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Perspectives on disclosure among children living with HIV in India

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1. Introduction

The advent of combination anti-retroviral treatment (ART), better healthcare delivery systems and wider access to ART, has ushered in an era of increased survival for children living with HIV (World Health Organization, 2011). Lifespans of people living with HIV now have been estimated to be almost equal to the general population (Broder, 2010). From the pediatric perspective, the prospect of a longer life span brings forth new issues related to the impact of HIV infection on the normative developmental processes such as growth, peer relationships, puberty, and sexuality. One of the greatest challenges is that of disclosure to the child of their own seropositive status by their parents or caregivers (Wiener et al, 2007). Disclosure in children is generally considered to have occurred when the HIV status of the child has been divulged to him or her. (World Health Organization, 2011). Disclosure of the HIV status entails communication about a potentially life-threatening, stigmatized, and transmissible illness, and can pose challenges ranging from ensuring appropriate understanding and internalization of the diagnosis, maintenance of adherence, sustenance of familial and community relationships, and long-term disease management. Guidelines for disclosure of HIV status were first put into place by the American Academy of Pediatrics in 1999, that stated that all adolescents should know their HIV status and that disclosure should be considered for school-age children (American Academy of Pediatrics Committee on Pediatrics AIDS, 1999). In recognition of the health benefits of disclosure even in younger

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children, and little evidence of psychological or emotional harm from HIV disclosure, the World Health Organization (WHO) in 2011 published guidelines on HIV disclosure counseling for children up to 12 years of age (World Health Organization, 2011). In India, the National AIDS Control Organization (NACO), in its guidelines for care and treatment of pediatric HIV recommends that disclosure should take into consideration the child's maturity levels, ability to cope with the information as well as the family dynamics (National AIDS Control Organization, 2013).

Several studies and reviews have addressed the delicate issue of disclosure of HIV status to an affected child. However, it is important to note that a potential major factor confounding results in studies assessing disclosure is social desirability bias. Social desirability bias is the tendency of respondents to answer questions in a manner that would be viewed favorably by others. It can take the form of over-reporting ‘good behavior’ or under-reporting ‘bad’ or undesirable behavior (World Health Organization, 2003). An analysis of the impact of this response bias would be critical in comprehending the true perspectives and experiences following the disclosure of HIV status. To the best of our knowledge, no studies describing the process of disclosure of HIV status to children have evaluated the effects of this important confounder on children's responses.

Recent reviews from low and middle income countries (LMICs) have suggested that rates of disclosure are low (Pinzón-Iregui, Beck-Sagué, & Malow, 2013; Britto et al., 2016). Data about the rates of disclosure among children living with HIV in India are scanty. We undertook this study to assess the rate of disclosure, understand the experiences following disclosure of HIV status and study the impact of social desirability bias amongst Indian children living with HIV.

2. Methods

2.1 Study population and sites

This was a questionnaire-based cross-sectional study. HIV-infected children younger than 18 years and their caregivers attending the ART centers at two institutions in south India; St. John's Medical College Hospital in Bangalore, and Indira Gandhi Institute of Child Health in Bangalore, were invited to participate in this study between October 2011 and March 2013.

2.2 Data collection

After informed consent, caregivers who reported that their children knew their HIV status were asked for permission to interview the children. These children were administered a structured questionnaire. The questionnaire was derived from published pediatric disclosure literature and was pilot tested on four children by two different researchers. Following their feedback, the modified questionnaire was confirmed as ready to be used in the study.

To encourage unbiased reporting by caregivers and children, the interviews were conducted by trained non-medical personnel who were not associated with their medical care. Participants were assured of confidentiality, and caregivers were assured that their children's present disclosure status would be maintained. Following assent, those children whose caregivers reported to have had disclosure were further administered the questionnaire assessing their knowledge about HIV, ART, perceptions following disclosure, stigma and ideas about their future. In some of the sections of the questionnaire, (knowledge about HIV and ART, and perceptions following disclosure) children were allowed to select multiple options. There was a single open-ended question about what the child desired to become when he or she grew up, all other questions were close-ended.

2.3 Assessment of social desirability

We adapted a modified 12-item childhood social desirability (CSD) questionnaire based on the original Marlowe-Crowe social desirability scale (Marlowe & Crowne, 1961), which has also been previously modified (Baxter et al., 2004; Centers for Disease Control and Prevention, 2003) to assess the tendency of social desirability bias in the childrens' responses. The children who scored ≥75% on modified social desirability scale were deemed as having responded in a socially desirable manner, and the children's responses to disclosure questionnaire were interpreted with consideration of the degree of social desirability bias.

