] because I wanted her to know everything in case I was sick and ill to the extent of not moving, she can go and get it [the device] for me.” Female, 31

Conclusions:

- Although being seen with an electronic adherence monitoring device can trigger unwanted disclosure, the consequences of disclosure were positive for some participants.
- By *facilitating* disclosure, the device can increase social resources available to support overall health and ART adherence for HIV-infected individuals.

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Questions?