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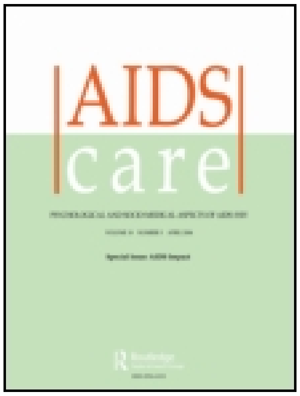

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Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya

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Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya

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Disclosure to HIV-infected children regarding their diagnosis is important as expanding numbers of HIV-infected children attain adolescence and may become sexually active. In order to define correlates of pediatric disclosure and facilitate development of models for disclosure, we conducted a cross-sectional survey of primary caregivers of HIV-1 infected children aged 6–16 years attending a pediatric HIV treatment program in Nairobi, Kenya. We conducted focus group discussions with a subset of caregivers to further refine perceptions of disclosure. Among 271 caregiver/child dyads in the cross-sectional survey, median child age was 9 years (interquartile range: 7–12 years). Although 79% of caregivers believed children should know their HIV status, the prevalence of disclosure to the child was only 19%. Disclosure had been done primarily by health workers (52%) and caregivers (33%). Caregivers reported that 5 of the 52 (10%) who knew their status were accidentally disclosed to. Caregivers of older children (13 vs. 8 years; $p < 0.001$), who were HIV-infected and had disclosed their own HIV status to the child (36% vs. 4%; $p = 0.003$), or who traveled frequently (29% vs. 16%, $p = 0.03$) were more likely to have disclosed. Children who had been recently hospitalized (25% vs. 44%, $p = 0.03$) were less likely to know their status, and caregivers with HIV were less likely to have disclosed ($p = 0.03$). Reasons for disclosure included medication adherence, curiosity or illness while reasons for nondisclosure included age and fear of inadvertent disclosure. Our study found that disclosure rates in this Kenyan setting are lower than observed rates in the USA and Europe but consistent with rates from other resource-limited settings. Given these low rates of disclosure and the potential benefits of disclosure, strategies promoting health worker trainings and caregiver support systems for disclosure may benefit children with HIV.

Keywords: disclosure; pediatric; HIV; stigma; adherence

Introduction

As pediatric antiretroviral therapy (ART) expands, an increasing number of HIV-infected children will attain adolescence and adulthood. To promote treatment adherence and safe sexual behavior, it is important that HIV-infected children be made aware of their diagnosis.

Disclosure of diagnosis to children with chronic diseases has been found to be beneficial. Studies have shown that children with serious illnesses are able to comprehend illness and death at very early ages and, when informed of their illness and the consequences, fare better psychologically than children who remain uninformed (Bibace & Walsh, 1980; Slavin, O'Malley, Koocher, & Foster, 1982). HIV-specific studies have shown that children who know their infection status score higher in quality of life assessments and have improved medication adherence (Battles & Wiener, 2002; Bikaako-Kajura et al., 2006; Blasini et al., 2004; Butler et al., 2009; Oberdorfer, Louthrenoo, Puthanakit, V. Sirisanthana, & T. Sirisanthana, 2008). Children who know their status have also been shown to have slower rates of CD4% decline and lower AIDS-related mortality (Ferris et al., 2007). Despite these benefits, studies evaluating rates of disclosure in developing countries have found extremely low rates of complete disclosure (naming HIV) and high rates of partial (nonspecific) or nondisclosure (Abebe & Teferra, 2012; Biadgilign, Deribew, Amberbir, Escudero, & Deribe, 2011; Bikaako-Kajura et al., 2006; Brown et al., 2011; Kallem, Renner, Ghebremichael, & Paintsil, 2010; Menon, Glazebrook, Campain, & Ngoma, 2007; Moodley, Myer, Michaels, & Cotton, 2006; Vaz et al., 2011; Vreeman et al., 2010).