2.4 Ethical considerations

Ethical clearance was obtained from the respective Institutional Ethical Review Boards at each institution. Written informed consent was taken from the parents or legal guardians willing to participate in the study, and assent was obtained from the children prior to their interviews at each institution. All patients were given standard clinical care and counseling as per the existing national guidelines (National AIDS Control Organization, 2013).

2.5 Definitions

Disclosure was considered to have occurred when the caregiver reported that the child had been informed about his or her own HIV status. It did not involve the disclosure of the child's status to others. (Wiener et al., 2007)

2.6 Statistical Analysis

Descriptive statistics consisted of frequency tabulations for categorical variables, and means and standard deviations (SD) for continuous variables. The frequencies of responses given by the disclosed children were tabulated and analyzed. The t-test was used to analyze the impact of social desirability bias on the children's responses.

3. Results

3.1 Demographical and clinical data

Twenty-four caregiver-child dyads participated in this sub-study. The subset constituted children who had been told of their HIV diagnosis from a larger study of 247 dyads. (Mehta et al., 2016) Of these 247 dyads, only 24 (9.7%) caregivers reported that their child had experienced HIV disclosure. The mean age of these children was 14.0 ± 1.8 years (range 10-18 years); and 14 (58.3%) were males. A parent was the primary caregiver in 16 of the cases, and in the case of 17 children, both parents were also HIV infected. Three of the children were orphans, and over 50% had lost at least one parent. Mean CD4 count was

654.95 ± 465.26 cells/mm^3, and almost half (11/24) of the children had clinical stage 3 or 4 as their highest treatment stage. Among these 24 children, 20 (83.3%) were on ART, and 15 of these children had undetectable viral loads, while five were in virological failure. (Table 1)

3.2 Details about disclosure

The mean age at disclosure was 10.9 ± 2.5 years. Among five (21%) children, the disclosure took place in a single sitting, while in the remaining 19 (79%) of the children, the topic was discussed more than once, and in steps, culminating in full disclosure of status. Fourteen children (58.3%) were disclosed to by medical personnel only, while parents or caregivers alone were involved in the disclosure process in three (12.5%) cases. In four (16.7%) instances, parents or caregivers disclosed to their children in the presence of medical personnel. Among the remaining three (12.5%) children, disclosure took place by a relative other than the primary caregiver (Table 1). In a total of 21 (87.5%) instances, there was subsequent disclosure of the child's status to others, generally other members of the family, and rarely to the child's teachers or friends.

3.3 Knowledge about HIV following disclosure

In this section exploring HIV knowledge, specific options were presented, and children were allowed to select multiple options. When asked what they knew about HIV, eight children (33%) mentioned that HIV was an infection, and nine (37.5%) mentioned that HIV was a germ that could make the body weak. However, nine (37.5%) children were unable to explain what they knew about HIV. While 19 (79%) children were correctly aware of their parental HIV status, one responded incorrectly that parents were not infected, and four (16%) children mentioned that they were unaware of their parents' HIV status. When asked about how HIV spreads, 17 (71%) children thought this was through blood or unsafe needles, nine children (37%) were aware that it could spread sexually, and eight children (33%) were aware that HIV could be transmitted from parent to child. However, five children (21%) did not know how HIV could spread. Fourteen children (58%) knew that infection with HIV could be prevented by testing blood prior to transfusion, 11 (46%) by using safe needles, while seven children (29%) reported that it could be prevented by safe sex. Three children (12.5%) were unaware of how infection with HIV could be prevented.

3.4 Knowledge about antiretroviral therapy

Among the 24 disclosed children, 20 (83%) were on ART. When asked why they needed to take ART, 10 children (50%) mentioned that they need to do so because they had HIV, while eight (40%) stated that ART was needed to maintain good health for their ‘sickness’. Thirteen children (65%) were aware that they needed to take ART lifelong. All except one child on ART mentioned that they were able to take ART without any problem, and three-fourths of the children on ART mentioned that they were able to take ART by themselves without any problem. Fourteen children (70%) were aware that it was dangerous to miss even a single dose of ART.

3.5 Perceptions and stigma

When asked about their reactions following disclosure, 16 children (67%) revealed that they felt upset upon hearing about their HIV status. Five children each (21%) said that they felt angry and sad, while six (25%) “felt nothing”. Four children mentioned that they were relieved to finally find out what was wrong. Almost all (23 of the 24) children did not feel that they were treated differently by their family members because they had HIV, and over 75% did not feel that they were treated differently by their friends/classmates or teachers. However, over 50% (11/20) of the children on ART mentioned that they needed to hide taking their ART medicines, and 25% of the children did feel that they were avoided by the community. When asked about what they felt was the hardest thing about living with HIV, nine children (37%) mentioned ‘taking medicines daily’, while four (16%) mentioned ‘getting sick frequently’. However, seven children (29%) felt that nothing was hard for them and that they could deal with the difficulties HIV would have to offer.

