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Disclosure to South African children about their own HIV status over time

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Abstract

Disclosure to children living with HIV (CLHIV) about their own status is associated with positive outcomes such as treatment adherence, but prior cross-sectional studies in sub-Saharan Africa report disclosure rates of <50%. This study aims to assess pediatric disclosure over time. 548 CLHIV were followed from 2/2013–4/2018 in Johannesburg, South Africa. Cumulative incidence of disclosure was calculated with Kaplan-Meier analysis, and disclosure characteristics assessed with a Cox model. By end of follow-up, cumulative disclosure was 70.3% (95% confidence interval: 60.0–79.9). Median age at disclosure was 9 years (range: 3–13). Baseline predictors of disclosure included older child age and the child having a history of going hungry. Prior to disclosure, 98.0% of caregivers who disclosed had conversed with their child about their illness or

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an HIV-related topic, or their child had asked about HIV, versus 88.6% of caregivers who never disclosed. While many children did not receive disclosure during this relatively large, longitudinal study of South African CLHIV, caregivers who had not yet disclosed may have been preparing to do so by discussing their child's health or HIV generally with their child. This highlights the need for clinicians to consistently support caregivers during throughout the incremental disclosure process.

Keywords

HIV; pediatric; disclosure; South Africa; longitudinal cohort study

Introduction

Antiretroviral therapy has led to improved survival among children living with HIV (CLHIV), including those in sub-Saharan Africa (Berk et al., 2005; Davies et al., 2016; Fatti et al., 2011; Patel et al., 2008). With improved survival, disclosure to school-age children about their own HIV status and discussions around treatment and the natural course of illness are increasingly important due to their association with better HIV treatment adherence and health outcomes (Madiba & Diko, 2020; World Health Organization, 2011). The child's ability to comprehend and cope with their diagnosis, as well as the caregivers' ability to cope with the stress of disclosure, are important factors for deciding when to disclose (Wiener et al., 2007).

Sub-Saharan African cross-sectional studies report pediatric full disclosure rates <50% (Atwiine et al., 2015; Brown et al., 2011; Eneh et al., 2019; Kalembo et al., 2019; Menon et al., 2007; Tadesse et al., 2015; Vreeman et al., 2010). Longitudinal studies on the subject are sparse yet critical for understanding the dynamic process of disclosure (Finnegan et al., 2019; Sutcliffe et al., 2020). The current study aims to address this gap with a substantial cohort size by assessing disclosure over time and associated factors.

Materials and Methods

Between 2/2013 and 8/2014 following caregiver recruitment by study counselors, 553 CLHIV ages 4–9 years enrolled in a prospective cohort study designed to examine the effects of early childhood events on perinatally-acquired HIV outcomes at two sites in Johannesburg, South Africa (Murnane et al., 2017; Ramteke et al., 2018). These children were prior participants in clinical studies, had initiated therapy during the first two years of life, and had detailed clinical information available. This analysis includes follow-up through 4/2018. At each six-month visit, caregivers were asked "Has your child been told his/her HIV status?" (i.e., full disclosure). Caregivers were also asked whether: 1) they had conversations with their child about their illness or medications; 2) they had ongoing conversations with their child about illness or HIV; and 3) their child had asked questions about HIV. Child food insecurity, which may be a barrier to HIV care and adherence (Young et al., 2014), was also assessed.

Statistical analysis

Cumulative incidence of first-reported disclosure was calculated among all 548 children who participated beyond the baseline visit with Kaplan-Meier analysis. To evaluate disclosure among the entire sample, one day was added to the baseline visit date of children who had already been disclosed to at baseline. Among children without disclosure at baseline, clinically important and statistically significant (in bivariate analysis) characteristics were included in a multivariable Cox regression model to evaluate predictors of full disclosure (Murnane et al., 2017). Analyses were conducted with SAS® Studio 3.8 (SAS Institute Inc., Cary, NC).

