Adherence misfits: Divergent perspectives on ART-defaulting among HIV-positive adolescents, caregivers and healthcare workers

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Background

Adherence to antiretroviral treatment (ART) is one of the greatest healthcare challenges facing people living with HIV. In Southern Africa, adolescents have poorer ART adherence than adults, with associated lower rates of viral suppression and immune recovery, higher rates of HIV-related morbidity and mortality, and lower costs of ART (1). Adopting a mixed-methods approach, this study investigated ART adherence among HIV-positive adolescents and explored divergent understandings of ART non-adherence, with a focus on the burden of illness and the social determinants of poor adherence. Current models of adherence mainly focus on the individual and their primary caregiver, but do not account for the role of healthcare providers and bloated clinic attendance or inpatient settings (2). This study aimed to develop a more complex understanding of ART adherence and testing among HIV-positive adolescents across a range of sub-Saharan African countries.

Methods

This descriptive qualitative study of the Mzantsi Wakho study and operational research by Partners-In-Action (PATA) is ongoing (10). Mzantsi Wakho is the largest, longest, geographically diverse sub-Saharan African study on ART adherence among adolescents aged 13–19 years. The study is a collaboration between the University of Cape Town (UCT), the University of Zambia, the University of the Witwatersrand, and the Stellenbosch University, with funding from the Nuffield Foundation, the International AIDS Consortium, and the Robert Carr Fund. This collaboration is supported by the INSTlicht/Health Systems Hub South Africa and the Robert Carr Fund.

The study was conducted through mixed-methods in-depth interviews with adolescents, caregivers, and healthcare providers. The Mzantsi Wakho study aimed to investigate the adherence to ART and HIV outcomes of 10,850 adolescents in 218 facilities in 23 countries. The study was conducted from July 2014 to August 2017, with a total of 971 interviews conducted. The study included 426 healthcare providers operating programmes in partnership with adults in southern Africa.

Results

Healthcare worker perspectives: ‘We don’t have to lose face this dialogue happens!

When asked about the concept of ‘non-adherence’ to ART, many healthcare workers acknowledged its variability for adherence among adolescent patients, who perceived a need to balance the benefits of adherence whilst living with HIV. In identifying and monitoring poor adherence to ART, terms such as ‘non-adherent’ or ‘defaulting’ were used. Healthcare providers acknowledged the complexity of engaging with adolescents on ART adherence and the social determinants of poor adherence, such as eating breakfast or brushing teeth.

Adolescent perspectives: ‘I think I am NOT!!

When asked about their own adherence to ART, adolescents typically report adhering well to ART, seeking to maintain adults’ impressions that they are adherent. They admitted that they may sometimes forget to take their medication, and they sometimes use strategies to hide their non-adherence, such as eating breakfast or brushing teeth.

Caregivers perspectives: ‘We don’t lose face!

Caregivers understood non-adherence as an act of defiance. They reported difficulty in accepting adolescents’ poor adherence to ART and their defaulting behaviour, and found little sense in engaging with them. They believed that adolescents are not motivated to take their ART and that they will default when they are feeling well.

Conclusion

ART adherence is a major issue of HIV-related mortality and morbidity among young people in Africa. Healthcare providers, adolescents, and caregivers have different perceptions of adherence to ART. This study highlights the complexity of engaging with adolescents on ART adherence and the social determinants of poor adherence. Effective interventions to support adherence among adolescents need to involve healthcare providers and caregivers as well as adolescents themselves. Healthcare providers and caregivers need to have a better understanding of the underlying social determinants of adherence to ART. Further reading:

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References: