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HHS Public Access
Author manuscript
*Child Care Health Dev*. Author manuscript; available in PMC 2016 July 01.

Published in final edited form as:
*Child Care Health Dev*. 2016 July ; 42(4): 553–564. doi:10.1111/cch.12338.

# Issues around childhood disclosure of HIV status – findings from a qualitative study in West Bengal, India

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## Abstract

**Introduction—**Informing the children living with HIV (CLH) about their disease (disclosure) is important from the perspective of disease treatment and overall psychosocial development. There are no published studies that qualitatively explored HIV disclosure-related issues among CLH in India. Our aim was to provide insights into the perceptions of informal caregivers of CLH regarding childhood disclosure.

**Methods—**Children were defined as those aged <16 years. In-depth interviews were conducted with 34 primary caregivers of CLH aged 8 to 15 years old who were residing in West Bengal, India. The participants were recruited with the help of a community-based organization that provides need-based services to people living with HIV.

**Results—**We obtained caregivers' perspectives on the motivators and barriers of childhood disclosure. Health benefits such as medication adherence emerged as an important motivator, while distress caused by disclosure and potential for stigma were identified as barriers. Health care providers were the preferred disclosers for most caregivers, followed by the caregivers themselves. Some caregivers wanted their child to learn about his/her HIV status by him/herself. There was no consensus among the caregivers about the ideal age for disclosure. Many preferred to wait until the child attained maturity or was of marriageable age.

**Discussion—**Disclosure of HIV status to children is an emotional issue, both for the caregiver and the child. Like most low-or middle-income countries, no standardized, age-appropriate disclosure guidelines exist in India. Our findings advocate adoption of a multi-faceted approach, including increased availability of social and familial support, for childhood HIV disclosure.

### Keywords

disclosure; discrimination; HIV; psychosocial development; qualitative

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## Introduction

Globally, 3.3 million children under 15 years of age were living with human immunodeficiency virus (HIV) infection at the end of 2012 (UNAIDS 2013). India has the third largest number of people living with HIV (PLH) worldwide, and children under the age of 15 years comprise 7% of the estimated 2.1 million PLH in India (National AIDS Control Organisation 2014). Previously, access to antiretroviral therapy (ART) was limited in India, and most HIV-positive children failed to survive into adulthood. Recent emphasis on early infant diagnosis and scaling up of the ART programme has led to drastic reductions in childhood and adolescent mortality due to HIV. However, improvements in paediatric HIV diagnosis, treatment, and longevity pose further challenges for health systems in low- and middle-income countries such as India, including improving and maintaining adherence to ART, reducing secondary transmission, and comprehensive improvement of the psychological and physical health of children living with HIV (CLH) (Vreeman *et al.* 2014).

Informing a CLH about his or her diagnosis (disclosure) is considered critical from the perspective of disease treatment and overall psychosocial development (Wiener *et al.* 2007). The decision about disclosing HIV status to a CLH is one of the principal dilemmas for caregivers (Wiener *et al.* 2007). As with other life-threatening diseases, disclosure of HIV status to a child or adolescent can be either partial or full. Partial disclosure may omit some of the disconcerting or stigmatizing aspects about HIV (such as not specifying HIV), whereas full disclosure involves discussing the specifics of HIV (Chazal & Medecins Sans Frontieres 2005). However, recent guidelines suggest that disclosure to children should be a continuing process rather than all at once, so that complete disclosure occurs over a period of time and increases the amount of information to be shared with children as their mental faculties mature (World Health Organization 2011; Cantrell *et al.* 2013). Findings from cognitive research conducted in developed countries endorse implementation of a process-oriented disclosure framework that promotes developmentally appropriate information sharing and takes into account emotional, social, and developmental needs of children and caregivers (Cantrell *et al.* 2013). Although there is still no consensus on the appropriate age of disclosure, guidelines from the World Health Organization (2011) and the American Academy of Pediatrics (1999) recommend that school-going children be made aware of their HIV status. However, these guidelines also suggest that efforts should be made to ensure a child's right to privacy and reduce possible discrimination that might arise from disclosure.

Compared with Western countries, a much smaller proportion of CLH in low- and middle-income countries receive disclosure about their HIV status (Pinzon-Iregui *et al.* 2013). A number of barriers to HIV disclosure in low- and middle-income countries have been recognized, including apprehension about discrimination (Bhattacharya *et al.* 2011; Vaz *et al.* 2010), concerns about the impact on the child's psychological health (Boon-Yasidhi *et al.* 2005; Abadia-Barrero & Larusso 2006; Bhattacharya *et al.* 2011), young age and/or perceived immaturity of the child (Biadgilign *et al.* 2011; Brown *et al.* 2011; Bhattacharya *et al.* 2011), and caregivers being unprepared to face questions from the child (Demmer 2011; Abadia-Barrero & Larusso 2006; Boon-Yasidhi *et al.* 2005). Prior research in low- and middle-income countries identified certain benefits for disclosure, including better adherence to treatment (Bikaako-Kajura *et al.* 2006; Brown *et al.* 2011; Vaz *et al.* 2008),

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higher self-esteem (Lee & Oberdorfer 2009), and ability to cope with stigmatizing behaviour (Midtbo *et al.* 2012). However, some have noted a few negative impacts of disclosure, including rejection and blaming of the caregivers (Oberdorfer *et al.* 2006), difficulties in social interactions (Petersen *et al.* 2010), and stigmatization (Petersen *et al.* 2010; Vaz *et al.* 2010).