Results

Among 548 CLHIV, mean follow-up was 3.9 years (standard deviation: 0.7); 530 were retained through 4/2018. By study completion, 303 of 548 caregivers reported their child receiving full disclosure (i.e., the disclosure group). Differences in baseline characteristics compared with the non-disclosure group are reported in Table 1.

Overall cumulative incidence of disclosure by end of follow-up was 70.3% (95% confidence interval [CI]: 60.0–79.9), up from 13.5% (95% CI: 10.9–16.7) at 1 year (Figure 1 and Table 2). Probability of disclosure was higher for older children, girls, children living with adults who were all aware of their seropositivity, and children who had experienced food insecurity (Supplemental Figure 1).

Caregiver-reported child age at disclosure was not consistent over time. 124 children (40.9%) of the 303 in the disclosure group had at least two different ages reported. Using the lowest age, median age at disclosure was 9 years (interquartile range [IQR]: 7, 10; range: 3–13). Further, 80 (26.4%) caregivers reported that their child had not yet been disclosed to after disclosure was reported at an earlier visit.

Among the 498 children who had not been disclosed to at baseline, the median time to first-reported disclosure was 3.98 years (95% CI: 3.81–4.11). Compared with children enrolled at ages 4–5, those enrolled at age 6 had 3.2 times, age 7 had 6.4 times, and ages 8–9 had 9.4 times the adjusted hazard of disclosure ($p < .0001$; Table 3). Children who sometimes went hungry had 1.6 times the adjusted hazard of disclosure versus children who did not go hungry ($p = 0.0152$).

Conversations related to illness or HIV

Among the 303 caregivers who reported their child receiving full disclosure, 214 (70.6%) reported having general conversations with their child about their illness or medications pre-disclosure, versus 286 (94.4%) post-disclosure. Only 69 (22.8%) caregivers reported having ongoing conversations about illness or HIV with their children pre-disclosure, versus 276 (91.1%) post-disclosure. Before disclosure, 123 (40.6%) children had asked about HIV, versus 233 (76.9%) children after disclosure. Overall, 297 (98.0%) caregivers had already answered “yes” to at least one of the three conversation topics before disclosure.

Among the non-disclosure group of 245, 209 (85.3%) caregivers reported having general conversations with their child about their illness or medications, 37 (15.1%) reported having ongoing conversations with their child about illness or HIV, and 82 (33.5%) reported that their child had asked about HIV at least once during follow-up. 217 caregivers (88.6%) ever answered “yes” to at least one of the three topics.

Discussion

In this longitudinal cohort of CLHIV in South Africa, cumulative incidence of full disclosure was 70% at a median age of 9 years. Prior to disclosure, caregivers reported ongoing conversations with children about illness and HIV, which were less commonly reported among caregivers never disclosed during the study. Although cumulative disclosure is higher than previously reported (Atwiine et al., 2015; Eneh et al., 2019; Kalembo et al., 2019; Tadesse et al., 2015; Vreeman et al., 2010), children—especially younger ones—remained undisclosed to at the end of the study. Earlier disclosure could bring benefits to CLHIV such as improved adherence to treatment, slower disease progression, and reduced anxiety (Odiachi, 2017; Santamaria et al., 2011; Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013; Vreeman et al., 2010).

The current study found that increasing age of the child has the strongest association with full disclosure, consistent with prior work (Murnane et al., 2017; Pinzón-Iregui et al., 2013; Vreeman et al., 2013). We identified 9 years as the median age of disclosure, which is comparable with other studies conducted in sub-Saharan Africa (Atwiine et al., 2015; Brown et al., 2011; Butler et al., 2009; Guta et al., 2020; Tadesse et al., 2015), as well as South African guidelines (Department of Health, 2015).

Of interest, we found that sometimes going hungry, a measure of food insecurity, also predicted full disclosure. Mothers with lower income are more likely to disclose their HIV status to their children, perhaps because they have fewer options for child care and require their children accompany them to clinic appointments, thus making it difficult to keep their HIV status secret (Armistead et al., 2001). A similar dynamic may be at play with pediatric disclosure wherein CLHIV from food-insecure households are told their HIV status at younger ages and given greater responsibility for their own health due to fewer household resources. How these children fare with respect to psychologic and clinical outcomes remains to be determined.

