

# Healthcare Providers' Perspectives on Discussing HIV Status with Infected Children

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## Summary

The disclosure of HIV status to infected children has received relatively little attention to date in sub-Saharan Africa. We conducted 40 semi-structured interviews with healthcare providers working in a large paediatric HIV clinic in Cape Town, South Africa regarding attitudes and experiences around discussing HIV with infected children. Most providers felt that the optimal age for general discussions about an HIV-infected child's health should happen around age 6, but that specific discussions regarding HIV infection should be delayed to a median of 10 years. Though most providers said that primary caregivers were the most appropriate individuals to lead disclosure discussions, there were strong views that caregivers require support from healthcare providers. These findings indicate the complexities involved in the disclosure of HIV status to infected children, and point to the need for interventions to support caregivers and providers in disclosure discussions.

## Introduction

Although there are an estimated 1.6 million children living with HIV/AIDS in sub-Saharan Africa [1], issues of disclosure of HIV status to infected children has received relatively little attention to date in resource-limited settings. However with growing access to antiretroviral therapy (ART) in many African countries, HIV-infected children are surviving to older ages, and in turn discussing HIV status with infected children is likely to become an important issue in paediatric HIV care. In particular, there is evidence to suggest that an appropriate disclosure process can contribute to improved long-term health outcomes for infected children and adolescents [2, 3].

Despite the emerging significance of discussing HIV with infected children, there are few insights

into the challenges associated with disclosure. One qualitative study among 17 caregivers of HIV-infected children found that many caregivers do not tell infected children about their HIV status, and that healthcare providers may have an important role to play in this regard [4]. Another study showed that the vast majority of caregivers (96% of 174 individuals interviewed) would like support from healthcare providers working with HIV-infected children around the disclosure process [5].

Although there are few studies on this issue from sub-Saharan Africa, these findings echo the results of similar work in the United States [6], and suggest that healthcare providers may need to play a central role in supporting disclosure of HIV status to infected children. However there are few direct insights into healthcare providers' opinions on this matter, and no research specifically from sub-Saharan Africa. We investigated South African healthcare providers' perspectives on discussing HIV status with infected children.

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## Methods

The study took place in a primary care paediatric HIV clinic based in a large tertiary hospital in Cape Town. Participants were all healthcare providers working in this clinic. Semistructured interviews

were conducted by a trained interviewer and lasted approximately 45 min. These included open-ended questions with probes to explore participants' opinions, experiences and attitudes regarding paediatric HIV disclosure. All participants provided written informed consent prior to the interviews, and ethical approval for this study was provided by the Research Ethics Committee of the Stellenbosch University Faculty of Health Sciences. In analysis, quantitative data were analysed using SAS Version 9.2 (Cary, NC, USA) and responses to open-ended items were coded and analysed qualitatively using a thematic analytic approach [7].

### Results

Overall, 40 providers were interviewed: 11 doctors, 13 nurses, 9 counsellors and 7 other providers (including social workers and pharmacists). Participating providers had a median of 10 years of experience working in paediatric care, and a median of 4 years of experience working with HIV-infected children (range, 1–15).

Of those interviewed, half ( $n=20$ ) said that they had talked with a caregiver about discussing HIV with an infected child in the past, while 18% ( $n=7$ ) said they had been involved in disclosing a child's HIV status to the child. Most providers stated that the optimal age for the general discussion about a child's health should happen at age 6, with the most common reasons for this age being the emerging ability of child to understand the concept of health and disease, and/or when they start formal schooling and interacting with peers. By contrast, participants gave the age of 10 years as the best time to have specific discussions about HIV/AIDS with infected children, usually because this would be the approximate age at which they would be able to understand more complex concepts of chronic illness, or before the onset of puberty.

Three-quarters of providers ( $n=30$ ) said that caregivers themselves were the most appropriate individuals to lead disclosure discussions with infected children. However almost all participants ( $n=39$ , 98%) felt that caregivers should be supported in disclosure discussions by some type of healthcare worker – with 63% ( $n=25$ ), 43% ( $n=17$ ) and 15% ( $n=6$ ) saying that counsellors, doctors and nurses, respectively, should also be involved (participants could suggest more than one type of provider). The most commonly recommended roles for providers in disclosure discussions were to provide: appropriate biomedical information to caregivers and infected children (noted by 38% of participants); emotional support to children and/or caregivers (28%); and/or practical guidance regarding when and how to best raise this topic with children (25%). 98% of participants ( $n=39$ ) said that they felt a need for formal recommendations or guidelines to assist

caregivers and healthcare providers in their discussions of HIV disclosure to infected children.

### Discussion

These findings indicate the complexities facing healthcare providers regarding the disclosure of HIV status to infected children and their families. Interestingly, most providers we interviewed agreed that disclosure should occur as a process, with a general discussion of health and illness at an earlier age, followed by more specific discussions about HIV/AIDS when children are older. While this view of paediatric HIV disclosure as a process rather than a single event is probably the most appropriate approach [8], it poses a considerable challenge to caregivers and providers to manage the process through time.

Interestingly, the majority of the providers we interviewed felt that caregivers should be primarily responsible for managing the disclosure process but that the input of different types of providers was required – both of which appear to agree with the views of caregivers themselves from previous research in this setting. However, almost all the providers felt that recommendations or guidelines would be useful in assisting this process. To our knowledge, no support materials exist to assist the paediatric HIV disclosure process in resource-limited settings. It is possible that a simple intervention targeting healthcare providers may be useful in facilitating the disclosure process, potentially leading to improved outcomes for HIV-infected children themselves [9].

It is important to note that we interviewed a total sample of providers from one large paediatric HIV clinic, but the views and experiences of these participants are not necessarily generalisable to all settings. Further research is required into the issues of paediatric HIV disclosure, from the perspectives of caregivers, healthcare providers, and children themselves, in different countries in order to identify the range of different opinions and support needs.

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