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Permalink

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Journal

Journal of Tropical Pediatrics, 64(4)

ISSN

0142-6338

Authors

Ekstrand, Maria L

Heylen, Elsa

Mehta, Kayur

et al.

Publication Date

2018-08-01

DOI

10.1093/tropej/fmx079

Peer reviewed

Disclosure of HIV Status to Infected Children in South India: Perspectives of Caregivers

by Maria L. Ekstrand,^{1,2} Elsa Heylen,¹ Kayur Mehta,³ G. N. Sanjeeva,⁴ and Anita Shet⁵

¹Division of Prevention Science, Department of Medicine, University of California, San Francisco, CA 94158, USA

²St John's Research Institute, Bangalore, Karnataka 560034, India

³Division of Pediatric Infectious Diseases, The Hospital for Sick Children, University of Toronto, Toronto, Canada

⁴Department of Pediatrics, Indira Gandhi Institute of Child Health, Bangalore, Karnataka 560029, India

⁵International Vaccine Access Center, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA

Correspondence: Maria L. Ekstrand, Professor of Medicine, Division of Prevention Science, University of California, San Francisco, 550 16th Street, 3rd Floor, San Francisco, CA 94158-2549, USA. Tel: (415) 476-6268. Fax: (415) 476-5348. E-mail <mariaekstrand@gmail.com> or <mekstrand@gmail.com>

ABSTRACT

This study was designed to examine the rates of HIV serostatus disclosure in a sample of HIV-infected children in the state of Karnataka in South India, their reactions to learning their HIV-positive status and the reasons for and barriers to disclosure from the point of view of their caregivers. We enrolled 233 HIV-infected children, aged 5–18 years and their caregivers between July 2011 and February 2013 at HIV clinics in three tertiary care centers. Caregiver interviews included information about demographic characteristics, medical history, type of disclosure to the child and other related factors, including disclosure barriers. Three quarters ($n = 185$) of the caregivers reported that there had been no disclosure to the child, 15.4% ($n = 38$) reported partial disclosure (e.g. telling the child he or she had a 'chronic illness') and only 9.7% ($n = 24$) reported full disclosure, at a mean age of 10.9 (SD: 2.5) years. Caregivers, who planned to disclose in the future, stated on average that 16 years would be the right age. Those who favored a later disclosure reported that they feared strong negative emotional reactions from the child ($p = 0.03$) and social isolation ($p < 0.001$) following disclosure. These results show that the level of full disclosure is low among South Indian youth living with HIV, and that when disclosure occurs, it is most likely to be partial. The majority of children who learned their status had been informed by a health-care provider, possibly reflecting the difficulty for a caregiver of having this conversation. The caregivers reported multiple disadvantages of disclosure, mostly because of fears of stigma and discrimination. Despite some evidence from the literature that disclosure can have positive effects on a child's health, it is thus clear that we need to develop, implement and evaluate community-based stigma reduction programs to reduce the social barriers to disclosure.

KEYWORDS: HIV, pediatric disclosure, India, caregivers, stigma

INTRODUCTION

Informing HIV-infected children of their status is an important component of their care, especially as they approach adolescence and assume increased responsibility for their health and adherence to their HIV-related medical regimen [1, 2]. The World Health Organization (WHO) [3] and India's National AIDS Control Organization (NACO) both recommend disclosure to pediatric patients in a developmentally appropriate and culturally sensitive manner, with WHO recommending that this should occur with 'school-aged children'. Most studies on this practice and its effects in resource-limited settings appear to have been conducted in Africa [2, 4, 5], and little data have been reported from India or other Asian countries. We found only two Indian quantitative studies on pediatric disclosure, both from northern India, which showed that only 14% [6] and 41% [7] of HIV+ children in their samples knew they had HIV. Caregivers in those studies stated that they thought disclosure should happen when the children were in their mid-teens primarily to facilitate adherence, improve treatment and enable the child to protect himself or herself. At the same time, many expressed fear that the child would tell others, and that as a result would experience stigma and discrimination. These fears and perceptions are similar to those expressed in other global settings [2, 4, 8].

