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Extent of disclosure: what perinatally HIV-infected children have been told about their own HIV status

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Abstract

How and when to disclose a positive HIV diagnosis to an infected child is a complex challenge for caregivers and healthcare workers. With the introduction of antiretroviral therapy, pediatric HIV infection has transitioned from a fatal disease to a lifelong chronic illness, thus increasing the need to address the disclosure process. As HIV-infected children mature, begin to take part in management of their own health care, and potentially initiate HIV-risk behaviors, understanding the nature of their infection becomes essential. Guidelines recommend developmentally-appropriate incremental disclosure, and emphasize full disclosure to school-age children. However, studies from sub-Saharan Africa report that disclosure to HIV-infected children is often delayed. Between 2013-2014, 553 perinatally HIV-infected children aged 4-9 years were enrolled into a cohort study in Johannesburg, South Africa. We assessed the extent of disclosure among these children and evaluated characteristics associated with disclosure. No children 4 years of age had been told their status, while 4% of those aged 5 years, and 8%, 13%, 16%, and 15% of those aged 6, 7, 8, and 9 years, respectively, had been told their status. Age was the strongest predictor of full disclosure (odds ratio 1.6 per year, p=0.001). An adult living in the household who was unaware of the child's status was associated with a reduced probability of disclosure, and knowing that someone at the child's school was aware of child's status was associated with an increased probability of disclosure. Among caregivers that had not disclosed, 42% reported ever discussing

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illness in general with the child, and 17% reported on-going conversations about illness or HIV. In conclusion, a small minority of school age children had received full disclosure. Caregivers and healthcare workers require additional support to address disclosure. A broader public health strategy integrating the disclosure process into pediatric HIV treatment programs is recommended.

Keywords

HIV; disclosure; children; South Africa

Introduction

Approximately 1.8 million children under 15 years of age are living with HIV worldwide, including 1.5 million in sub-Saharan Africa. Despite significant progress in prevention of mother-to-child transmission, about 150,000 children acquired HIV in 2015 (UNAIDS, 2016). With the introduction of antiretroviral therapy (ART), pediatric HIV infection has transitioned from a fatal disease to a lifelong chronic illness, requiring special management as children develop into adolescence and adulthood.

How and when to disclose a positive HIV diagnosis to an infected child is a complex challenge for caregivers. Guidelines recommend disclosure to school-age children and emphasize the importance of age-appropriate disclosure according to the child's emotional and cognitive development (American Academy of Pediatrics: Committee on Pediatric AIDS, 1999; National Department of Health South Africa, 2015; World Health Organization, 2011). Disclosure is described as an incremental process, beginning with “partial” disclosure in younger children (i.e., telling the child some information about the illness that is consistent with HIV but without naming HIV), and leading up to “full” disclosure when the child is informed of his or her HIV diagnosis. Full disclosure should be followed with on-going education and support, including informing the child about how the infection was acquired, the nature of HIV, and the role of ART (American Academy of Pediatrics: Committee on Pediatric AIDS, 1999; Atwiine, Kiwanuka, Musinguzi, Atwine, & Haberer, 2015; Funck-Brentano et al., 1997; National Department of Health South Africa, 2015; World Health Organization, 2011). Full disclosure is strongly recommended prior to adolescence, when children transition to managing their own health care and may initiate HIV risk behaviors (American Academy of Pediatrics: Committee on Pediatric AIDS, 1999; National Department of Health South Africa, 2015; World Health Organization, 2011).

Despite broad agreement on the importance of disclosure, interventions that support caregivers and healthcare providers in the disclosure process are limited, and many feel unprepared (Kiwanuka, Mulogo, & Haberer, 2014). Studies from sub-Saharan Africa report about 10% prevalence of full disclosure among HIV-infected school-going children up to 10 years of age (Abebe & Teferra, 2012; Atwiine et al., 2015; Brown et al., 2011; John-Stewart et al., 2013; Kallem, Renner, Ghebremichael, & Paintsil, 2011; Tadesse, Foster, & Berhan, 2015; Vreeman et al., 2014). Understanding factors associated with full disclosure may inform the development of strategies that support disclosure to HIV-infected children.