Caregivers who had not yet fully disclosed to their child by end of follow-up nonetheless appeared to engage in the disclosure process by discussing illness, treatment, or HIV in general with their children. Conversely, we found that many caregivers inconsistently reported whether their child had been previously disclosed to and at what age. Inconsistent responses may reflect the challenging nature of sustained engagement in the disclosure process and lack of documentation about disclosure as it occurs, or the fact that disclosure is a process understood and experienced differently by the involved individuals.

A strength of our study is the longitudinal design which enabled us to systematically capture the temporality of the disclosure process. As previously observed in Zambia, 89.5% of

children with full disclosure first had partial disclosure (Sutcliffe et al., 2020). Advising initial partial disclosure could help alleviate some caregiver fears and allow them to assess child's readiness. Still, the nature of full disclosure requires further investigation. Notably, after one year of follow-up among Zimbabwean CLHIV who had not received disclosure at baseline, although 59.6% of these children learned their HIV status, only 17.1% also learned how they were infected, and that the virus was transmissible (Finnegan et al., 2019). Future studies should examine what CLHIV who have been disclosed to actually understand about HIV in order to identify knowledge gaps that may impact prevention of transmission and treatment adherence.

Limitations

The current study has several limitations. First, reports of disclosure and related conversations by caregivers were retrospective and susceptible to recall errors and social desirability bias. We did not ask children about disclosure and thus cannot know whether the child understood their diagnosis or other information they may have been told. Also, among the children who had been disclosed to at baseline, we do not know whether conversations about their illness or medication or questions about HIV occurred prior to or after disclosure. Finally, the study included limited measures of household wealth and resources, including social capital.

Conclusion

Older children and children with a history of food insecurity experienced higher rates of disclosure. It is important that healthcare providers encourage age-appropriate disclosure, support caregivers during the disclosure process, record what information was shared, and reinforce previously shared HIV-related information when sharing new information. Incorporating active interventions into clinical practice to encourage and support timely and meaningful pediatric disclosure and ongoing psychological and emotional support for CLHIV, especially those who are younger and from impoverished households, is warranted.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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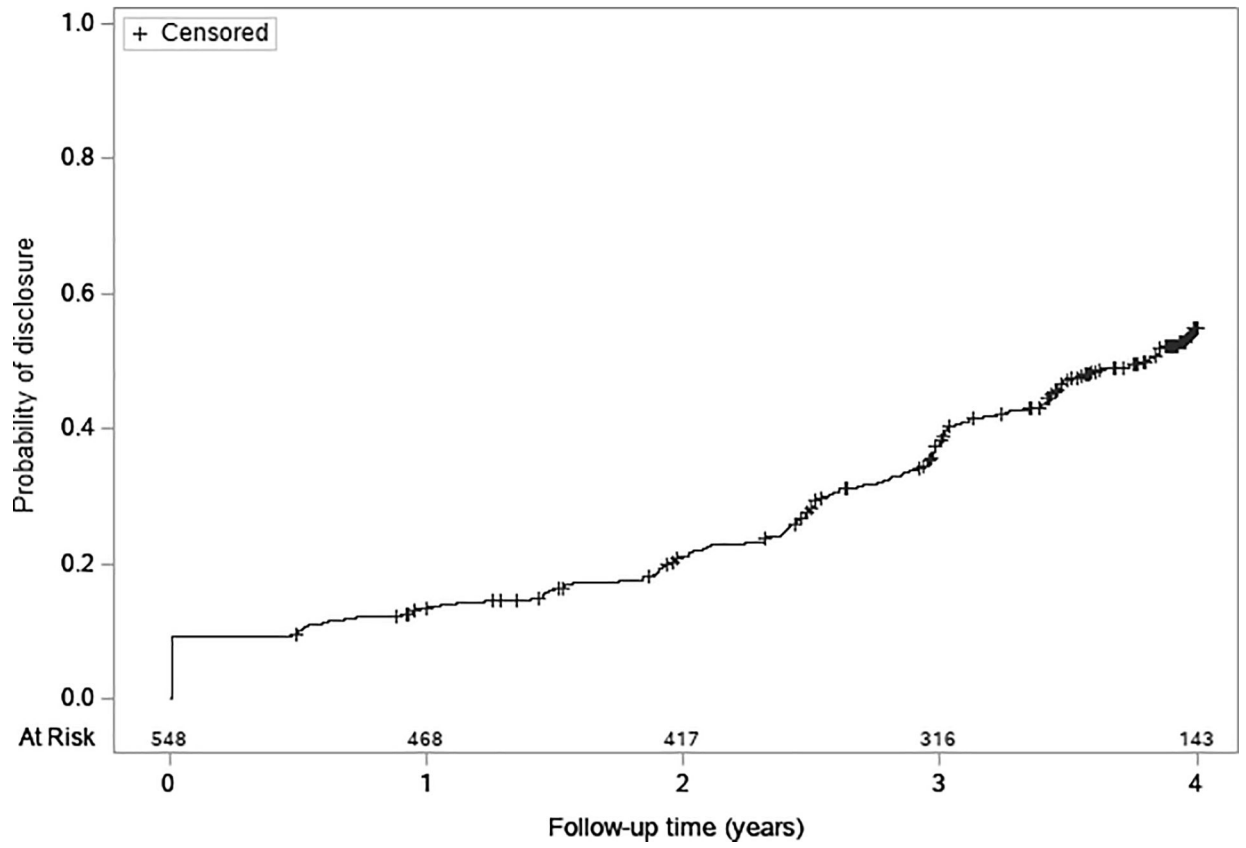