3.6 Academic impact

Among the 24 disclosed children, 20 (83.3%) mentioned that they currently went to school, the remaining four had dropped out of formal schooling and were home schooled. All these children mentioned that they had many friends despite their illness. Over 75% of these children felt that they could do well in school despite their illness, and did not feel that their grades had suffered because of their illness. However, the main complaint of 14 (70%) of these children was that they needed to miss school often (on an average of 1-2 days a month; for clinic visits and minor infections) as a result of their illness.

3.7 Ideas for their future

Over 75% off the children mentioned that they did not feel lost or hopeless because of their illness, and more than half the children agreed that they could grow up and have their own family. Some intended to join the medical profession, while others planned to become engineers, lawyers, and teachers or join the military or administrative services.

3.8 Childhood Social Desirability scale and the role of social desirability bias

We found that only five out of the 22 children (22.7%) who answered the CSD questionnaire had scored ≥75% on the social desirability scale. Furthermore, as shown in Table 2, an examination of responses on HIV and disclosure-related questions that seemed most prone to social desirability bias, showed that there was no difference in mean social desirability score between those children who gave what would be considered socially desirable responses versus those who gave other responses to questions related to their HIV positive status, suggesting that social desirability was not significantly associated with the children's answers ($p>0.05$) (Table 2).

4. Discussion

Our study showed that rates of disclosure in these settings continue to remain very low, and that medical personnel had a major role in the process of disclosure to children. Among the disclosed children, most seemed comfortable to learn about their status, received support from their immediate family, exhibited a positive outlook towards their future, and tended to experience the perceived ‘benefits’ of disclosure of status. However, over a third of the disclosed children were unaware of key aspects of HIV, including a basic idea of what HIV was, the mode of spread and prevention, and the requirement of lifelong ART. This indicates a significant gap in the disclosure process and outcomes.

Disclosure of HIV status to an individual involves informing the individual about a potentially life-threatening and transmissible illness associated with significant social stigma. It is usually approached with much anxiety and fear of negative consequences, notably stigmatization and discrimination, and is often avoided altogether in several settings, especially in LMICs (Pinzón-Iregui et al., 2013). The disclosure of diagnosis to children, in particular, has been shown to be dependent on the growing child's cognitive abilities as well as attitudes and goals of the caregiver towards disclosure (Chaudoir, Fisher, & Simoni, 2011). Caregivers' concerns towards non-disclosure stem from its potential negative impact, including fear of negative psychological reactions among the children, and fear of subsequent disclosure to others, leading to stigmatization and further discrimination (Britto et al., 2016; Pinzón-Iregui et al., 2013). However, several clinical reports have indicated positive outcomes associated with disclosure including the promotion of trust, improved adherence, enhanced access to support services, open family communication and better long-term health and emotional well-being in children (Wiener et al., 2007; Lipson, 1994; Funck-Brentano, 1995; Mellins & Brackis-Cott, 2002). The benefits of disclosure seem quite tangible in our study with most children exhibiting a positive outlook towards their future following disclosure. Guidelines about pediatric HIV in India put forth by the National AIDS Control Organization (National AIDS Control Organization, 2013) recommend that children should be informed about the nature of their illness on the premise that knowing one's HIV status would be likely to encourage adherence to treatment. In our study of disclosed children, notwithstanding the small numbers, we found that all the children had optimal adherence. Such evidence should serve to motivate caregivers and health care providers towards disclosure to their children.

This is one of the first studies in the region to assess the quality of the child's knowledge about HIV and ART following disclosure. Our study found that several of the children had gaps in their knowledge of HIV, particularly regarding prevention and treatment. These lacunae in knowledge could potentiate risky behavior and sustain HIV transmission in the community. Such findings underscore the urgent need to review the quality of information passed on during the process of disclosure to such children. Further, we found that parents and caregivers in this study seemed to be quite dependent on medical personnel for the process of disclosure. This may reflect the somewhat more paternalistic role played by medical personnel in some cultural settings (Britto et al., 2016). Future guidelines will need to delve deeper into the specific details of what information would qualify as ‘disclosure’ and address the need for support from medical personnel during the process of disclosure.