We assessed the prevalence of full disclosure in a cohort of HIV-infected children in South Africa and aimed to identify socio-demographic and clinical factors associated with full disclosure. To better understand the process of reaching full disclosure, we also investigated whether conversations about illness and HIV between caregivers and their children had occurred.

Methods

Study sample

Between February 2013 and May 2014, 553 perinatally HIV-infected children aged 4-9 years were enrolled into a prospective cohort study. Children were recruited at two sites in Johannesburg, South Africa: Empilweni Services and Research Unit (ESRU) at Rahima Moosa Mother and Child Hospital, and the Perinatal HIV Research Unit (PHRU) at Chris Hani Baragwanath Hospital in Soweto. All children had previously participated in clinical trials at these sites (Coovadia et al., 2010; Coovadia et al., 2015; Cotton et al., 2013; Kuhn et al., 2012; Violari et al., 2008) and the majority initiated ART before 2 years of age. Socio-demographic and clinical characteristics of children and their caregivers were collected at enrollment. Additionally, in a structured interviewer-administered questionnaire, caregivers were asked about discussions with the child regarding illness and HIV, including whether the child had been told his/her HIV status. Here we report a cross-sectional study of disclosure at the time of enrollment.

Definitions of disclosure

Children were classified as having received full disclosure if their caregiver answered “yes” to the question “Has your child been told his/her HIV status?”. “Partial” disclosure was assessed in four yes/no questions: (1) “Have you ever talked in general about illness with your child (not mention HIV directly)?”; (2) “Have you ever talked with your child about HIV (naming it)?”; (3) “Do you have on-going conversations with your child about illness or HIV?”; and (4) “Does the child ask questions about HIV?”. For children who had not been told their status, mention of HIV in questions 2 and 3 is presumably not about the child's infection. A “yes” response to any of these questions could reflect partial disclosure, or, could reflect misinformation provided to the child. Discussions between caregivers and children were further characterized with an open-ended question: “What have you told your child regarding why he/she is taking medications or going to the doctor frequently?”. Answers to this question were categorized manually by one investigator (PMM) and category assignment was reviewed by two investigators (SLS and RS). The following categories were assigned: 1) not discussed; 2) especially vague with some misinformation; 3) especially vague with some truth; 4) vague and true; 5) moderately specific and true; 6) specific misinformation; 7) specific and true (consistent with full disclosure).

Statistical analyses

We described characteristics of children and caregivers and tested for differences between study sites with the chi-squared test or Fisher's exact test for categorical variables and the Wilcoxon rank-sum test for continuous variables. To evaluate factors associated with disclosure, we first estimated unadjusted odds ratios (ORs) using simple logistic regression.

Characteristics marginally associated with disclosure (p-value <0.10) were included in a multivariable model to estimate adjusted ORs. We further assessed the association of each characteristic with disclosure within age groups, then tested for interaction when potential differences in effect were observed. P-values <0.05 were considered statistically significant. All analyses were conducted in SAS 9.3 (Cary, NC).

Results

Study population

Among 553 HIV-infected children enrolled in the cohort study, 550 enrolled with a caregiver who completed the disclosure questionnaire, including 281 at ESRU and 269 at PHRU. Across sites, 54% of the children were female. Those enrolled at ESRU were younger, with a median age of 5.9 years compared to 7.2 at PHRU (p<0.0001). All children had initiated ART previously; 29 at PHRU were not on ART at the time of enrollment due to prior participation in a treatment interruption trial (Cotton et al., 2013). The median age at ART initiation was 2.3 months at PHRU and 6.9 months at ESRU (p<0.0001). For the majority of children (89% across sites), the primary caregiver was the biological mother. In a quarter of all households an adult did not know the child's HIV status, and 19% of caregivers reported that someone at the child's school or crèche was aware of the child's status (Table 1).