In many areas of Africa, a minor's guardian has the prerogative to disclose or conceal HIV diagnosis,

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and caregivers face challenges to disclosure because of the stigma associated with HIV and modes of its transmission (Blasini et al., 2004; Cohen, 1994; Gerson et al., 2001; Lee & Johann-Liang, 1999; Slavin et al., 1982). Caregivers are often reluctant to inform children of their HIV diagnosis because of concerns regarding the child inadvertently revealing the family's HIV status to others, perceptions of the child's inability to cope with results, guilt regarding transmission, and perception of the child's lack of interest in their health (Corneli et al., 2009; Domek, 2010; Gerson et al., 2001; Lee & Johann-Liang, 1999; L. S. Wiener, Battles, & Heilman, 1998; L. S. Wiener, Battles, Heilman, Sigelman, & Pizzo, 1996). Caregivers are also concerned with the stigma placed on HIV-infected children and have witnessed how children can lose friends and social standing in school when their positive status becomes known (Corneli et al., 2009; Ostrom, Serovich, Lim, & Mason, 2006).

Disclosure of HIV diagnosis to children remains understudied in resource-limited countries and few guidelines regarding disclosure exist. To better define caregiver and child characteristics associated with disclosure, and to inform disclosure model development, we conducted a study to determine correlates of disclosure of HIV diagnosis to children receiving HIV services in Nairobi, Kenya. We also sought to determine the attitudes, practices, and barriers regarding disclosure within this cohort.

Methods

Study design and site

We conducted a cross-sectional survey of parent/caregiver–child dyads attending the Comprehensive Care Centre (CCC) at Kenyatta National Hospital (KNH) between November 2006 and December 2007. The CCC provides free or subsidized ART, treatment of opportunistic infections, nutrition counseling and supplementation, psychosocial care, and laboratory and radiologic tests through a PEPFAR-funded program of the University of Nairobi. At the time of the study, ~300 children aged <18 years were receiving HIV care at KNH.

Study subjects

We approached all primary caregivers of HIV-infected children aged 6–16 years in regular follow-up at the KNH CCC. Caregivers who were willing to participate in the study were enrolled after providing written informed consent. In addition, two focus group discussions were conducted with a selected subset of caregivers who participated in the survey. Caregivers who participated in focus group discussions signed an additional consent form.

Study procedures

Disclosure survey questionnaires were administered by trained study personnel through one-on-one interviews with primary caregivers and lasted 45 minutes to 1 hour. Survey questionnaires combined structured and semi-structured open-ended questions. To assess attitudes towards disclosure, subjects were asked questions regarding the importance of disclosure, the preferred age of disclosure, and their willingness to disclose. Disclosure was classified as complete, partial, or nondisclosure. Complete disclosure was defined as sharing HIV-specific information with the child and naming the virus as "HIV." In contrast, partial disclosure was defined as providing the child with nonspecific or incorrect health information regarding their infection and using explanations of TB, malaria, asthma, and cancer to account for clinic visits and the need for medication. Lastly, nondisclosure was defined as providing the child with no explanation of their health condition. To determine caregiver perceptions of the importance of disclosure, caregiver responses to the statement "It is important for a parent/caregiver to inform a child of his/her status," were assessed on a 5-point Likert scale. For children who had already received disclosure of their HIV status, data on the practices of disclosure were sought using questions regarding the circumstances surrounding disclosure. For caregivers who had not yet disclosed, data on the barriers preventing disclosure were obtained.

We held two focus group discussions: one with caregivers who had disclosed the child's HIV diagnosis to the child, and the other with caregivers who had not yet disclosed the child's HIV status. Focus group discussions were facilitated by two social scientists and assisted by the principal investigator and study counselors. Discussions were recorded and later transcribed.

Ethical considerations

Procedures and materials were approved by the University of Washington Institutional Review Board and the Ethical Review Committee at KNH and all subjects provided prospective informed consent.

Statistical methods

Responses from the survey questionnaires were coded using SPSS Version 13.0 and analyses conducted with SPSS Version 15.0 (SPSS Inc., Chicago, IL, USA).