Figure 1. Cumulative incidence of disclosure over time, overall (n=548).

Table 1.

Clinical and sociodemographic characteristics of study participants at baseline, by disclosure status at end of follow-up (n=548).

	Disclosure status at the end of follow-up		p-value
	Disclosure (n=303)	Non-disclosure (n=245)	
Study site, n (%)			
ESRU	120 (39.60)	158 (64.49)	<.0001
PHRU	183 (60.40)	87 (35.51)	
Child characteristics at baseline			
Sex, n (%)			
Male	126 (41.58)	124 (50.61)	0.0349
Female	177 (58.42)	121 (49.39)	
Age in years, median (IQR)	7.00 (6.00, 8.00)	5.00 (5.00, 6.00)	<.0001
Age at ART initiation in months, median (IQR)	4.67 (1.97, 10.42)	4.60 (2.20, 7.79)	0.9825
Currently on ART ^a , n (%)			
Yes	284 (93.73)	230 (94.26)	0.4840
No	19 (6.27)	13 (5.33)	
Unknown	0 (0)	1 (0.41)	
HIV RNA <400 copies/ml ^b , n (%)			
Yes	273 (96.13)	219 (95.22)	0.6125
No	11 (3.87)	11 (3.78)	
CD4 count (no./ml), median (IQR)	1063.00 (798.00, 1421.00)	1162.00 (812.50, 1507.50)	0.0573
CD4 percent, median (IQR)	34.66 (30.85, 39.56)	34.24 (29.62, 39.22)	0.4655
Ever hospitalized, n (%)			
Yes	166 (54.79)	148 (60.66)	0.3738
No	136 (44.88)	95 (38.93)	
Unknown	1 (0.33)	1 (0.41)	
Caregiver characteristics			
Relationship to child, n (%)			
Mother	269 (88.78)	219 (89.39)	0.8205
Other	34 (11.22)	26 (10.61)	
Age in years, median (IQR)	26.00 (32.00, 40.00)	35.00 (31.00, 39.00)	0.0459
Marital status, n (%)			
Single	221 (72.94)	168 (68.57)	0.4317
Married	66 (21.78)	65 (26.53)	
Divorced/widowed/other	16 (5.28)	12 (4.90)	
Graduated from high school, n (%)	134 (44.22)	117 (47.76)	0.4095
Has paid job, n (%)			
Yes	152 (50.17)	125 (51.02)	0.6584