Our literature search revealed only two studies in India that specifically addressed HIV status disclosure to children (Arun *et al.* 2009; Bhattacharya *et al.* 2011). However, neither qualitatively explored the knowledge, attitudes, and practices of caregivers or various barriers/facilitators related to the process of disclosure. The aim of this study was to explore the perceptions of caregivers in West Bengal about HIV status disclosure to children and, in turn, to inform India's national HIV programme on formation of a framework for childhood disclosure.

## Methods

### Study setting

Participants in this study were primary caregivers of CLH aged 8 to 15 years who were residing in the districts of Purba Medinipur and Paschim Medinipur in West Bengal. Access to the study population was gained with the help of a community-based organization (CBO), the Society for Positive Atmosphere and Related Support to HIV/AIDS (SPARSHA), an organization composed of and managed by PLH and their friends, which has been working with children and adults living with HIV in rural and urban settings of West Bengal since 2000 (Panda *et al.* 2014).

### Participant recruitment

The SPARSHA prepared a roster of its service recipients residing in the two study districts, and participants in this study were a convenience sample from that roster. Primary caregivers of CLH on this roster were contacted by outreach workers from SPARSHA, who used a recruitment script to briefly inform them about the study objectives and procedures and determine eligibility. Eligible caregivers who expressed willingness to participate were invited to come to the nearby SPARSHA field office for an interview. At the field office, a trained interviewer explained the study procedures in detail and obtained informed consent. If a participant wished to be interviewed in his or her home, an interviewer, accompanied by a SPARSHA outreach worker, visited their home by appointment for consent and interviews. Participants were assured that their decision about participation would not affect their relationship with SPARSHA or any other aspects of their lives.

### Ethical approval

The study was approved by the Institutional Review Board of the University of California, Los Angeles, and the Institutional Ethics Committee of the National Institute of Cholera and Enteric Diseases (under the Indian Council of Medical Research), the collaborating research institute located in Kolkata, West Bengal.

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## Participants

Eligibility criteria for participation included the following: (i) being the primary caregiver of one or more CLH aged 8–15 years; (ii) being ≥18 years old; (iii) living in the same household as the CLH; (iv) fluent in Bengali, the local language; and (v) willing to give informed consent. No gender-specific criteria were used to determine eligibility. Caregivers of institutionalized children or children who spent ≥2 weeks/month or ≥6months/year away from the caregiver were not eligible. As the most likely route of infection of CLH was parent-to-child transmission, the biological parents of some of the CLH might have died or were too ill to be their caregivers, and many of the CLH were orphaned by one or both parents. Thus, we expected some of the CLH to be under the care of persons other than their biological parents, and we recruited both biological parents and non-parent caregivers to the interview pool.

## Interviews

Between July and September 2014, caregivers responded to a 1-h in-depth interview with a study staff member. Interviews were conducted in a private room at the SPARSHA field office or in participants' homes. Permission to take written notes and digitally record the conversations was specifically obtained prior to initiating the interviews. Written notes were used to emphasize important points in the interview and record details about participants' characteristics, emotional expressions, body language, and so on, as well as for recording interviewers' comments. All the interviews were conducted in Bengali, the native language of the area. A semi-structured interview guide with broad questions was used and aided by open-ended probes to draw out information from participants. Questions/issues included in the guide were formulated from the review of relevant literature and probable themes that were anticipated to emerge on the basis of prior interactions with CLH and their caregivers. The sample size was determined according to the Green and Thorogood (2014) method, with a target of 40 interviews (20 with caregivers who were biological parents and 20 who were not), or until thematic saturation was reached, whichever was lower. In total, 20 biological parents and 14 non-parent caregivers were interviewed.

## Data management and analysis

Audio recordings of the interviews were transcribed verbatim into MS Word in Bengali. The notes taken during the interviews were used to facilitate transcription and to enhance the transcripts by insertion of relevant comments (e.g. moods and emotions of interviewees). These were also utilized later for content analysis. Electronic transcription for each interview was completed within 24 h of the interview. The transcripts were then reviewed for preliminary coding by the investigators. This process continued until the study team felt that theme saturation had been achieved (Corbin & Strauss 2008). The interview transcripts were then imported into the ATLAS.TI 7.5 (Berlin, Germany) software package for coding and data analysis. We analysed the interview transcripts for emergent themes in accordance with the grounded theory principles (Corbin & Strauss 2008). At the time of initial readings, an 'open coding' technique was used, followed by 'axial/thematic coding' during re-readings. The Bengali transcripts were used for the coding process, and only relevant quotations were later translated into English. Any disagreements regarding coding were resolved by

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discussion between study team members. Quotations and codes were grouped according to perceived themes for further comparison.