Full disclosure

Among all 550 children, 50 (9%) had received full disclosure. The median age at disclosure was 6 years (interquartile range 5-7). Prevalence of full disclosure increased with age, from 0% at 4 years of age to 4% at 5 years, 8% at 6 years, and 13%, 16%, and 15% at 7, 8, and 9 years. In addition to age, site and some social characteristics were significantly associated with full disclosure (Table 2). In multivariable logistic regression, age remained the strongest predictor of full disclosure (OR 1.6, 95% CI 1.2-2.1, p=0.001). An adult living in the household who did not know the child's status was associated with a decreased probability of disclosure to the child (OR 0.3, 95% CI 0.1-0.9, p=0.02); disclosure to someone at the child's school or crèche was associated with an increased probability (OR 2.0, 95% CI 1.0-4.0, p=0.04) and children living in smaller households, i.e., with 0-1 other children, were less likely to know their status compared to households with more children (OR 0.4, 95% CI 0.2-0.9, p=0.02).

Child age and full disclosure—The increasing probability of disclosure associated with child age is shown within strata of selected characteristics in Figure 1. Across all ages, the prevalence of full disclosure was slightly higher at PHRU than at ESRU, although this difference did not reach statistical significance within age groups (Figure 1a). Girls were significantly more likely to know their status than boys at 5-6 years, while there was no difference by sex at 7-9 years (Figure 1b). Caregivers 40 years of age and older were more likely to report the child had received full disclosure than younger caregivers, though this difference was only significant among children aged 7-9 years (Figure 1c). While the decreased probability of disclosure among married caregivers compared to unmarried caregivers was only marginal in the cohort overall, among children aged 5-6 this difference

was significant (Figure 1d). Despite these differences limited to selected age groups, no significant interactions were detected.

Discussions about illness between caregivers and children

Among caregivers of children who had not received full disclosure, conversations about illness were reported with increasing frequency by age (Figure 2). Among caregivers of children 4 years of age, 31% reported ever having talked in general with the child about illness, increasing to 64% of caregivers of 9 year olds (p=0.009). No caregivers of children aged 4 years reported mentioning HIV directly, increasing to 5% of caregivers of children aged 5 and to 55% of children aged 9 (p<0.0001). Only 1% of caregivers of children 4 years of age reported on-going conversations about illness or HIV, while 36% of caregivers of children aged 9 years reported on-going conversations (p<0.0001). No children aged 4 years asked questions about HIV, while 22%, 16%, and 18% of children aged 7, 8, and 9 years, respectively, had asked about HIV (p<0.0001).

Among caregivers of children who had received full disclosure, 76% reported general discussions about illness, 86% reported discussions naming HIV, 90% reported on-going conversations about illness or HIV, and 62% reported the child asked questions about HIV. The prevalence of these discussions did not differ by age (data not shown).

Reasons caregivers provide the child about medication and frequent doctor visits

Among children who had not received full disclosure, in response to the open-ended question about why the child goes to the doctor frequently, nearly half (45%) of caregivers reported that it was simply not discussed, that the child never asked, or if the child asked an answer was not provided (Table 3). Among caregivers who did tell the child something about their HIV care without disclosing, most provided vague answers. Answers consistent with the truth ranged from especially vague, e.g., “because you are special” (6%), to vague, e.g., “to prevent illness” (20%) to moderately specific, e.g. “to treat a germ” (5%). Misinformation was not uncommon, with 2% providing vague misinformation such as the medications are vitamins for growth, and 18% providing specific misinformation such as telling the child his or her care was for another illness.

The majority of caregivers who reported that the child had received full disclosure answered this question consistently with full disclosure (62%). Five (10%) reported that it was not discussed because the child never asks. Two (4%) answered that the child was told misinformation. The remainder provided truthful answers with a range of specificity, from “to grow strong” to “to treat a germ”.

Discussion

In this South African cohort of perinatally HIV-infected children 4-9 years old, fewer than 10% had received full disclosure regarding their HIV diagnosis, including only 13%, 16%, and 15% of children aged 7, 8 and 9 years respectively. Among those who had not received full disclosure, fewer than half of caregivers of children aged 4-7 had ever discussed illness in general with the child, increasing to 51% and 64% of caregivers of children aged 8 and 9 years. On-going conversations about illness or HIV with the child were reported by less than

half of all caregivers who had not disclosed, including children up to 9 years of age, suggesting a reluctance to tackle disclosure with the child.