The construct of social desirability was developed to help explain the tendency to give overly positive self-descriptions in social science research, since this behavior could potentially distort the responses given by individuals. An early and useful tool developed to measure this phenomenon is the Marlowe-Crowne Social Desirability scale (MCSD) (Marlowe & Crowne, 1961).We adapted a version of this scale to study the potential impact of social desirability bias on the responses given by the participants of our study. We found that social desirability bias did not play a role in these children's answers. Future studies of disclosure among children living with HIV could be strengthened by incorporating similar assessments of the relationship of social desirability bias on the children's responses.

While this study is strengthened by the use of the social desirability scale, it does have certain important limitations. The sample yielded only 24 children who were disclosed to, limiting the power of the study. Further, the study was restricted to only two centers in one state of south India, and since factors associated with disclosure are usually contextual, this precludes generalization of the results to other regions in India. A larger multi-site study would likely yield data more representative for India. The instrument was adapted from questionnaires used in other disclosure studies, reviewed by experts and pilot tested on a small number of subjects, but was not extensively tested for reliability and validity before using it in this study.

5. Conclusions

Disclosure rates among children living with HIV in India continue to remain low. Most of the disclosed children in this study were comfortable to learn about their status, received good support from their immediate family and community and exhibited a positive outlook towards their future. Incorporating disclosure into the care process for older children is likely to be beneficial. The knowledge about HIV despite disclosure was found to be inadequate, and parents depended on medical personnel for disclosure. Additional studies using a longitudinal cohort design to prospectively examine disclosure and its potential effects on adherence and psychological well-being among children and adolescents, and qualitative research to examine this complex issue in different cultural contexts would be potential avenues of study in order to understand these preliminary findings and advance the field.

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Highlights

- Children living with HIV in India exhibited low rates of disclosure of HIV status.
- Disclosure was done mostly by medical personnel, rather than primary caregivers.
- Most disclosed children exhibited a positive outlook about their future.
- Knowledge about HIV despite disclosure was inadequate.

Table 1

Demographic and clinical details of children with disclosure of their HIV status (n=24): n (%)

Mean age (years ± SD)	14.0 ± 1.8 (Range 10-18)
Female	10 (41.7)
Anthropometry	
Mean BMI (kg/m^2 ± SD)	16.48 ± 2.40
Family details	
Primary caregiver	
Mother/Father	16 (66.7)
Grandmother	4 (16.7)
Aunt	2 (8.3)
Other	2 (8.3)
Caregiver education > 8 years	11 (45.8)
Parental HIV status	
Father positive	18 (75)
Mother positive	18 (75)
Both parents positive	17 (70.8)
HIV-positive siblings	6 (25)
Parental death	
Father deceased	12 (50)
Mother deceased	5 (20.8)
Both parents deceased	3 (12.5)
Disclosure details	
Who disclosed	
Counselor/physician	14 (58.3)
Parents/caregivers	3 (12.5)
Parents/caregivers & counselor/physician	4 (16.7)
Others	3 (12.5)
Clinical correlates	
Highest WHO clinical stage	
1	3 (12.5)
2	10 (41.7)
3	8 (33.3)
4	3 (12.5)
Mean CD4 count (cells/mm^3 ± SD)[†]	654.95 ± 465.26
On ART	20 (83.3)
ART regimen (n=20)	
Zidovudine-based	9 (45)

Stavudine-based	10 (50)
Other	1 (5)
Optimal adherence to ART (≥95%)	20 (100)
Viral load undetectable [*]	15 (62.5)

[*] 4 of the 9 children who had detectable viral load did not qualify for ART based on existing national treatment guidelines. The remaining 5 children on ART were referred for second-line ART.

[†] Normal CD4 counts in children are age dependent. The range for these are available in the consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection published by the World Health Organization. (World Health Organization, 2016)

SD: Standard deviation

Table 2

Mean CSD score (range 0-12) by social desirability of response to the following HIV or disclosure related questionnaire items

Item	**Socially desirable response**[a]	**Non-socially desirable response**	**p-value**[b]
I often need reminder to take ART	(n=13) 7.3	(n=5) 6.8	0.52
Felt upset when learned HIV status	(n=7) 7.0	(n=15) 7.2	0.82
Hardest thing about being HIV+: nothing	(n=7) 7.4	(n=14) 6.8	0.56
Felt nothing when learned HIV status	(n=5) 7.2	(n=17) 7.1	0.94
Does well in school, despite illness	(n=14) 7.4	(n=4) 7.5	0.92

CSD, Childhood Social Desirability

[a] Socially desirable response is negative response to first two items and positive response to last three items.

[b] based on t-test, to distinguish if children with socially desirable response on average scored significantly higher or lower on the CSD scale than children with non-socially desirable response.