More recently, a qualitative study of 33 families was conducted by a non-governmental organization (NGO) in Mumbai to evaluate their HIV disclosure protocol [9]. Their home-based disclosure program was initiated when the child was between 11 and 15 years of age and supported by a counselor and social worker in a graded process. Interviews with both parents and children suggested that this program led to a reduction of stress and improved family relationships. However, while these results were promising, the program was not tested in a controlled study, preventing any conclusions about efficacy.

The current study was designed to update and extend the existing pediatric disclosure knowledge base to southern India, by examining the rates of disclosure in a sample of HIV-infected children in the state of Karnataka, their reactions to learning their HIV-positive status and the reasons for and barriers to disclosure from the point of view of their caregivers. Previous

analyses have described the perspectives of the children in this sample [10]. The present article will report on these factors from the perspective of the caregivers.

METHODS

Caregivers of 247 HIV-infected children, aged 2.5–18 years, were interviewed between July 2011 and February 2013 at HIV clinics in three tertiary care centers in Karnataka State, India, as part of a study on caregiver adherence to antiretroviral therapy (ART) regimen. For the disclosure analyses, only caregivers of school-aged children (5–18 years) were included, which reduced the sample size in this manuscript to 233. The recruitment sites included St. John's Medical College Hospital, Bangalore, Indira Gandhi Institute of Child Health, Bangalore and Krishna Rajendra Hospital, Mysore. All staff members were certified in the protection of human research participants and administered informed consent to interested caregivers, following referrals by ART clinic counselors. The structured pen and paper questionnaire was administered by trained study staff in a private setting to ensure confidentiality. Data were double-entered and verified before upload on a shared, password-protected server. The questionnaire assessed the following variables:

Demographic information, including child's age, gender and caregiver's relation to child.

Medical history, including parents' and siblings' HIV and vital status, child's ART regimen and clinical stage using medical chart review.

Disclosure, each child's disclosure status was assessed and classified as full disclosure (stating HIV), partial (stating chronic illness only) or no disclosure to the child of his/her HIV status.

Disclosure-related factors were also examined. In case of full disclosure, follow-up questions included who disclosed, at what age and how many times. If partial or no disclosure (see above) was reported, caregivers were asked about future disclosure plans, and answered 'yes' or 'no' to a list of perceived advantages and disadvantages of disclosure.

Data Analyses, *Data Analyses*, frequencies and means with SDs were calculated for the whole sample and by disclosure status. Comparisons between

disclosure groups were done via chi-square tests. In the case of a significant chi-square value ($p < 0.05$), residuals in the cells of the cross-tabulation were examined to interpret the specific nature of the association between disclosure and the characteristic in question: an adjusted standardized residual over 1.96 in a given cell was taken as evidence that the subgroup with that particular combination of disclosure status and value for the other variable occurred more frequently than expected by chance (at $p < 0.05$). Analyses were performed in SPSS (version 18), and p -values reported are two-sided.

All caregiver participants provided written consent. The study received clearance from the institutional review boards at St John's National Academy of Health Sciences and the University of California, San Francisco.

RESULTS

Chart reviews showed that the vast majority (88%, $n = 206/233$) of the children were infected perinatally. An additional four children were infected via blood transfusions and one child via a needle stick. The remaining 9% ($n = 22/233$) were unknown. Nearly three quarters ($n = 171/233$) of the caregivers reported that there had been no disclosure to the child, 16.3% ($n = 38/233$) reported partial disclosure and only 10.3% ($n = 24/233$) reported full disclosure. A majority of the 24 children, who had been told they were HIV positive, had received this information from a physician or counselor alone ($n = 14/24$, 58.3%) or physician/counselor plus a parent ($n = 4/24$, 16.7%). In 3 of the 24 cases (12.5%), parents had disclosed on their own, and the remaining 3 children (12.5%) had found out in other ways. Most (19/24, 79.2%) of these children had been told at least twice. The 24 children were between 4 and 15 years old when they were told that they were HIV-infected, with the mean (SD) age at time of full disclosure being 10.9 (2.5).