In our study, as in others (Atwiine et al., 2015; Brown et al., 2011; Tadesse et al., 2015; Vreeman et al., 2014), increasing age of the child was associated with an increased probability of full disclosure. A recent review reported a range of 1.2% to 75% full disclosure across cohorts of children from low and middle income countries; much of this variation can be explained by the wide range of ages of the children within these studies, including cohorts as young as 0 to 14 years with a mean age of 7 (with 3.2% disclosure) and others including teenagers up to age 19 (with 75% disclosure) (Pinzon-Iregui, Beck-Sague, & Malow, 2013). The low prevalence of disclosure overall in our cohort is consistent with several other studies in sub-Saharan Africa. In Ethiopia, the prevalence of disclosure was 12% in one cohort among children aged 6-10 years (Abebe & Teferra, 2012) and 8% in another cohort among those aged 5-10 years (Tadesse et al., 2015). A study of Ugandan children reported 9.5% prevalence in children aged 5-8 years (Atwiine et al., 2015), and in a Nigerian cohort, prevalence was 9% among those 6-10 years of age (Brown et al., 2011). In these same studies, prevalence of disclosure was higher among adolescents, from 30% in children aged 11-14 in Nigeria (Brown et al., 2011), 56% in children aged 13-14 in Kenya (Vreeman et al., 2014), to 74% in children aged 12-17 in Uganda (Atwiine et al., 2015). Still, guidelines recommend disclosure prior to adolescence, when children transition to managing more of their own health care and may initiate risky behaviors. Data from developing countries in other regions are limited. Two studies from Thailand report a slightly higher prevalence of disclosure, with 21% of children aged 6-10 (Oberdorfer et al., 2006) and 21% of children aged 6-12 years (Sirikum et al., 2014) having received full disclosure.

Other than the child's age, few factors have been found to be associated with disclosure to children. Comparable to a study in Uganda which found that disclosure to others in the household was associated with disclosure to the child (Atwiine et al., 2015), we found that disclosure to adult household members or to others at the child's school or crèche was associated with disclosure to the child. Whether disclosure to others at home or school provides an environment conducive to disclosure to the child, or whether disclosure to the child leads to other disclosures is not known. We might speculate that disclosure to others may provide support to the caregiver in preparation for disclosure to the child, or that other reported disclosures simply reflect an environment less driven by stigma. We also found that in homes with 2 or more other children, disclosure was more likely than in smaller households. This could reflect differences in privacy, in resource sharing, or perhaps experienced parents with more children are better equipped to engage in complex discussions.

Although not significant in multivariable analysis, the difference in the prevalence of full disclosure between ESRU (6% overall) and PHRU (13% overall) was noteworthy. While this was partially driven by the older average age at PHRU, we still observed a trend of increased disclosure at PHRU across all ages. Explicit policies on disclosure support were not in place at either site at the time. Many of the children at PHRU had been in care at that site for a longer duration than children at ESRU, and perhaps a longer relationship with the clinic

could contribute to disclosure readiness. Additionally, we observed an association between being off treatment and an increased probability of full disclosure. Because the sole reason for being off treatment in these children was prior participation in a treatment interruption trial, we believe this observation was due to an increased level of counseling in this particular trial.

We did not systematically categorize children as having received “partial” disclosure, but instead described a range of questions asked of caregivers that may indicate stages of partial disclosure. As first described by Funck-Brentano, with partial disclosure to children, developmentally-appropriate information may be shared with the child about their illness without disclosing the diagnosis (Funck-Brentano et al., 1997). We found that about a quarter of caregivers who had not fully disclosed to the child told them vague information about why they were seeing the doctor. Fewer than 5% informed children about the nature of their illness, such as to fight a germ or bug, or having been born with a chronic illness. Nearly a fifth reported telling the child misleading information about his or her illness. When asked generally if caregivers had on-going conversations about illness or HIV, few of those who had not fully disclosed responded yes. These data suggest that partial disclosure was not common in this cohort, which is consistent with other studies (Atwiine et al., 2015; John-Stewart et al., 2013). Nevertheless, roughly one fifth of children aged 7-9 who had not received full disclosure had asked their caregivers questions about HIV, suggesting potential readiness for the disclosure process among these children.

