



Paediatric HIV disclosure in South Africa – caregivers' perspectives on discussing HIV with infected children

Keymanthri Moodley, Landon Myer, Desiree Michaels, Mark Cotton

To the Editor: Most paediatric HIV infections in South Africa are transmitted perinatally. Lack of widely available HIV treatment means that most children do not survive to an age at which disclosure becomes a relevant concern. However, with the expansion of HIV treatment programmes the proportion of HIV-infected children surviving to an advanced age is likely to increase substantially during the next 5 - 10 years. A similar phenomenon was observed in Europe and North America with the advent of antiretroviral therapy (ART) in the mid-1990s, and in resource-rich settings approximately half of perinatally infected children are expected to survive beyond 13 years of age.¹

While guidelines on the discussion and disclosure of HIV infection among adult patients have received considerable attention, there are no such guidelines focusing on the disclosure of paediatric HIV infection in South Africa and other resource-limited settings. Yet in many respects disclosure and discussion of paediatric HIV infection may be more complex than with adult infection. Research from the USA and Europe has shown that when and how a parent discloses to a child can affect the provision of care for the child² and may influence the child's psychosocial adjustment and development.³ Beyond the parent-child relationship, public disclosure of a child's HIV status can have significant impact on children and families.^{4,5} Particular sensitivity is required in the case of larger families or households that include both HIV-infected and uninfected members.⁶ As HIV infection remains highly stigmatised in many communities, disclosure of paediatric HIV infection may also be accompanied by threats to the child's physical and/or psychological health.⁷

To date there has been no empirical research investigating issues of paediatric HIV disclosure in sub-Saharan Africa, although studies from other regions have suggested that caregivers may seek to balance the perceived risks and benefits of disclosure. Most commonly, this manifests in caregivers' attempts to avoid deceiving the infected child out of respect

for the child's emerging autonomy, while seeking to protect the child (and often the caregiver) from perceived emotional confusion and/or social stigma.^{8,9}

Given the complex issues involved in paediatric HIV disclosure, and the lack of insight into these issues in resource-limited settings, there is a clear need for research examining paediatric HIV disclosure in South Africa. We investigated the concerns raised by parents and caregivers when considering discussing HIV with infected children.

Methods

The study was conducted at a paediatric HIV clinic in a large urban hospital in Cape Town. The clinic receives children referred from primary care services around the city and patients from paediatric wards at the hospital. All interviews took place in a separate, private office at the clinic between April and June 2004.

A total of 174 semi-structured interviews were conducted with consecutive caregivers waiting at the clinic, representing a total sample of caregivers of children attending this service. The questionnaire was developed with inputs from health care providers working with HIV-infected children and was pilot-tested and revised. In addition to fully structured items, the final instrument contained a number of open-ended questions investigating participants' experiences or preferences. Interviews lasted approximately 25 minutes and were conducted by an experienced interviewer working in the caregiver's home language (isiXhosa, English or Afrikaans).

Data were analysed using SAS Version 9.1 (SAS Corporation, Cary, USA). Descriptive analyses employed means, medians and proportions, which were compared using Student's *t*-tests, Wilcoxon's rank-sum tests, and chi-square tests, respectively. Logistical regression models were used to examine the relationship between caregiver or child characteristics and disclosure-related outcomes after adjusting for participant demographics. All statistical tests are two-sided at $\alpha = 0.05$.

All participants provided written informed consent before data collection, and ethical approval to conduct the study was granted by the Research Ethics Committee of Stellenbosch University.

Results

The mean age of caregivers interviewed was 33 years (range 17 - 73 years). The majority (91%, $N = 158$) were female. Most caregivers were either a parent of the infected child (80%,

Bioethics Unit, Faculty of Health Sciences and Centre for Applied Ethics, Stellenbosch University, Tygerberg, W Cape

Keymanthri Moodley, MB ChB, MFamMed, MCFP (SA), MPhil, DPhil

Infectious Diseases Epidemiology Unit, School of Public Health and Family Medicine, University of Cape Town

Landon Myer, MA, MPhil, PhD

Desiree Michaels, BSocSci, MPhil (MCH), MSc (Epi)

Department of Paediatrics, Stellenbosch University, Tygerberg, W Cape

Mark Cotton, MB ChB, FCPaed (SA), MMed, DCH (SA), DTM&H, PhD

Corresponding author: K Moodley (km@sun.ac.za)



$N = 139$) or a grandparent (10%, $N = 17$), and most of those interviewed (95%) described themselves as primary caregivers of the child ($N = 165$). The 174 caregivers were accompanying 176 children who were patients at the paediatric HIV clinic. The median age of child patients was 3.3 years (range 5 months - 11 years) and most of the children (74%, $N = 131$) were younger than 6 years of age.