Correlates of disclosure were determined using Mann–Whitney U and Pearson's chi-square tests for continuous and categorical variables, respectively. Variables statistically significant ($p \leq 0.05$) in univariate analyses were included in a multivariate logistic regression model. Variables were assessed for collinearity before being included in the multivariate model. Descriptive statistics were used to summarize the data on the attitudes, practices, and barriers.

Transcripts from the focus group discussions were read and coded independently by two social scientists and the principal investigator. The principal themes explored were the societal and cultural norms and beliefs of illnesses, the practices of disclosure, the effects of disclosure and barriers to disclosure. There was agreement on all the major themes.

Results

During the study period, 271 caregivers of HIV-infected children participated in the survey. The children had a median age of 9 years (interquartile range [IQR]: 7–12 years) and half (51%) were female. The majority of children (63%) had experienced a death in the family. Of these, 33% had both parents deceased, 46% had only the mother deceased and 21% had only the father deceased. At the time of the interview, children had been diagnosed as being HIV-infected for a median duration of 8.2 months (IQR: 1.5–20.2 months). The majority (73%) were in the WHO clinical stages 3 or 4 and 171 (63%) were on ART with a median duration of ART use of 12 months (IQR: 4–24 months) (Table 1).

The majority of caregivers were female (73%), married (79%), and had at least some secondary school education (71%). Median caregiver age was 35 years (IQR: 31–42 years) and primary caregivers were predominantly biological parents (59%). One hundred and ninety (70%) primary caregivers reported having had an HIV test, among whom 112 (59%) reported being HIV-infected.

Disclosure

Of 271 caregivers, 52 (19%) reported that HIV diagnosis had been disclosed to the child. Among caregivers who reported disclosing, disclosure was complete for 81% and partial for 19%. Despite low rates of disclosure to the child, most caregivers (93%) had disclosed the child's status to at least one other person, most commonly immediate family members (55%), and other relatives (52%), and sometimes to nonfamily members (13%). Main reasons given for disclosing included the child asking questions (11%), the child being ill (14%), feeling that the child should know (14%), and for medication adherence (47%). Disclosure had been done by the parents/caregivers (33%), health workers (52%), and relatives (6%). Disclosure was accidental in 5 (10%) of the 52 cases.

When assessing caregiver willingness to disclose their personal HIV status, 83% of the HIV-infected caregivers had disclosed to at least one person. However, only 7% had disclosed their personal status to their child (Table 2).

Caregiver perceptions regarding disclosure

Overall, caregivers felt disclosure was important. When asked if they believed HIV-infected children should be informed of their HIV-positive status, 213 (79%) caregivers responded yes and 55% of the caregivers interviewed strongly agreed with the statement "It is important for a parent/caregiver to inform a child of his/her status." Not surprisingly, a greater proportion who strongly agreed were caregivers who had already disclosed the status to their child (89% vs. 47%; $p < 0.001$). Over half of the caregivers (64%) believed that children on medication should know their status. The median preferred age of disclosure was 12 years (IQR: 10–14 years). Most caregivers (96%) believed that at the preferred age of disclosure, the child would understand the meaning of being HIV-positive.

Although 84% of caregivers who had not disclosed stated that they did not think their children suspected they themselves were HIV-infected, 25% of these caregivers reported that the children asked questions about their illness. Caregivers responded to these queries by avoiding the question (15%), attributing it to another etiology (24%), or disclosing only the co-morbid condition the child had at the time (26%).

Caregivers who believed disclosure was important cited varied reasons why they deemed it important, including having the child understand reasons for taking medication (29%) and the ability to take care of themselves and prevent transmission (38%). Almost half of caregivers (46%) said they would prefer to be the ones to disclose while 31% would prefer to be assisted by a counselor and 13% would prefer to have only the counselor disclose. Concern about the child being too young to understand was identified by a majority of caregivers (67%) as a reason for nondisclosure. Other reasons included fear of the child disclosing to others (43%), fear of discrimination (22%), fear of the child experiencing depression (24%), being blamed by the child (8%), and not knowing how to disclose (25%) (Table 2).