Some studies have reported caregivers' reasons for non-disclosure, including fear that the child is too young for the burden, fear of negative psychological or emotional effects, concern that the child may inadvertently disclose to others, a general sense of not knowing how to disclose, and for mothers, guilt about transmission to the child (Atwiine et al., 2015; Kiwanuka et al., 2014; Lorenz et al., 2016; Pinzon-Iregui et al., 2013). Training that emphasizes incremental disclosure may reduce caregiver anxiety around point-in-time disclosure of the diagnosis, and caregivers may feel that partial disclosure serves as protection against young children inadvertently disclosing to others. Furthermore, a developmentally appropriate incremental process may promote the child's ability to understand the nature of the diagnosis at the time of full disclosure (Lorenz et al., 2016).

Despite consistency in guidelines recommending disclosure, strategies to support caregivers and healthcare providers in this challenging process are not broadly implemented. Two studies have evaluated interventions to train healthcare workers and support caregivers in disclosure to the child (Blasini et al., 2004; O'Malley et al., 2015). Both studies reported that additional training and support not only promoted disclosure but also reduced stress and improved confidence among caregivers and healthcare providers. One of the interventions included intensive counseling and a team approach to disclosure (Blasini et al., 2004), while the other relied primarily on a cartoon book to incrementally inform the child about their illness (O'Malley et al., 2015). We are encouraged that the vast majority of caregivers in our study reported reading to the child; a reading-based intervention may be a simple and feasible option for such communities. These and other intervention strategies require further research on the practicalities of implementation and scale-up. Innovative approaches to integration of disclosure training and support for healthcare workers, caregivers, and their

children within standing pediatric ART programs are needed, and must address the long term engagement required across the spectrum of the disclosure process.

Our study has potential limitations. First, we classified "full disclosure" on the basis of one question to the caregiver. It is possible that some children classified as having received full disclosure did not actually understand their diagnosis. Additionally, our clinical trial experienced study population may have a higher prevalence of disclosure than HIV-infected children in South Africa overall. Nonetheless we do not expect that the associations between social factors and disclosure would differ in trial participants compared to non-participants. One strength of our study is the systematic report of discussions about illness and HIV. These data provide insight into the limited readiness for disclosure among these caregivers.

In conclusion, a small minority of school age children had received full disclosure in this South African cohort. Partial disclosure, which may begin with on-going conversations about illness in general, was also not common. A broader public health strategy integrating the disclosure process into pediatric HIV treatment programs is recommended.

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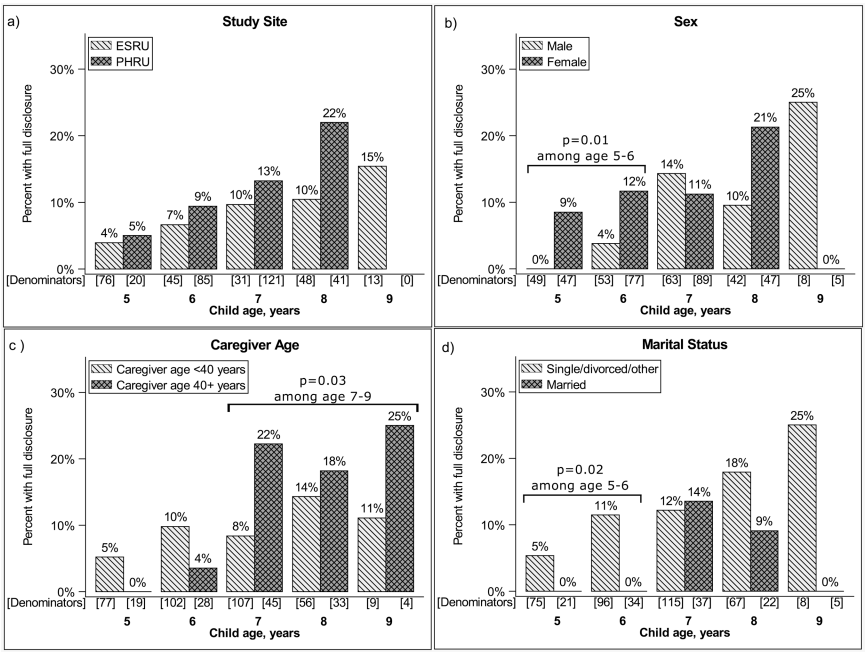

