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ART adherence monitors improve adolescent-caregiver relationships

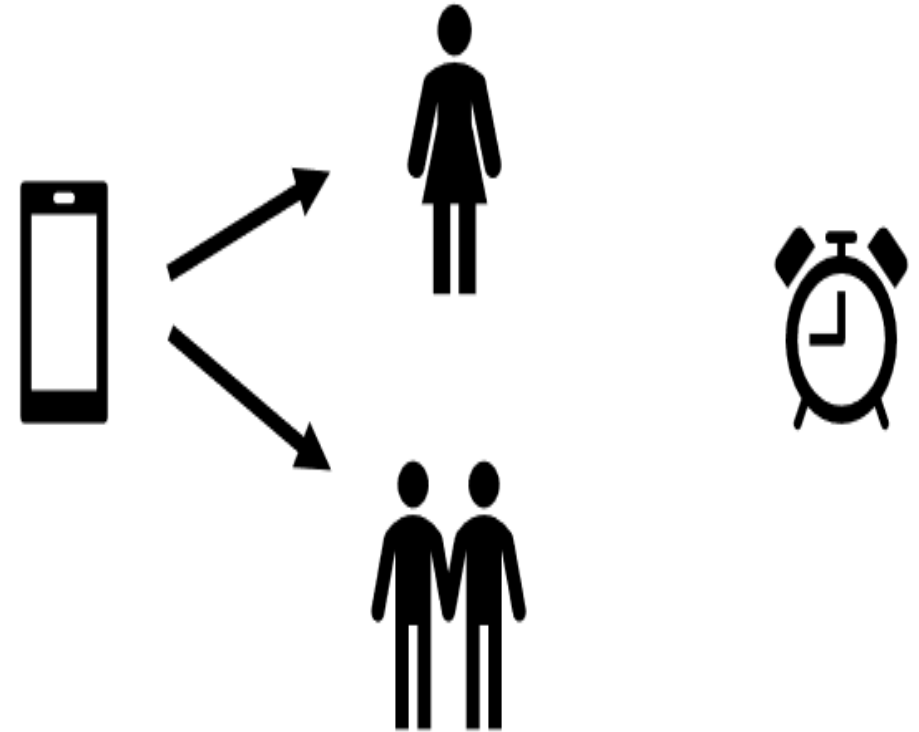
Julian Adong, Research Fellow, MUST
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Background

- About 30-70% of adolescents and young adults with HIV (AYWH) struggle with adherence compared to adults
- In 2020, AIDS was the second cause of death among AYWH in sub-Saharan Africa
- Relevant factors include forgetfulness related to their neurobiology, as well as expected prioritization of other goals
- Caregivers play an important role in AYWH adherence through reminders
- Important caregiver roles may be compromised as AYWH transition to treatment independence

mHealth and AYWH

- mHealth interventions to address adherence among AYWH are few and generally address forgetfulness
- mHealth interventions have been shown to be acceptable by AYWH, but show mixed results on efficacy
 - SMS (1-way, 2-way; Linnemayr, 2017, *AJPH*)
 - Social media (Henwood, 2016, *AIDS Care*; Dulli, 2020, *JMIR*)



The OAsIS study

Participants

- AYWH aged 15-24
- Enrolled in Mbarara, Uganda

OAsIS study procedures

- Participants were given relatively low-cost adherence monitors and/or
 - SMS self-reminders
 - SMS notifications for treatment supporter for delayed/missed dose
 - Alarm reminder



Study objective

Parent study

- Understand relevant factors for implementation of the monitors and associated interventions for routine care

Current analysis

- Explore the experiences of AYWH, their caregivers and the health care workers after use of the adherence monitors

Study methods and procedures

- We qualitatively explored experiences of AYWH-caregiver dyads
- We conducted in-depth interviews (IDIs) with 15 AYWH-Caregiver dyads post deployment and with 5 health care workers (HCWs)
- Interview questions included:
 - Like/dislikes
 - Suggested improvements
 - Experience using the monitor at home
 - Privacy/stigma concerns
 - Effect on clinical care
- IDIs were conducted until saturation was achieved