Table 1. Cohort characteristics and correlates of disclosure.

	Number (percent) or median (IQR)			
	Total ($N = 271$)	Disclosed status to child ($N = 52$)	Not disclosed status to child ($N = 219$)	p Value*
Child characteristics				
Age (years)	9 (7–12)	13 (11–15)	8 (7–11)	**<0.001**
Female	138 (50.9)	31 (59.6)	107 (48.9)	0.32
Time since diagnosis (months)	8.2 (1.5–20.2)	9.3 (1.4–19.2)	8.1 (1.7–20.9)	0.75
Recent hospitalization[a]	108 (39.9)	13 (25.0)	95 (43.4)	**0.03**
WHO stage				0.23
I and II	71 (26.6)	17 (33.3)	54 (25.0)	
III and IV	196 (73.4)	34 (66.7)	162 (75.0)	
Having family member with HIV-related illness				
Mother	44 (16.2)	4 (7.7)	40 (18.3)	0.06
Father	29 (10.7)	8 (15.4)	21 (9.6)	0.22
Sibling	12 (4.4)	2 (3.8)	10 (4.6)	0.82
Death in family	171 (63.5)			
Both parents deceased	53 (19.6)	16 (30.8)	37 (16.9)	**0.02**
Father deceased	33 (12.2)	22 (42.3)	64 (29.2)	0.07
Mother deceased	74 (27.3)	29 (55.8)	98 (44.7)	0.15
Child's sibling deceased	20 (7.4)	1 (1.9)	19 (8.7)	0.14
On ART	171 (63.1)	34 (66.7)	137 (62.6)	0.58
Duration of ART use (months)	12 (4–24)	5.5 (0–16)	3 (0–17)	0.62
Caregiver's characteristics				
Age	35 (31–42)	40 (33–45)	35 (30–40)	**0.009**
Female	198 (73.1)	36 (69.2)	162 (74.0)	0.49
Marital status				
Ever married	214 (79.0)	42 (80.8)	172 (78.5)	0.72
Highest level of education				
Primary or less	79 (29.2)	19 (36.5)	60 (27.4)	0.19
Number of years of education	11 (8–12.5)	11 (7–13)	11 (8–12)	0.48
Socioeconomic status				
Monthly rent (Ksh)	3000 (1500–6000)	3750 (2500–5000)	3000 (1500–6000)	0.45
Size of house (number of rooms)	3 (1–4)	3 (2–5)	2 (1–4)	0.07
Household person density	5 (3–6)	5 (3–6)	5 (3–6)	0.8
Toilet type				0.81
Pit	131 (48.2)	26 (50.0)	105 (47.9)	
Flush	139 (51.3)	26 (50.0)	113 (51.6)	
Shared toilet with other households	136 (50.2)	24 (48.0)	112 (51.1)	0.69

Table 1 (*Continued*)