## Results

### Participant characteristics

Major characteristics of the participants are presented in Table 1. Forty-eight eligible primary caregivers identified from the SPARSHA roster were approached for participation, and 34 agreed to be interviewed. The main reason for refusal was lack of time on the part of the caregivers. Among the 34 caregivers interviewed, 20 were biological parents (19 mothers and one father), and the other 14 were grandfathers, grandmothers, uncles, or aunts. There was a single case where a male child orphaned by both parents was being cared for by a neighbour who was also HIV infected. Among participating caregivers, 17 (50%) were HIV positive, and among the CLH, only four were infected through blood transfusions for thalassemia care, and the rest reportedly were infected by vertical transmission.

### Emerging disclosure themes

The broader themes that emerged from content analysis were (i) perceived difficulties with disclosure, (ii) rationale for disclosure, (iii) reluctance of caregivers to disclose, (iv) preferred individuals to perform disclosure, and (v) best times and places to disclose. We could not identify any important differences between perspectives of biological parents and nonparents. Table 2 provides participant quotes according to themes.

### Perceived difficulties with disclosure

For many, disclosure of HIV status to CLH was likened to revealing a dark secret. Caregivers were afraid to face questions on the topic from the child and were often unsure about how to answer. Nevertheless, some caregivers expressed their perceptions and experiences of how external assistance could ease discussing HIV. Parents who were HIV positive mentioned various awareness programmes and interventions that helped them talk to their children.

### Rationale for disclosure

Rationale for disclosure of HIV status varied among study participants. We grouped them as follows: (i) perceived health benefits of disclosure for CLH and others; (ii) anticipation of caregiver's impending death; and (iii) fear of negative repercussions owing to late disclosure.

### Perceived health benefits of disclosure for CLH and others

A commonly perceived benefit of disclosure was that knowledge about the disease might motivate CLH to maintain their own health, and many caregivers felt that awareness about HIV would improve their health-seeking behaviours and motivate them to take their medications regularly.

Participants were also concerned about protecting others from becoming infected. Most said that it was the responsibility of PLH to avoid transmitting HIV to others, and caregivers of

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CLH should teach them how to avoid transmitting. They felt that such knowledge would prepare CLH for the future so that they could avoid further threats to their health and/or avoid transmission of HIV to others.

### Anticipation of caregiver's death

Some of the caregivers who were HIV positive said that they often thought about their own deaths and worried about the care of their child after they died. They felt that timely disclosure might prepare the child to live a better and healthier life. Even HIV-uninfected but aged caregivers were concerned about the future of their CLH after their deaths. They were worried that their child would be at a disadvantage if their caregiver did not tell them about their disease and its implications before they died.

### Fear of negative consequences owing to late disclosure

A few caregivers, mostly biological parents, were worried that if they did not start priming their children about their HIV status at an early age, there would be negative repercussions when the CLH would come to know about it later. Responses revealed that late disclosure (e.g. after the child reached adulthood) might be uncomfortable for both the caregiver and the CLH. The caregiver might feel awkward about answering questions and the child might be traumatized.

### Reluctance of caregivers to disclose

Among the 34 participating caregivers, 16 said that they did not want their CLH to know about their HIV status in the immediate future. These caregivers were apprehensive about potential negative consequences following disclosure. Contextual exploration revealed three main concerns, namely, (i) distress caused by disclosure, (ii) apprehension of blame, and (iii) fear of discrimination.

### Distress caused by disclosure

Among the reasons that caregivers are reluctant to disclose, the most common reasons given were the distress of the CLH and feelings of sorrow, hopelessness, and shame. These caregivers did not want their child to be burdened by stress due to disclosure.

### Apprehension of blame

HIV-positive caregivers who were the biological parent of a CLH were concerned that the child might blame them, unless the child had been infected through a contaminated blood transfusion.

### Fear of discrimination

Caregivers feared discrimination about being HIV positive, and that following disclosure, the CLH, owing to lack of cognitive maturity, might not completely understand the social implications of being HIV positive. Thus, they might fail to keep it confidential or inadvertently reveal HIV status, resulting in stigma and social isolation.

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### Preferred individuals for performing disclosure

Participants were asked who they considered to be most suitable for disclosing HIV status to the children under their care, which revealed two major sub-themes: (i) identifying suitable individuals for disclosure and (ii) letting CLH discover their HIV status by themselves.

### Identifying suitable individuals to make the disclosure

As indicated in Table 3, the majority of caregivers, either the biological parents or non-parents, felt that healthcare providers (HCPs) were best suited to disclose to CLH. The principal reason was that HCPs were much more well informed about the disease, and they would be able to explain it better. Some caregivers thought that hearing it from the HCPs would hurt the child less. Some felt that children would pay more attention to the advice of a doctor (or other HCP). Most of the caregivers who did not prefer an HCP felt that responsibility of disclosure should be on the caregivers themselves or other family members or friends. Although they recognized the difficulty associated with it, they reasoned that they understood their children better than anyone else and were better equipped to handle the disclosure process. Some of these caregivers also appeared to believe that it was solely the obligation of parents living with HIV to share the information with their children because it was no one else's business. There were some caregivers who said that they did not have any particular preference regarding the choice of disclosing persons. One non-parent caregiver suggested that even if there was a preference, that could change based on individual scenarios.