As shown in Table 1, only 4% of the children <10 years of age had received full or partial disclosure compared with 44% of children more than or equal to 10 years of age ($\chi^2_{(2)} = 47.494, p < 0.001$). Of those more than or equal to 12 years of age, 54% had received either partial ($n = 26/91$) or full ($n = 23/91$) disclosure. Caregivers with >12 years of education were more likely to have partially disclosed than

were those with less education ($\chi^2_{(2)} = 7.461, p = 0.024$), but none of the more highly educated caregivers had fully disclosed. Single or double orphans were more likely to have been at least partially disclosed to than children whose parents were still alive ($\chi^2_{(2)} = 7.893, p = 0.019$), while the presence of HIV-infected siblings was significantly associated with full disclosure ($\chi^2_{(2)} = 7.191, p = 0.027$).

In total, 80% of the caregivers who had not yet fully disclosed ($n = 167/209$) planned to do so in the future, stating, on average, that 16 years (SD = 2.9; range 8–25) would be the right age. A comparison of those who intended and did not intend future disclosure showed (Table 2) that the two groups did not significantly differ in terms of endorsement of perceived disadvantages of disclosure. Perceived advantages of disclosure did vary by disclosure intent. Those who intended to disclose were significantly more likely to see disclosure as a way to enable the child to prevent transmission compared with caregivers who did not intend to disclose ($\chi^2_{(1)} = 8.721, p = 0.003$).

We also compared the perceived advantages and disadvantages of disclosure among caregivers who thought the best age to disclose was when the child was >16 years vs. those who thought it preferable to disclose at a younger age. More caregivers favoring later, rather than earlier, disclosure reported that they feared strong negative emotional reactions from the child ($\chi^2_{(1)} = 4.718, p = 0.030$) and social isolation ($\chi^2_{(1)} = 16.554, p < 0.001$) and fewer such caregivers saw the risk of the child disclosing to others as a disadvantage ($\chi^2_{(1)} = 5.099, p = 0.024$). The two groups did not differ in perceived advantages of disclosure.

DISCUSSION

Based on the reports by their caregivers, the level of full HIV status disclosure is low among these South Indian youth living with HIV, and when disclosure occurs, it is more likely to be partial. Similar to the reports from north India and Sub-Saharan Africa, the results show that both full and partial disclosures were more likely to occur with older children, those with more highly educated caregivers and children who had lost a parent or had an HIV-infected sibling [6, 7].

Table 1. Correlates of disclosure n (row %)

Characteristic	No disclosure (n = 171)	Partial disclosure (n = 38)	Full disclosure (n = 24)	χ^2 -value (df = 2)	p-value
Gender				2.309	0.315
Male	94 (70.1)	26 (19.4)	14 (10.4)		
Female	77 (77.8)	12 (12.1)	10 (10.1)		
Age of child at caregiver interview (median split)				47.494	<0.001
<10 years	97 (96.0)	4 (4.0)	0		
≥10 years	74 (56.1)	34 (25.8)	24 (18.2)		
On ART				3.700	0.157
Yes	109 (70.3)	26 (16.8)	20 (12.9)		
No	62 (79.5)	12 (15.4)	4 (5.1)		
Worst clinical stage				4.865	0.088
I or II	105 (70.9)	30 (20.3)	13 (8.8)		
III or IV	63 (76.8)	8 (9.8)	11 (13.4)		
Caregiver years education				7.461	0.024
≤12 years	162 (74.7)	32 (14.7)	23 (10.6)		
>12 years	9 (60.0)	6 (40.0)	0		
Parent(s) deceased				7.893	0.019
Yes	80 (68.4)	23 (19.7)	14 (12.0)		
No	87 (84.5)	9 (8.7)	7 (6.8)		
Any HIV+ siblings				7.191	0.027
Yes	20 (74.1)	1 (3.7)	6 (22.2)		
No/unknown	151 (73.3)	37 (18.0)	18 (8.7)		

Table 2. Advantages and disadvantages of disclosure by intention of future disclosure n (%)