Analysis

- Qualitative data were analysed using inductive content analysis
- We identified relevant content and then formulated codes based on this content and assembled a codebook
- We developed labels to represent the concepts and wrote operational definitions
- Finally, we selected illustrative quotes from the interviews as evidence

Results:

- 15 AYWH-caregiver dyads completed interviews
- 67% of the AYWH were female
- Mean age was 16 years
- 60% lived with their biological mother
- 87% were virologically suppressed at enrolment (VL <40 copies/ml)
- Of the 15 caregivers, 93% were female, mean age was 40 years
- Of the 5 HCWs included in the analysis, 4 were female and 1 male, mean age was 36 years

Summary of content analysis

AYWH

- Improved ART self-efficacy
- Improved relationship with caregivers, HCWs
- Monitor acceptable, some privacy concerns
- Monitor dependence for two AYWH

Caregivers

- Relief of burden of reminders
- Improved relationship with AYWH

HCWs

- Targeted counseling
- Acceptable

Improved AYWH ART self-efficacy

- The adherence monitor and the associated interventions empowered the AYWH to take charge of the medication and encouraged some level of independence with ART adherence

“It became part of her instinct in that before even the alarm rang. She would feel it in her life, and she would find the alarm ringing as she went to take her drugs.” (caregiver of AYWH)

“Even when you took it away from me you might think I still have an alarm, I can swallow in real time” (AYWH, 15 years)

Improved AYWH-caregiver relationship

- The monitors relieved caregivers of the burden of reminding AYWH about medication and improved dyadic relationships

“I was not worried that she would forget to take her drugs or have the burden of having to remind her to take her drugs whenever it was time” (female caregiver)

“The time before we used to remind her that its time but when she got the monitor, she knew that it was going to remind her so which means even if I was not around, she knew what to do already (female caregiver)

Improved counselor-AYWH relationships

- AYWH with poor prior adherence had had strained relationships with the clinic counselors. With introduction of the monitors, their ART adherence improved and so did their relationships with clinic ART adherence counselors

“I reached there they saw the results and were all happy they bought me a cake and encouraged me to continue swallowing that way.”
(female AYWH, 17 years)

“They would test my viral load they would tell me that my viral load is high. I would lie to them/deceive them (counsellors) that I take my drugs well but now, you can’t lie because of the monitor data” (male AYWH, 16 years)

Rebound poor adherence after monitor withdrawal

- Two AYWH who joined the study with detectable viral load became suppressed during the study period, and later had rebound viraemia after withdrawal of the monitor.

“It affected me because the virus increased, I think it’s because of missing time. I mean that sometimes I could forget to swallow the medicine at the right time because there was no reminder to guide about the time.” (female AYWH, 16 years)

AYWH with rebound viraemia

Below is a conversation with one of the AYWH with rebound viraemia

Question from interviewer: Why do you think a person should use it (monitor) forever?

Response from AYWH: *“Because when the person has already been used to it and you take it he/she gets disorganized”.*

Question from interviewer: Do you have any example of the person who was disorganized after taking the monitor away?

Response from AYWH: *“Yes, it happened to me because I started swallowing medicine late because of lacking reminder. When I reached at the clinic, they told me that my viral load had increased.”*

Conclusions

- The ART adherence monitors and associated tools were largely acceptable to AYWH and their caregivers in home settings
- The intervention helped improve AYWH self-efficacy and alleviated burden from some AYWH-caregiver relationships
- Rebound poor adherence suggests the need for on-going support and/or other means to achieve intrinsic mechanisms for sustained adherence

Study limitations

- Short follow-up period thus inability to observe sustained effect of the monitors
- Adherence monitor data reflects pill box opening and may not reflect pill-swallowing.

Next Steps...

- We plan to use these monitors in a larger sample of AYWH to see if the reported effects are generalizable and have impact on adherence and viral suppression
- We are also testing the preliminary efficacy of social media-based mHealth interventions to improve adherence among AYWH

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Questions/comments?