While describing her ideal scenario of disclosure, a mother of a thalassemic son suggested that children would be more at ease with the revelation about their disease status if that information was shared by CLH who had a similar experience. She thought that such peer-to-peer information sharing could also help in raising awareness.

### Letting CLH discover their HIV status by themselves

A few caregivers said they would prefer to leave the onus of disclosure to the child under their care. They felt that their school-going children were getting a better education than them and were more exposed to the outside world. Their children, they thought, were capable of discovering their HIV status by themselves when they matured. Caregivers also suggested that the child learning by himself or herself could probably lead to a better understanding of the disease and its implications.

### Best times and places to disclose

Another broad theme that emerged was caregivers' perceptions about the ideal scenario or circumstances for the disclosure process. The 'how' and 'when' of approaching disclosure had two sub-themes: (i) suitable environment and way to initiate disclosure and (ii) appropriate age of the child.

### Suitable environment and ways to initiate disclosure

Caregivers expressed their thoughts about how to initiate the disclosure process and the best environments for it. Most participants said that to make the process easier, they would talk to

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the child like a friend. Widowed mothers who were infected by their husbands and mothers whose children were infected from contaminated blood transfusions felt that blaming the father or contaminated blood might make it easier to talk about it. Opinions varied about the right environment for disclosure. An aunt of a CLH commented that it was better to undertake disclosure in the evening, as it was the time of the day when kids are more likely to be calmer. A mother said that her disclosure would be aided by television commercials on HIV awareness.

### Appropriate age of the child for disclosure

Overall, the age of the child emerged as the most common and probably the most important factor affecting caregivers' decisions about disclosure. There was consensus among the caregivers who had yet to tell their child about HIV that disclosure should occur only after the child had reached a certain age, or when suitably mature. Many participants had an age range in mind rather than a specific age. Some felt that disclosure should be initiated when the child could understand about HIV/AIDS, without referring to any particular age (Table 4).

Some caregivers wanted to delay disclosure until the child reached marriageable age or might start seeking a partner. Caregivers were aware of the risk of inadvertent sexual transmission if a CLH was not aware of being HIV positive, and they wanted to disclose HIV status as a preventive measure when the children reached reproductive age.

## Discussion

Disclosure of HIV status to CLH is an emotional process, for both the caregiver and the child. This is especially true for low-and middle-income nations such as India, where anticipation of stigma often prompts HIV-infected individuals to conceal their diagnosis (Bailey & Darak 2013). It has been reported that non-disclosure can undermine efforts to reduce discrimination, make the child secretive, reduce health-seeking behaviours, and even increase the possibility of accidental sexual transmission (Kohrt *et al.* 2012). Thus, the current consensus is, if done in an age-appropriate way and as a continuing process rather than a single interaction, disclosure is likely to be beneficial for both CLH and their caregivers (Watermeyer 2015).

The findings of the current study reveal the complexity of disclosure of HIV status to children. In terms of rationale pertaining to disclosure, a number of perceived benefits were cited by caregivers, and they intended to obtain those benefits for themselves and their children through disclosure. Improved treatment adherence was an important perceived benefit that motivated caregivers for disclosure. This is similar to findings from other low- and middle-income countries (Vreeman *et al.* 2013). However, the association between children's awareness about their own disease status and medication adherence has been reported to be inconsistent (Simoni *et al.* 2007). As reported in studies from Asian countries (Chew *et al.* 2012; Liamputtong & Haritavorn 2014), other positive goals of disclosure included willingness to protect healthy individuals from getting infected and avoiding damage to caregiver–child relationships owing to late disclosure. Similar to a study in China (Qiao *et al.* 2014), caregivers who anticipated dying in the near future felt that it was their

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responsibility to disclose to their child to better prepare him or her for the future. As has been suggested by others (Mothi *et al.* 2012), caregivers probably assume that in the event of their own death, they may miss the chance to communicate with their children, which might deny the child's potential sources of future support.

Another dimension of our findings was related to emotional and cognitive barriers that might prevent caregivers from supporting disclosure, such as perceived immaturity of the child that makes him or her unable to understand the information shared about HIV. However, this indicates that caregivers probably perceived disclosure as a single event rather than an ongoing and evolving process. As has been suggested in the literature, the results of one-time disclosures are often unsatisfactory, as a child needs to adapt to the new information and adjust his or her understanding all at once, often leading to confusion, isolation, and depression (Kiwanuka *et al.* 2014). Thus, any programmatic intervention on systematic disclosure to children should be recommended as a continuous process rather than a single event.

There was no consensus among participants regarding the appropriate age of disclosure, similar to what was suggested by a recent review (Pinzon-Iregui *et al.* 2013). Overall, in the current study, biological parents were found to favour earlier disclosure (i.e. at or before early teens) than non-parents. Although a prior study in India (Arun *et al.* 2009) reported that mid-teens was the preferred age for disclosure, we did not find any age group that was clearly favoured by the caregivers in our study. Interestingly, the age of the child was perceived as both a facilitator and a barrier for disclosure. Some caregivers, mostly biological parents, reasoned that children should be primed about their disease status from an early age, as late disclosure might lead them to blame their parents. On the other hand, as mentioned earlier, many considered immaturity to be a barrier for HIV status disclosure. Parent–child (or caregiver–child) communication in India tends to be less open and direct than in Western countries (Segal 1991), and it is unlikely to be different for a sensitive issue such as HIV. Thus, it is essential to develop context-specific interventions that endorse communication about the disease, while taking into account the child's age or developmental maturity, domestic environment, and cultural factors, as has been suggested by Wiener *et al.* (2007). To facilitate the communication process, studies from other low- and middle-income countries have proposed that any such planned interventions need to reflect the nuances of the communication process within families (Vaz *et al.* 2010). As the age of the child has been reported to be an essential element, formulation of age- and culture-sensitive guidelines on the nature and content of communication is an absolute necessity (Kajubi *et al.* 2014).

Caregivers expressed numerous personal and societal fears as hindrances for confiding to the child. On a personal level, they feared that disclosure might cause psychological stress to the child, but this has not been substantiated in the published literature. It has been suggested that although children might suffer initially after being informed about their HIV status, possibilities of any long-term psychological adverse effects, such as depression and behavioural problems, are not greater for CLH who have undergone disclosure than those who were yet to be informed (Riekert *et al.* 1999; Lester *et al.* 2002; Vaz *et al.* 2010; Kiwanuka *et al.* 2014). On the other hand, some HIV-positive parents reported their concern

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that they might be subjected to emotional backlash from the child, who may end up blaming his or her parents for his or her condition. Many parents thus considered themselves guilty and expressed their inability to discuss HIV with their children out of this fear of repercussions. As has been suggested by a study of caregivers of CLH in Singapore (Chew *et al.* 2012), self-blame might be more pronounced in Asia, where parents are expected to assume a central and protective role in the family. We found that some widowed mothers wanted to blame the child's father, possibly to avoid self-blame and/or being blamed by the child. Thus, it is important to implement interventions that can help caregivers come to terms with their own HIV status and their relationships with their children, in order to improve the likelihood of disclosure to children.

There was also widespread concern that the caregiver and/or child might be subjected to discrimination if the child, owing to his or her lack of understanding of the implications, revealed his or her HIV status to others. This finding was in agreement with reports from various studies conducted in different settings (Vaz *et al.* 2011; Vreeman *et al.* 2013; Qiao *et al.* 2014). It has been suggested in other studies conducted in Asia that caregivers often feared that they might lose their reputation or social status if their child inadvertently told others about their diagnosis (Chew *et al.* 2012). We maintain, as has been recommended by others, that national HIV programmes need to address apprehensions about discriminatory behaviour and psychosocial impact to improve the acceptability of childhood disclosure (Vreeman *et al.* 2013).

Interview excerpts revealed that HCPs were suggested by most caregivers to be their preferred choice as the disclosing person, which is in contrast to previous findings from India (Arun *et al.* 2009) and China (Qiao *et al.* 2014) that reported parents/caregivers as primary choices. The principal reason for this choice was that HCPs were perceived to have greater knowledge about HIV that better equipped them to perform disclosure. It can be reasoned that the low educational level of our study participants, with about 90% receiving only primary schooling or less, led them to this 'disease-centric' choice for the disclosing person. Informal caregivers were favoured as disclosing persons by those who felt that they 'understood their child best', and HIV-positive caregivers who considered sharing disease status and related information as their duty. Some caregivers wanted to avoid disclosure and leave their child to learn about their HIV status by themselves. The policy gap on the issue of HCPs' assistance to informal caregivers about disclosure has been identified in many studies, according to a recent review on childhood disclosure (Pinzon-Iregui *et al.* 2013). We suggest that this be addressed through future operational research. Being prompted by the varied context-specific findings revealed in this research, we propose that the ongoing HIV prevention and care programme in India should provide multi-component strategies for disclosure of HIV status to children.

Several factors might limit interpretation of the findings in this study. Although we interviewed 34 primary caregivers (20 parents and 14 non-parents), which may be considered adequate, based on the broader categorization (Green & Thorogood 2014), some demographic categories could be considered under-represented. Among the parent caregivers, only one of the 20 parents was the father (widower), making mothers' perspectives dominant in our findings. However, this was not unexpected, as local cultural

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beliefs dictate that it is the mother's duty to look after her children. In addition, non-parent caregivers participating in this study were a heterogeneous population, with representation from a group composed of grandparents, uncles, aunts, and even neighbours. As the number of interviews from each group was small, it could not be determined whether opinions varied among different groups of non-parent caregivers. Moreover, in terms of broader representativeness, the participants were recruited through a single CBO that provides various preventative and awareness services to adults and CLH. In the Indian setting, recipients of such services mostly belong to the lower socioeconomic strata of society, as indicated by the low educational levels of the participants. Thus, we cannot assume that our study participants were representative of the caregivers of CLH from all strata of society.

Capturing the perceptions of both parent and non-parent caregivers was a major strength of this study, as prior studies in Asia were often restricted to parents only (Chew *et al.* 2012; Liamputtong & Haritavorn 2014; Qiao *et al.* 2014). The caregiver's own health-related conditions would affect his or her perceptions about the child's quality of life. Interviewing both biological parents and non-parents helped us explore differing concerns that these caregivers had about the CLH under their care. Not all caregivers participating in this study cared for children who were perinatally infected, as some had been infected through contaminated blood transfusions. Thus, it was possible to record the disclosure-related perceptions of a varied group of caregivers. Additionally, CLH and their caregivers were recruited from the community through a local CBO, and interviews were conducted in an informal setting, in either homes or the field office of the CBO. As these events occurred away from hospital or treatment settings, we believe that the interviewees were more at ease because they did not fear any negative consequences to treatment or discriminatory behaviour based on their participation.

Despite these limitations, the current research, to the best of our knowledge, is the first study in India to qualitatively explore caregivers' perceptions about diagnosis disclosure to CLH and may thus inform policymaking. Several organizations such as WHO and Medecins Sans Frontieres have suggested frameworks on disclosure of HIV status to CLH (Chazal & Medecins Sans Frontieres 2005; World Health Organization 2011). There are also guidelines from different countries with culturally appropriate recommendations regarding the process (American Academy of Pediatrics 1999; South to South, Faculty of Health Sciences, Stellenbosch University 2010). However, as in other low- and middle-income countries (Oberdorfer *et al.* 2006), there are few context-specific paradigms in India, and a standardized, age-appropriate procedure for disclosure is rarely followed. This study is in agreement with the existing literature that any intervention for childhood disclosure of HIV demands a multifaceted approach and should consider not only the disease but also the entire family/social structure.

## Acknowledgments

We thank Wendy Aft for her assistance in preparing the manuscript. We also express our gratitude to Dr Frank Sorvillo (Professor, Department of Epidemiology, UCLA) and Dr Abdelmonem A. Afifi (Professor, Department of Biostatistics, UCLA) for their invaluable advice and constant encouragement.

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**Key Messages**

- Childhood disclosure of HIV status is a complex issue that depends on multiple factors.
- Caregivers are often apprehensive about negative impacts from disclosure, such as distress, stigma, and damaged parent–child relationships.
- Young age/immaturity of children is perceived by some caregivers as an obstacle for disclosure, while other caregivers preferred initiating the disclosure process at an early age.
- Healthcare providers were preferred by caregivers to perform disclosure.
- A culturally appropriate guideline on disclosure of HIV status to Indian children is highly recommended.

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**Table 1**

Characteristics of caregivers and children under their care ($n = 34$)

| Characteristics | Frequency | Percent |
|---|---|---|
| Caregiver's age (in years) | | |
| 21–30 | 9 | 26.5 |
| 31–40 | 15 | 44.1 |
| 41–50 | 2 | 5.9 |
| 51–60 | 4 | 11.8 |
| 61–70 | 4 | 11.8 |
| Caregiver's gender | | |
| Male | 6 | 17.6 |
| Female | 28 | 82.4 |
| Caregiver's relationship to the child | | |
| Biological parents | | |
| Mother | 19 | 55.9 |
| Father | 1 | 2.9 |
| Other relatives | | |
| Grandmother | 5 | 14.7 |
| Grandfather | 3 | 8.8 |
| Aunt | 2 | 5.9 |
| Uncle | 3 | 8.8 |
| Neighbour | 1 | 2.9 |
| Caregiver's educational status | | |
| Illiterate | 5 | 14.7 |
| Literate but no formal education | 9 | 26.5 |
| Primary | 16 | 47.1 |
| Secondary or higher | 4 | 11.8 |
| Caregiver's HIV status | | |
| Infected | 17 | 50.0 |
| Uninfected | 17 | 50.0 |
| Age of CLH | | |
| 8–12 years | 19 | 55.9 |
| 13–15 years | 15 | 44.1 |
| Mode of transmission to CLH | | |
| Vertical | 30 | 88.2 |
| Blood transfusion | 4 | 11.8 |
| Gender of CLH | | |
| Male | 21 | 61.8 |
| Female | 13 | 38.2 |
| CLH taking ART | | |
| Yes | 19 | 55.9 |
| No | 15 | 44.1 |

CLH, children living with HIV; ART, antiretroviral therapy.