	Disclosure not intended (n = 42)	Disclosure intended (n = 167)	χ^2 -value (df = 1)	p-value
What are the advantages of telling (child) about his/her status?				
Take better care of health	36 (92.3)	161 (96.4)	1.272	0.259
Prevent transmission	30 (76.9)	155 (92.8)	8.721	0.003
What are the disadvantages of telling (child) about his/her status?				
Disclosure to others	11 (26.2)	46 (27.5)	0.031	0.860
Will not understand	15 (35.7)	49 (29.3)	0.642	0.423
Become distressed/suicidal	25 (59.5)	99 (59.3)	0.001	0.977
Blame parents	20 (47.6)	91 (54.5)	0.636	0.425
Face stigma/isolation	22 (59.5)	78 (52.7)	0.544	0.461

Most caregivers in our study reported that disclosure happened repeatedly. This fits with the NACO and WHO guidelines [1, 3], which emphasize that disclosure needs to be an ongoing, gradual process, taking into consideration the cultural context, the child's age, maturity levels and emotional health. Only three caregivers in this sample reported that they had fully disclosed the child's status by themselves, while an additional four reported that they had done so together with a physician or counselor, likely reflecting the difficulty of having this conversation. In contrast, most children (58%), who learned about their status, received this information from health-care personnel in the absence of their caregivers. Given the different caregiver preferences, it might be helpful for clinics to develop flexible protocols for handling disclosure in a way that ensures that it is done in a collaborative manner that is respectful of both the needs of the families and the rights of the children. Perhaps, such programs can emphasize disclosure as a way of empowering one's children to take care of themselves and prevent transmission to others, which were views expressed by caregivers in this sample who planned to disclose to their child.

Consistent with the existing disclosure literature [2, 4, 8, 11], caregivers reported multiple disadvantages of disclosure, including fears that their child would tell others about his/her infection, or that the child would not understand what it meant or that disclosure would lead to distress, mostly because of stigma and discrimination. These concerns were expressed both by caregivers who planned and who did not plan to disclose. Despite some evidence from the literature discussed earlier [9] that disclosure can have positive effects on a child's health, it is thus clear from the interviews with caregivers that stigma remains a significant barrier and that there is a great deal of fear of discrimination in this context. Unfortunately, our research on HIV stigma suggests that such fears might be warranted and that stigma and discrimination are prevalent in families, communities and health-care facilities [12–14].

While this study provides important new information about factors involved in caregiver disclosure of HIV infection to their children, it also has two important limitations that need to be considered when interpreting the data. First, recruitment was

limited to only two ART clinics in one Indian state, which precludes generalization of the results to other regions in India. Second, this was a cross-sectional study, which prevents us from attributing causality to any disclosure correlated.

The late Jonathan Mann, former head of the WHO's Global Program on AIDS, referred to stigma as 'the third epidemic', following the rapid spread of HIV transmission and the increased number of people diagnosed with AIDS [15]. He considered addressing these three epidemics to be key to preventing HIV transmission and reducing the impact of the disease. Similarly, Peter Piot [16], former Executive Director of UNAIDS, identified the targeting of enacted stigma as one of five key components for success in the fight against HIV. In addition to targeting stigma in health-care settings [17], we urgently need to develop, implement and evaluate community-based stigma reduction programs to reduce the social barriers to disclosure. Only a focused, multilevel effort, targeting individuals, families, communities and institutions is likely to lead to a substantial and sustained impact on stigma and discrimination, thus reducing the barriers to both HIV prevention and treatment.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the staff at Indira Gandhi Institute of Child Health, Bangalore and the ART Centre, St. John's Medical College Hospital for referring the study participants as well as the Prerana study staff for assisting with interviews and data entry.

FUNDING

This research was supported by grant awards R01MH067513 and R01 MH095659 to MLE from the National Institute of Mental Health (NIMH), Bethesda, MD, USA and by the Wellcome Trust-Department of Biotechnology India Alliance Senior Fellowship awarded to AS [IA/S/13/2/50101].

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