	Number (percent) or median (IQR)			
	Total ($N = 271$)	Disclosed status to child ($N = 52$)	Not disclosed status to child ($N = 219$)	p Value*
Relationship to child				0.39
Biological mother	106 (39.1)	16 (30.8)	90 (41.1)	
Biological father	54 (19.9)	12 (23.1)	42 (19.2)	
Grandmother/Other	111 (41)	24 (46.2)	87 (39.7)	
Duration nonparent caregiver has cared for child (months)	48 (24–84)	0 (0–55)	0 (0–36)	0.25
Other children in household	2 (1–3)	2 (1–4)	2 (1–3)	0.51
Frequency of travel out of town				
Travels at least monthly	50 (18.5)	15 (28.8)	35 (16.0)	**0.03**
Have had an HIV test	190 (70.1)	32 (61.5)	158 (72.1)	0.13
Caregiver's HIV status				**0.03**
Negative	78 (28.8)	19 (36.5)	60 (27.4)	
Positive	112 (41.3)	13 (25.0)	99 (45.2)	
Unknown	81 (29.9)	20 (38.5)	60 (27.4)	
Willing to have an HIV test[b]	56 (69.1)	11 (57.9)	46 (85.2)	**0.02**
Having another HIV-infected household member	119 (44.4)	16 (30.8)	103 (47.0)	**0.03**
Preferred age of disclosure (years)	12 (10–14)	12 (10–13)	12 (10–14)	0.19
Disclosed child's status to others				
Father	98 (36.1)	14 (26.9)	84 (38.4)	0.12
Mother	62 (22.9)	10 (19.2)	52 (23.7)	0.49
Sibling	28 (10.3)	10 (19.2)	18 (8.2)	**0.02**
Relative	141 (52.0)	32 (61.5)	109 (49.8)	0.13
Nonfamily members	15 (5.5)	1 (1.9)	14 (6.4)	0.32
Other	21 (7.8)	6 (11.5)	15 (6.8)	0.26
None	20 (7.4)	5 (9.6)	15 (6.8)	0.55
Disclosure of own status to child by HIV-infected caregiver[c]	8 (7.1)	4 (36.4)	4 (4.1)	**0.003**
Disclosure of own status to others by HIV-infected caregiver[c]				
Caregiver's siblings	2 (1.8)	0 (0.0)	2 (2.0)	1
Relatives	36 (32.1)	4 (30.8)	32 (32.3)	1
Nonfamily members	5 (4.5)	0 (0.0)	5 (5.1)	1
Other	15 (13.4)	2 (15.4)	13 (13.1)	0.69
None	19 (17.0)	4 (30.8)	15 (15.2)	0.23

*Variables statistically significant ($p < 0.05$) have been bolded.

[a] Among children who were hospitalized during the past year.

[b] Among $n = 81$ not already tested for HIV.

[c] Among HIV-infected caregivers.

Table 2. Caregiver's attitudes regarding disclosure.

Characteristic	Number (Percent)
Believe HIV-infected children should know their status	213 (78.9)
Reasons disclosure is important[a]	
To care for oneself/not transmit HIV	80 (37.7)
To take or adhere to medications	61 (28.8)
Knowledge	39 (18.4)
Is of age	17 (8.0)
Avoid questions	8 (3.7)
Avoid accidental disclosure	4 (1.9)
Other	3 (1.4)
Strongly agree that caregivers should inform the child of their status	149 (55.0)
Preferred person to disclose	
Parent/caregiver alone	124 (45.8)
Caregiver and counselor	85 (31.4)
Counselor alone	37 (13.7)
Other family member	5 (1.8)
Doctor	13 (4.8)
Other	7 (2.6)
Preferred age at disclosure	
<10 years	22 (8.1)
10–15 years	233 (86.0)
>15 years	14 (5.2)
Believe child on medication should be disclosed to	173 (64.1)
Disclosed own status to child[b]	8 (7.1)
Disclosed own status to at least one person[b]	
Immediate family members	52 (53.6)
Relatives	36 (32.1)
Nonfamily members	5 (4.5)
None	19 (17.0)
Other	15 (13.4)
Disclosed child's status to at least one person	
Immediate family members	150 (55.4)
Relatives	141 (52.0)
Nonfamily members	36 (13.3)
None	20 (7.4)
Disclosed child's status to the child	52 (19.2)
Type of disclosure[c]	
Full	42 (80.7)
Partial	10 (19.3)
Person who disclosed[c]	
Health care worker	27 (51.9)
Caregiver	17 (32.7)
Relatives	3 (5.8)
Accidental	5 (9.6)
Reason for disclosure[c]	
Asked questions	4 (11.1)
Medication/adherence	17 (47.2)
Knowledge	5 (13.9)
Age/ability to understand	2 (5.5)
Illness	5 (13.9)
Other	3 (8.3)
Effect of disclosure on the child[d]	
Denial	0 (0)
Sadness and depression	16 (30.8)
Rejection of the parent/caregiver	0 (0)
Withdrawal	3 (5.8)
No effect	19 (36.5)
Other effect	18 (34.6)
Believes child does not know they are HIV-positive[e]	183 (83.9)
Child asks questions about their illness[f]	46 (25.1)
Caregiver's responses to questions[f]	
Avoids questions	7 (15.0)
Attributes illness to another etiology	11 (23.9)
Discloses co-morbid condition	12 (26.1)
Other response	16 (34.8)
Barriers preventing disclosure[d,e]	
Child too young	146 (67.0)
Unable to keep a secret	94 (43.1)
Fear of discrimination	49 (22.5)
Child will become depressed	52 (23.9)
Child will blame parents	18 (8.3)
Do not know how to tell the child	55 (25.2)
Other	33 (15.1)