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**Table 2**

Representative quotes by themes and sub-themes

| Theme | Sub-theme | Representative quotes |
|---|---|---|
| Perceived difficulties with disclosure | | HIV-positive widow and mother of a 9-year-old girl – 'My daughter had taken boiled drinking water to school…. and her classmates asked her why she had carried boiled water to school. She told them that her mother was sick and always had boiled water…. and gave her boiled water too. That day she came home and asked me about our disease…. I told her nothing about HIV that day…. I told her that I had skin lesions and got operated and the doctor advised me to drink boiled water…..'<br>HIV-positive mother of an 11-year-old boy – 'He always asks, "Mom, how did we get this disease?" Kids will always ask such questions. He is afraid of his dad, so it's me who has to listen (to his questions). He gets all the love from me, his dad drives trucks and doesn't stay much at home. He lives with me and keeps bothering me with questions. I tell him, "I don't know about diseases, anybody can get any disease." That's what I say.'<br>HIV-positive widower and father of 11- and 14-year-old boys – 'When the test results of my sons came positive…..they underwent counselling…… the adults are also instructed [by counsellors] on how to deal with the children, with care and nutrition advice. Then I told them "see this is the case….. I'm as helpless as you are…. you have this disease…. I have to live with it and you too." ' |
| Rationale for disclosure | Perceived health benefits to self and others | HIV-positive mother of an 11-year-old boy – 'In order to make the kids take the drugs [ART], one has to tell them. Once you get started on the drugs, you'll have to know it.'<br>HIV-negative mother of a 14-year-old thalassemic boy – 'I think I should inform my child about HIV….and explain to him about the preventive measures… so that he becomes conscious…and could protect himself and others.'<br>HIV-positive neighbour of a 14-year-old both parent orphan boy – 'I told him bluntly…. "You have HIV…. do not get involved with girls……" ' |
| | Anticipation of caregiver's death | HIV-positive mother of a 14-year-old boy – 'We always think about him [her son]. How will he live [after our death]? He is still so young, he has to live for many years. That's what we discuss, how can he survive for long. Whatever may happen to us, he has to survive.'<br>HIV-negative grandfather of an 8-year-old boy – 'He [grandson] has to be told someday. What would happen if I am not there? He might not understand it now… Everyone else in the family knows about it. But how would he perceive when we tell him? Today he doesn't know, but he has to know it soon. I have to tell him before I die.' |
| | Fear of negative consequences due to late disclosure | HIV-positive widow and mother of an 8-year-old girl – 'I think parents should inform the kids as early as possible, otherwise when they grow up and come to know, they might ask several questions. Say in my case, if I had not informed her [daughter], she would have definitely questioned me, "Why didn't you tell me before? You have the same disease, my father died because of this disease, and you did not even bother to inform me." Also, she might have asked [uncomfortable] questions, like "How did my father get the disease?" So, it's always better to tell them [early].'<br>HIV-positive widower and father of 11- and 14-year-old boys – 'It's better that we tell them at the beginning. You know the thing about their mind….. gradually learning about it [HIV] from an early age may help them mentally. But if they are told when they have become adults, they might be in for a shock.' |
| Reluctance to disclose | Distress caused by disclosure | HIV-negative mother of a 12-year-old thalassemic boy – 'I cannot inform my son about the disease. Why should I? If he comes to know [about HIV], he would keep thinking about it….that he is sick, that he is not like other kids.' |

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| Theme | Sub-theme | Representative quotes |
|---|---|---|
| | | HIV-positive mother of a 15-year-old girl – 'If you ask us, we will say there is no need to say it [disease disclosure]. If they get to know it, they will think, "We have this disease, we may not live for long." They will be unnecessarily worried.' |
| | Apprehension about being blamed by children | HIV-positive widow and mother of an 8-year-old girl – '[Following disclosure] many kids may think, "my father was an immoral person or my mother was an immoral person, they are the reason I got this disease." But they might not understand that this disease doesn't depend on a person's character.'<br>HIV-positive mother of a 14-year-old boy – 'He always says, "so, you have the disease, but why me, too?"…. I feel so sorry for him [crying]. Sometime he may say, "you have this disease, I have this disease, too…. you are solely responsible!" '<br>HIV-negative mother of a 14-year-old thalassemic boy – 'Some people say that we should not tell our children [about HIV]. I do not understand the reason, if I tell him would I turn into a bad person? I would still remain the same human being, and not become some obnoxious animal.' |
| | Fear about discrimination | HIV-positive, separated from husband, mother of an 8-year-old boy – 'We cannot tell him now, because his mind is not mature enough. He might go around telling people about his disease. Then people may start avoiding him.' |
| Individuals performing disclosure | Identifying suitable individuals for disclosure | HIV-positive mother of an 8-year-old girl – 'If they [health care providers] say it …… or those who are in this field inform us about how to disclose, I believe it will help… because, we are not sure how to disclose it to kids.'<br>HIV-negative grandfather of an 8-year-old boy – 'Yes, health workers should be present in the process. They should visit our homes and tell the children. We tell our kids …but health workers can be more open and say about it in detail….like how the infection spreads….what we should do or not do… I think we should appeal to the local administrators about this service by health workers.'<br>HIV-negative aunt of a 14-year-old girl – 'It is better if a medical professional tells her. She may be hurt if I tell her. It would be good if the NGO workers tell her or if the health center people, from the place she goes to get her medicines, tell her.'<br>HIV-negative uncle of an 11-year-old girl – 'It is better if the doctors tell the children about their HIV. The counsellors or nurses may also tell them. But the children will take the doctors seriously.'<br>HIV-positive mother of an 8-year-old girl – 'No, it's better that I say it. If anyone else tells her [her daughter] that you have the disease, however good he explains it… if anyone else tells her, I may not like it…she will not like it too. You know it's always better to hear the bitter truth from your own mother, rather than an outsider.'<br>HIV-positive widow and mother of a 9-year-old girl – 'I think when children grow up, it is the responsibility of the parents to tell, "see, we have such a condition." We should explain facts about living a healthy life. Take care that they do not transmit HIV to anyone else. That they should take care of themselves. It is the parents' responsibility.'<br>HIV-positive neighbour caring for a 14-year-old boy orphaned by both parents – 'I think parents should say it, whenever the time is right….depends on situation, overall mood etc…… Parents have an advantage as they are always around. Whenever they think that it's a suitable time…… that is if the child is told at that time it may cause less hurt, then they should [say it]……But in other cases, if parents are finding it difficult, they may have to resort to other options…… Say counselling, or maybe tell their children through friends… depends on what you have at your disposal.'<br>HIV-negative mother of an 8-year-old thalassemic boy – 'My suggestion is that a [HIV-positive] kid may tell others [other HIV-positive children] that "I have got this disease, you should take such and such precautions, so that it doesn't get any worse." A kid should be able to share that with other kids…' |
| | Letting CLH discover their disease by | HIV-positive mother of an 11-year-old boy – 'When such kids grow up, they will know by themselves…… they |

