

# ‘Children will always be children’: Exploring perceptions and experiences of HIV-positive children who may not take their treatment and why they may not tell

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HIV-positive children and young people may face substantial social barriers to maintaining appropriate levels of adherence to antiretroviral therapy (ART) during childhood and adolescence. In this paper, we focus on these children’s voices and the challenges they face growing up living with HIV in Uganda. Drawing on retrospective self-reports of 26 children living with HIV, taking ART and attending a clinic in central Uganda, we examine the reasons for non-adherence to ART among children and why they may not report when they miss their treatment. The reasons why children may not take their treatment are socially complex and similar to adult experiences and the struggles people face in adhering to life-long treatment of a condition that is stigmatised. Children are aware of the stigma that surrounds their condition and respond to adults who stress the importance of keeping their condition secret. The causes of non-adherence are not necessarily due to forgetting, but because of concerns about secrecy and children deliberately avoiding being seen taking their treatment, for example, to avoid identification. Children’s desire to maintain and protect relationships explains non-adherence as well as their failure to report it to adults. The clinical focus on exemplary adherence makes it more difficult for healthcare workers to discuss with children the social challenges that they may experience in taking treatment every day. If adults could approach non-adherence with greater empathy, recognising that children too are juggling treatment taking and social concerns then children may feel more willing to tell them about missed doses. Their poor adherence is not an inevitable element of the experience of being a child, but rather, like many adults, a substantial challenge if they are to manage their life-long treatment.

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