[a] Among $N=212$ who believe children should know their HIV status.
[b] Among $N=112$ HIV-positive caregivers.
[c] Among $N=52$ who have disclosed.
[d] As observed by the caregiver following disclosure; caregiver can list multiple reasons.
[e] Among $N=218$ who have not disclosed.
[f] Among $N=185$ who have not disclosed and do not think child knows positive status.

Correlates of disclosure

Caregivers who reported disclosure of child's status were similar to those who did not disclose with respect to marital status, education, socioeconomic factors, and relationship to the child. For children, time since diagnosis, ART use, and duration of ART were also similar between the groups (Table 1).

Children who had been disclosed to had a higher median age than those who had not (13 vs. 8 years; $p<0.001$). Similarly, caregivers who reported disclosure had a higher median age (40 vs. 35 years; $p=0.009$). Caregivers who frequently traveled out of town were more likely to disclose than caregivers who did not travel (OR $=2.13$, 95% CI: 1.06–4.29, $p=0.03$). HIV-infected caregivers were less likely to disclose than uninfected caregivers (OR $=0.42$, 95% CI: 0.19–0.90; $p=0.03$). However, HIV-infected caregivers who had disclosed their own status to the child were more likely to disclose than HIV-infected caregivers who had not disclosed their own status (OR = 13.3, 95% CI: 2.7–64.8; $p = 0.001$) (Table 1).

Children who had been hospitalized in the past year were less likely to have had their status disclosed (OR = 0.44, 95% CI: 0.22–0.86; $p = 0.02$). When there was another HIV-infected household member or if both parents were deceased, the caregiver was less likely to disclose to the child his/her HIV status. In multivariate analyses, only child's age remained a significant predictor of disclosure (OR = 1.62, 95% CI: 1.39–1.88; $p = 0.03$) (Table 3).

Focus group responses

Focus group discussions were conducted separately with seven caregivers who had disclosed the child's status to the child and seven caregivers who had not disclosed. Table 4 includes common themes and key quotes from caregivers illustrating perceptions of caregivers regarding disclosure age, barriers, and approach.

Discussion

Disclosure of HIV diagnosis is becoming an increasingly important part of pediatric HIV care in resource-limited countries. Unfortunately, studies have shown that the majority of HIV-infected children in resource-limited countries are not aware of their HIV status (Abebe & Teferra, 2012; Biadgilign et al., 2011; Bikaako-Kajura et al., 2006; Brown et al., 2011; Kallem et al., 2010; Menon et al., 2007; Moodley et al., 2006; Vaz et al., 2011; Vreeman et al., 2010). In this study ~20% of caregivers of children aged 6–16 years in an HIV Care Program reported that their children had been informed of their HIV diagnosis. Most children in our study were receiving ART, had lost a parent, and had been in care with repeated clinic visits, providing several opportunities for disclosure. However, the disclosure rate we observed was comparable to other studies in resource-limited countries (Biadgilign et al., 2011; Bikaako-Kajura et al., 2006; Brown et al., 2011; Kallem et al., 2010; Menon et al., 2007; Moodley et al., 2006; Vaz et al., 2011) but lower than studies conducted in Europe and the USA (L. Wiener, Mellins, Marhefka, & Battles, 2007), and it suggests that caregivers in these settings face more barriers to disclosure perhaps due to higher HIV prevalence and stigma.