Figure 1.

Prevalence of full disclosure among children age 5-9, by child's age and a) study site, b) child's sex, c) caregiver age, and d) caregiver marital status.

ESRU = Empilweni Services and Research Unit; PHRU = Perinatal HIV Research Unit

Age was significantly associated with disclosure within subgroups, including, among children at ESRU (p=0.004) and PHRU (p=0.02); among males (p=0.002) and females (0.001); and among caregivers <40 years (p=0.005) and older (0.008). Age was marginally associated with disclosure among married caregivers (p=0.05) and was significantly associated among unmarried (p=0.0003).

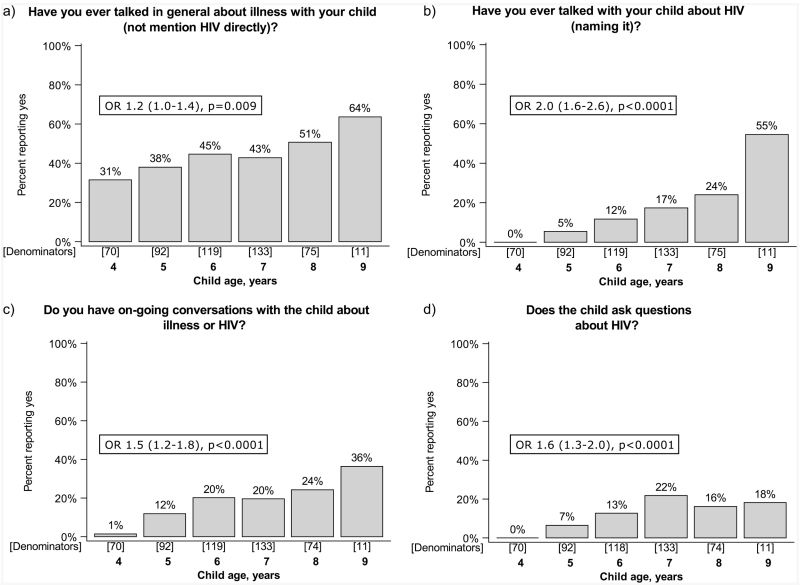

Figure 2.

Proportion of caregivers reporting discussions with the child regarding illness and HIV, by age, among children who had not received full disclosure. Odds ratios represent the association of each additional year in age with the odds of reporting each type of discussion.

Table 1

Clinical and demographic characteristics of study participants, stratified by site.