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| Theme | Sub-theme | Representative quotes |
|---|---|---|
| | themselves | will become aware. Nowadays kids study a lot, they will definitely become aware. All the kids who are on ART have become aware, my kids will know about it, too.' |
| | | HIV-negative mother of an 8-year-old thalassemic boy – 'When he asks, "Mother, what has happened to me? What disease do I have? How come you don't have it but I have?" He asks me again and again. I just tell him when you will grow old you will understand yourself.' |
| Best times and places to disclose | Suitable environment and way to initiate disclosure | HIV-positive widow and mother of a 9-year-old girl – 'While talking about it [disclosure related discussion] mother has to become a friend to her daughter. It doesn't matter whether it's a son or daughter, she has to interact like a friend while saying it. Do it when both of you are healthy, and maintain your cool during the process.' |
| | | HIV-positive, separated from husband, mother of an 8-year-old boy – 'One has to treat them like a friend and discuss about the disease. Then the child will easily understand and the mother would feel relaxed, too.' |
| | | HIV-positive mother of an 11-year-old boy – 'I'll tell him…. I have to take him into confidence first by saying that "I did not do it to you, it (infection) has come from your dad. You can't undo whatever has happened, but you need to undergo treatment." That's how it should be explained.' |
| | | HIV-negative mother of an 8-year-old thalassemic boy – 'When I'll tell him [about the disease] for the first time I'll say, "see you have got the disease from the blood that you received [for thalassemia]." He might ask, "how come I have the disease but you don't?" I'll reply that it came through blood, and nobody can help it.' |
| | | HIV-negative aunt of a 14-year-old girl – 'One should sweetly ask them to sit in the evening, and say that "you have this disease, try to take care of yourself." He will understand better if told in the evening. Your mind can be diverted by other things during the day, while you are more likely to be at peace in the evening.' |
| | | HIV-positive mother of an 8-year-old girl – 'The commercial (HIV awareness) that comes on TV…. that's what I mean… [I told her] "you have the same disease, take care of yourself, eat properly." That's how I could make her understand easily.' |
| | Appropriate age of child | HIV-positive widow and mother of a 9-year-old girl – 'It is our [parent's] responsibility to disclose about the disease when they turn 12 years old, because at twelve, I think, she would be mature enough to understand.' |
| | | HIV-positive widow and mother of a 15-year-old girl – 'I will let her know when she is of marriageable age.' |
| | | HIV-negative grandfather of an 8-year-old boy – 'This disease…… when he is of age of 16-17-18, then there will be chance that he might transfer it to others. Then I'll tell him, "you can't do it, you should know about prevention." ' |

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**Table 3**

Choice of disclosing person

| | Parents (%) | Non-parents (%) | Total (%) |
|---|---|---|---|
| HCP | 9 (45) | 6 (43) | 15 (44) |
| Caregiver/close persons | 4 (20) | 2 (14) | 6 (18) |
| CLH to learn by himself or herself | 2 (10) | 1 (7) | 3 (9) |
| HCP or close persons | 1 (5) | 1 (7) | 2 (6) |
| HCP or learn by himself or herself | 2 (10) | 3 (21) | 5 (15) |
| Close persons or learn by himself or herself | 1 (5) | 1 (7) | 2 (6) |
| HCP or other kids | 1 (5) | – | 1 (3) |

Percentages may not add to 100% because of rounding.

HCP= healthcare provider; CLH= children living with HIV.

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**Table 4**

Suggested age for disclosure

| | Parent (%) | Non-parent (%) | Total (%) |
|---|---|---|---|
| Early teens or before (≤15 years) | 7 (35) | 5 (36) | 12 (35) |
| Late teens/adulthood (>15 years) | 4 (20) | 7 (50) | 11 (32) |
| Whenever the child can understand | 9 (45) | 2 (14) | 11 (32) |

Percentages may not add to 100% because of rounding.