Table 3. Multivariate analysis of correlates of disclosure.

Characteristics	Adjusted OR	95% CI	p Value
Caregiver's age (years)	1	0.96, 1.05	0.84
Caregiver's HIV status			
Negative	1		
Unknown	0.71	0.29, 1.78	0.47
Positive	0.46	0.13, 1.63	0.33
Caregiver travels ≥ monthly	2.07	0.86, 5.00	0.11
Both parents deceased	1.47	0.56, 3.89	0.43
Child's age (years)	1.60	1.38, 1.85	<0.001
Child recently hospitalized	0.65	0.28, 1.51	0.67

Our study affirmed recently published WHO recommendations by demonstrating that caregivers in this setting believe that school-age children should know their status, and that laws and policies that reduce discrimination and stigma associated with HIV could improve willingness to disclose (Krauss, Letteney, De Baets, Murugi, & Akero, 2011). Despite the fact that few caregivers had disclosed, most (79%) believed that HIV-infected children should be informed of their status. The most commonly cited reason for nondisclosure was the child's age. Consistent with this preference, we found the most significant predictor of disclosure was the child's age and this observation was similar to other studies (Mellins & Ehrhardt, 1994; Mellins et al., 2002; Thorne, Newell, & Peckham, 2000; L. S. Wiener et al., 1996). Caregivers were concerned that the child would not keep the diagnosis private and feared subsequent stigmatization of the family; these concerns were consistent observations in previous studies (Boon-Yasidhi et al., 2005; Flanagan-Klygis, Ross, Lantos, Frader, & Yogev, 2001; Lester et al., 2002; Waugh, 2003; L. Wiener et al., 2007). Only ~40% of >10-year-olds in our study had been informed of their HIV status, which is a lower rate than observed in the USA (Grubman & Gross, 1995; Instone, 2000; L. S. Wiener et al., 1996). Consistent with this low disclosure rate, caregivers stated that the median age of preferred disclosure was 12 years. While disclosure is never easy and disclosure at an older age may enhance maturity and comprehension at disclosure, it may increase mistrust and depression (Instone, 2000) and miss earlier opportunities to optimize adherence and prevent transmission (Bikaako-Kajura et al., 2006; Hammami et al., 2004; Vreeman et al., 2010). In focus group discussions, caregivers spoke of tensions they face in considering early versus later disclosure. Waiting too late was considered suboptimal, but concerns about the child's maturity and how the child would handle the information led to delays in disclosing. In addition, the child's reactions were quite varied – some coped easily while others found it hard to comprehend their diagnosis.

Table 4. Focus group discussion themes.

Age of disclosure

"You know I think I have failed because I think the child should be disclosed to at 6, 7 years. That is my opinion though I don't have the courage to disclose up to now . . . As the child grows it is becoming harder to disclose . . . if I disclose it will just kill him." (Mother of 10 year old)

"You know when the child is 15, 16 it is not bad because s/he is growing up, can understand and can now keep a secret because if he tells his friends s/he will be ashamed of her/himself, so he will keep a secret . . .." (Mother of 12 year old)

Who should disclose to the child?

"When we bring children here I usually see them playing in groups . . . so the counselors can talk to them even if they do partial disclosure . . . it will be like the counselor is educating them . . . It should be gradual . . ." (Caregiver of 10 year old)

"Parents should disclose then the doctor to encourage the child. But if the child gets to know before you, parent, tell the child . . . it will be bad." (Caregiver of 14 year old)

Effect of nondisclosure on caregivers

"It has really affected us . . . we don't feel good . . . our hearts are troubled. You feel there is something missing in your life." (Caregiver of 12 year old)

