Experiences of Wisepill-facilitated HIV disclosure in rural southwestern Uganda

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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.
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

<table>
<thead>
<tr>
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<th>N (%) or Median (IQR)</th>
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</thead>
<tbody>
<tr>
<td>Gender (female)</td>
<td>40 (65%)</td>
</tr>
<tr>
<td>Median age (years)</td>
<td>25 (30-35)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Primary</td>
<td>36 (58%)</td>
</tr>
<tr>
<td>Greater than Primary</td>
<td>21 (34%)</td>
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<tr>
<td>Median CD4 count (cells/mm³)</td>
<td>309 (231-397)</td>
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</table>
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?