Of the caregivers interviewed, only 9% ($N = 16$) had discussed HIV with the infected child. The mean age of children who had been told their HIV status was 8.1 years (range 5 - 11 years). Among the 127 HIV-infected caregivers (representing 73% of the sample), those who had discussed their own infection with the child were more than 7 times more likely to have disclosed the child's status to him/her ($p = 0.07$ after adjusting for age of the child).

Caregivers gave a median age of 11 years as the best time to have a general discussion regarding the child's illness, and 12 years as the best age to tell a child about his/her HIV infection specifically. Of the caregivers interviewed 83% felt that the parent or primary caregiver would be the best person to discuss the diagnosis with the child, while 16% felt it would be best for a health care provider (doctor, nurse or counsellor) to tell the child.

When asked for reasons for disclosure, 98% of caregivers (162/165) said they felt that the child has a right to know his/her HIV status, while 90% (151/167) gave reasons related to the child's mental health. In addition, 70% of caregivers ($N = 122$) said that the availability of ART could make it necessary to discuss the child's HIV status with him/her. In discussing barriers to disclosure, most caregivers (73%) said that they were afraid of the child discussing his/her HIV infection with other people. In particular, most caregivers were concerned about the child discussing his/her infection with friends or children at school (89%, $N = 154$) and/or neighbours or in the community (59%, $N = 102$).

Most caregivers said that doctors should also be involved in disclosing HIV infection to a child.

One-quarter of the sample (44 caregivers) reported that they had discussed disclosure of the child's HIV status with a health care provider. After adjusting for the child's age, having discussed disclosure with a health care provider was associated with disclosure to the child ($p = 0.07$). Of those who had not discussed disclosure with a health care provider, 96% stated that they would like to do so.

Discussion

With most caregivers recognising both the importance of paediatric HIV disclosure and the challenges surrounding this process, these findings emphasise the complexity of discussing HIV status with infected children. In this study the low overall proportion of children who had been told their

HIV status is related to the relatively young age distribution of patients attending the paediatric clinic. However, only 26% of children older than 6 years attending the clinic knew their HIV diagnosis, suggesting that there may be substantial barriers to discussing HIV status with children in this setting.

These findings are in keeping with those of previous studies where the child's age was found to be an important predictor of whether or not disclosure had occurred.^{10,11} Even though disclosure rates appear somewhat low, there is a clear difference between the age at which disclosure actually occurs (on average 8.1 years of age in this study) and the age at which caregivers would prefer disclosure to occur (approximately 12 years of age in this study). This discrepancy requires further research attention, and if documented more generally, may warrant attention from health care providers working with infected children and their families.

Most caregivers in this study were parents who believed it was their responsibility to disclose the diagnosis to the child. Similarly, a Thai study found that 73% of caregivers believed that as parents they should disclose diagnosis to the child.¹² According to these data, caregivers saw themselves as primarily responsible for these discussions but most wanted a doctor to support them in the disclosure process. However, only 25% of the caregivers had actually discussed disclosure issues with a health care provider, and the majority who had not indicated that they would like to have this discussion. This suggests that paediatric HIV disclosure requires greater attention as part of clinical consultations in this setting.

The generalisability of these findings is limited by the young mean age of patients attending the clinic, and it will be important to monitor patterns of disclosure as an increasing number of infected children in South Africa survive for longer periods on ART. Furthermore, these findings may reflect norms and opinions among caregivers at a single urban clinic, but these issues also require examination in other parts of the country. Future research should also include both qualitative and quantitative methods to assess the effects of different disclosure styles on children of different ages and backgrounds.

In summary, this study highlights the growing importance of paediatric HIV disclosure, particularly in the context of the scale-up of HIV treatment services in many parts of South Africa. Greater attention to issues of disclosure of HIV status to infected children may contribute to the improved quality of long-term care for this vulnerable population.

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