Barriers to disclosure

"But if it was pneumonia I would have already told the child. Even when he tested TB positive I told him because it was just TB . . . . But for this 'one' a parent sees this is death and if you disclose is like killing your child by stabbing with a knife." (Mother of 10 year old)

". . . the child doesn't know the father. I left the father when the child was one and half years old. And you know they are aware of how this disease is transmitted. . . . Now if the child asks me where I got it from, where will I tell the child I got it from?"(Caregiver of 12 year old)

Reasons for disclosure

"One time I went to the toilet and I found that she had thrown the medicine in the toilet. I realized then I just have to tell her . . . At that time, she was 12 years old." (Caregiver of 16 year old)

"She started asking because of the wounds in her hair. We used to plait her and then we had to shave her hair. She used to wonder what the problem was. Then her father took her for testing and then he told her." (Caregiver of 12 year old)

Effect of disclosure on child

"From that day, she takes the medicine on her own, even when I leave her alone or she goes home for holidays." (Caregiver of 16 year old)

She just said, "Daddy, just buy me a watch" And I bought her that and she never takes it off her hand. So when seven o'clock reaches, even if there are visitors, she will leave and take her things to the kitchen. If we are just the family, she just takes them. She doesn't mind. (Caregiver of 10 year old)

"She came with her sister and told me she was happy she had been told, so that she can know what her illness is. She is happy because she is now taking medicine and she doesn't have any wounds. And when she comes for testing, they tell her that she is now tall." (Caregiver of 12 year old)

"When the doctors told him he was shocked. For two, three days when he was at home, he was just staying like this (Sitting still) . . . 'Don't people get this problem through having sex, and I have never done that?', he asked." (Caregiver of 11 year old)

Disclosure of parent's own HIV diagnosis to the child was associated with pediatric disclosure. This is consistent with previous studies in Europe, South Africa, and Ethiopia (Biadgilign et al., 2011; Moodley et al., 2006; Thorne et al., 2000). Intriguingly, we also found that HIV-negative caregivers were more likely to have disclosed the child's status to the child. Given that most HIV-infected children acquire their infection through vertical transmission (WHO, 2005), HIV-infected parents can feel guilt and fear that the child will lose respect for the parent following disclosure. Disclosure to the child can also result in simultaneous disclosure of parental status and may unveil other family secrets. Therefore, HIV-infected parents are faced with issues that make disclosure emotional and challenging.

This study had a number of strengths. Our study was larger than many previous studies and was strengthened by focus group discussions to gain a more in-depth perspective on disclosure. However, the study was limited in that it was conducted at a single health facility, which may limit generalizability, and assessed only caregiver opinions, which limits the accuracy of information on child reactions to disclosure. Subsequent studies could gain additional insight by including additional study sites and directly interviewing HIV-infected children about their disclosure experiences.

As pediatric ART has expanded, more HIV-infected children are reaching adolescence. Disclosure is consequently an important part of pediatric HIV care. Despite evidence of the benefits of disclosure, caregivers remain reluctant to disclose due to concerns including confidentiality, inadvertent disclosure, desire to avoid child depression, or guilt about HIV transmission. Although not overtly stated by caregivers in this study, the sexual transmission of HIV may pose an additional barrier to pediatric disclosure. In a South African study, only ~20% of adolescent females and ~10% of males discussed sex-related matters with their parents (Mturi, 2000). Given the wide and varied barriers to disclosure, there is a need for caregiver education on disclosure. Disclosure models informed by discussions with caregivers regarding their barriers to disclosure and models that incorporate strategies to overcome these barriers may be useful. For example, peer caregivers who have disclosed may provide specific counseling on techniques to facilitate disclosure. More training for health workers on disclosure may facilitate disclosure in practice. In addition, it may be useful for guidelines to emphasize gradualism of the disclosure process and the benefits of beginning the process early. Understanding of challenges practitioners and caregivers face regarding disclosure can facilitate development of guidelines and procedures. An ideal disclosure process will need to balance the complicated issues involved to arrive at a process that protects the health and well-being of all involved.

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