	By site			
	ESRU (N=281)	PHRU (N=269)	p-value	All children (N=550)
Child characteristics				
Sex, n(%)				
Male	140 (49.8)	113 (42.0)	0.07	253 (46.0)
Female	141 (50.2)	156 (58.0)		297 (54.0)
Age in years, median (IQR)	5.9 (5.0, 7.7)	7.2 (6.7, 7.8)	<0.0001	6.9 (5.6, 7.8)
Age at ART initiation in months, median (IQR)	6.9 (3.9, 13.1)	2.3 (1.7, 5.4)	<0.0001	4.7 (2.0, 9.4)
Currently on ART*, n(%)	281 (100.0)	240 (89.2)	<0.0001	521 (94.7)
HIV RNA <400 copies/mL**, n(%)	271 (96.8)	227 (94.6)	0.21	498 (95.8)
CD4 count, median (IQR)	1237 (933, 1525)	965 (720, 1292)	<0.0001	1096 (810, 1438)
CD4 percent, median (IQR)	36.6 (32.2, 40.5)	33.2 (28.4, 37.0)	<0.0001	34.4 (30.1, 39.3)
Ever hospitalized, n(%)				
Yes	200 (71.4)	117 (43.5)	<0.0001	317 (57.7)
No	80 (28.6)	152 (56.5)		232 (42.3)
Caregiver characteristics				
Relationship to child, n(%)				
Mother	254 (90.4)	235 (87.4)	0.26	489 (88.9)
Other	27 (9.6)	34 (12.6)		61 (11.1)
Age in years, median (IQR)	35.0 (31.0, 39.0)	36.0 (32.0, 40.0)	0.16	35.0 (32.0, 40.0)
Marital status, n(%)				
Single	191 (68.0)	199 (74.0)	0.16	390 (70.9)
Married	77 (27.4)	55 (20.4)		132 (24.0)
Divorced/widowed/other	13 (4.6)	15 (5.6)		28 (5.1)
Graduated from high school, n(%)	134 (47.7)	116 (43.1)	0.28	250 (45.5)
Has paid job, n(%)	148 (52.7)	128 (47.8)	0.25	276 (50.3)
Currently on ART, n(%)	206 (73.3)	190 (70.6)	0.48	396 (72.0)
Family and social characteristics				
Biological mother died, n(%)	9 (3.2)	19 (7.1)	0.04	28 (5.1)
Father died, n(%)	29 (10.6)	33 (12.5)	0.49	62 (11.5)
Sibling died, n(%)	52 (18.5)	34 (12.6)	0.06	86 (15.6)
Adult lives in home who doesn't know child's HIV status, n(%)	65 (23.2)	73 (27.1)	0.29	138 (25.1)
Someone at school or crèche knows child's HIV status, n(%)	46 (16.4)	56 (20.8)	0.18	102 (18.5)
Number of other children living in the home, median (IQR)	2.0 (2.0, 3.0)	2.0 (1.0, 3.0)	0.77	2.0 (1.0, 3.0)
Caregiver reads to the child, n(%)	239 (85.4)	241 (89.6)	0.13	480 (87.4)
Child sometimes goes hungry, n(%)	17 (6.1)	46 (17.1)	<0.0001	63 (11.5)

ESRU = Empilweni Services and Research Unit; PHRU = Perinatal HIV Research Unit; IQR = Interquartile range; ART = Antiretroviral therapy

*Children at PHRU who were not on ART had previously participated in a treatment interruption trial.

**The proportion with HIV RNA <400 copies/mL was estimated among children currently on ART.

Table 2

Association of clinical and demographic characteristics with full disclosure to the child.

Characteristic	N	n (%) full disclosure	Unadjusted odds ratio	p-value	Adjusted odds ratio**	p-value
Child characteristics						
Age in years*			1.7 (1.3-2.2)*	<0.0001	1.6 (1.2-2.1)	0.001
4	70	0 (0.0)				
5	96	4 (4.2)				
6	130	11 (8.5)				
7	152	19 (12.5)				
8	89	14 (15.7)				
9	13	2 (15.4)				
Study Site						
ESRU	281	16 (5.7)	0.4 (0.2-0.8)	0.006	0.6 (0.3-1.1)	0.13
PHRU	269	34 (12.6)	1			
Sex						
Male	253	17 (6.7)	0.6 (0.3-1.1)	0.08	0.6 (0.3-1.1)	0.08
Female	297	33 (11.1)	1			
HIV viral load						
Not on ART	29	7 (24.1)	3.2 (0.6-17.1)	0.18		
On ART, VL <400 copies/mL	498	41 (8.2)	0.9 (0.2-4.0)	0.89		
On ART, VL ≥400 copies/mL	22	2 (9.1)	1			
CD4 count						
<500	27	3 (11.1)	1.2 (0.4-4.3)	0.73		
≥500	515	47 (9.1)	1			
CD4 percent						
<25	43	6 (14.0)	1.7 (0.7-4.2)	0.27		
≥25	499	44 (8.8)	1			
Ever hospitalized						
Yes	317	27 (8.5)	0.8 (0.5-1.5)	0.57		
No	232	23 (9.9)	1			

Characteristic	N	n (%) full disclosure	Unadjusted odds ratio	p-value	Adjusted odds ratio**	p-value
Caregiver characteristics						
Mother is primary caregiver						
Yes	489	43 (8.8)	0.7 (0.3-1.7)	0.49		
No	61	7 (11.5)				
Age						
<40	411	32 (7.8)	0.6 (0.3-1.0)	0.07	0.7 (0.3-1.3)	0.23
>=40	139	18 (12.9)				
Marital status						
Married	132	7 (5.3)	0.5 (0.2-1.1)	0.09	0.4 (0.2-1.0)	0.06
Single/divorced/other	418	43 (10.3)	1			
Education						
Less than grade 12	300	32 (10.7)	0.6 (0.4-1.2)	0.16		
Finished high school	250	18 (7.2)	1			
Caregiver reads to the child						
Yes	480	48 (10.0)	3.7 (0.9-15.7)	0.07	3.3 (0.7-14.3)	0.12
No	69	2 (2.9)	1			
Household characteristics						
Child's biological mother died						
Yes	28	4 (14.3)	1.7 (0.6-5.2)	0.34		
No	520	46 (8.8)	1			
Child's father died						
Yes	62	6 (9.7)	1.1 (0.4-2.6)	0.87		
No	476	43 (9.0)	1			
Adult lives in home who does not know child's HIV status						
Yes	138	6 (4.3)	0.4 (0.2-0.9)	0.03	0.3 (0.1-0.9)	0.02
No	411	44 (10.7)				
Someone at school or crèche knows child's HIV status						
Yes	102	17 (16.7)	2.5 (1.3-4.7)	0.004	2.0 (1.0-4.0)	0.04
No	448	33 (7.4)				
Number of other children living in the home						

Characteristic	N	n (%) full disclosure	Unadjusted odds ratio	p-value	Adjusted odds ratio**	p-value
0-1	143	7 (4.9)	0.4 (0.2-1.0)	0.048	0.4 (0.2-0.9)	0.02
2 or more	407	43 (10.6)				
Child sometimes goes hungry due to not enough food in the house						
Yes	63	10 (15.9)	2.1 (1.0-4.4)	0.05	2.0 (0.9-4.5)	0.10
No	483	40 (8.3)	1			

ESRU = Empilweni Services and Research Unit; PHRU = Perinatal HIV Research Unit; ART = Antiretroviral therapy; VL = viral load

*Child age was entered into the logistic model as a continuous variable.

**The adjusted model includes all variables with $p<0.10$ in unadjusted analysis.

Table 3

Responses to the question "What have you told your child regarding why he/she is taking medications or going to the doctor frequently?", separately among caregivers who did and did not report full disclosure to the child.

Response category	Sample responses	Not full disclosure N=500n (%)	Full disclosure N=50n (%)
Not discussed	child never asked; will tell someday; not discussed	225 (45.0)	5 (10.0)
Especially vague, misinformation	vitamins for growth, child doesn't ask but believes the reason is another health concern	9 (1.8)	0 (0.0)
Especially vague, truth	going to the doctor for a check-up; because you are special; to grow strong	32 (6.4)	4 (8.0)
Vague and true	because you are sick; to prevent illness or going to the hospital	101 (20.2)	4 (8.0)
Moderately specific and true	because you were born with a chronic illness; will always need medication; to treat a germ or bug; to treat a problem with blood	23 (4.6)	2 (4.0)
Specific misinformation	because of a car accident; for a lung/chest/skin problem; for asthma, flu, cancer	90 (18.0)	2 (4.0)
Specific and true	HIV; checking CD4 count	0 (0.0)	31 (62.0)
Missing/don't know		20 (4.0)	2 (4.0)