	Disclosure status at the end of follow-up		p-value
	Disclosure (n=303)	Non-disclosure (n=245)	
No	150 (49.50)	121 (48.98)	
Unknown	1 (0.33)	0 (0)	
Currently on ART, n (%)			
Yes	225 (74.26)	168 (68.85)	0.2306
No	62 (5.28)	65 (26.64)	
Not applicable, caregiver is not HIV+	16 (5.28)	11 (4.51)	
Family and social characteristics at baseline			
Child's biological mother died, n (%)			
Yes	282 (93.07)	235 (96.31)	0.2136
No	20 (6.60)	8 (3.28)	
Unknown	1 (0.33)	1 (0.41)	
Child's biological father died, n (%)			
Yes	254 (83.83)	218 (88.98)	0.1614
No	40 (13.20)	24 (9.80)	
Unknown	9 (2.97)	3 (1.22)	
Child's sibling died, n (%)			
Yes	52 (17.16)	36 (6.57)	0.4340
No	251 (82.84)	209 (85.31)	
Adult lives in home who does not know the child's HIV status, n (%)			
Yes	62 (20.46)	73 (29.80)	0.0293
No	240 (79.21)	172 (70.20)	
Unknown	1 (0.33)	0 (0)	
Someone at school or crèche knows child's HIV status, n (%)			
Yes	55 (18.15)	47 (19.18)	0.5922
No	239 (78.88)	187 (76.33)	
Unknown	9 (2.97)	11 (4.49)	
Number of children living in the home, median (IQR)	2.00 (1.00, 3.00)	2.00 (1.00, 3.00)	0.6960
Caregiver reads to the child, n (%)			
Yes	272 (89.77)	207 (84.49)	0.1189
No	31 (10.23)	37 (15.10)	
Unknown	0 (0)	1 (0.41)	
Child sometimes goes hungry, n (%)			
Yes	44 (14.52)	19 (7.76)	0.0246
No	258 (85.15)	223 (91.02)	
Unknown	1 (0.33)	3 (1.22)	

Abbreviations: ART: antiretroviral therapy; ESRU: Empilweni Services and Research Unit; IQR: interquartile range; ml: milliliters; PHRU: Perinatal HIV Research Unit.

Note: Statistically significant p-values <0.05 are bolded.

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

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

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Cumulative incidence of disclosure over time, overall and by baseline sociodemographic characteristics (n=548).

Table 2.

	N at enrollment	N disclosed to at baseline				N disclosed to (Probability of disclosure, %)			
		At 1 year	At 2 years	At 3 years	At 4 years	At end of follow-up			
Overall	548	50	74 (13.5)	115 (21.2)	202 (37.9)	280 (55.0)	303 (70.3)		
Study site									
ESRU	278	16	25 (9.0)	44 (16.1)	83 (31.3)	113 (45.1)	120 (51.4)		
PHRU	270	34	49 (18.2)	71 (26.4)	119 (44.6)	167 (64.7)	183 (89.5)		
Child characteristics									
Sex									
Male	250	17	29 (11.6)	46 (18.5)	80 (32.5)	116 (49.7)	126 (60.1)		
Female	298	33	45 (15.1)	69 (23.5)	122 (42.5)	164 (59.4)	177 (84.9)		
Age									
4–5 years old	163	4	4 (2.5)	9 (5.6)	18 (11.4)	31 (21.0)	36 (29.7)		
6 years old	129	11	17 (13.3)	22 (17.3)	37 (29.7)	61 (52.8)	67 (67.7)		
7 years old	153	19	26 (17.0)	37 (24.4)	79 (53.3)	104 (73.6)	115 (1.0)		
8–9 years old	103	16	24 (23.3)	47 (45.7)	68 (67.4)	84 (85.6)	85 (90.4)		
Family and social characteristics									
Adult lives in home who does not know the child's HIV status									
Yes	135	6	10 (7.4)	22 (16.8)	38 (29.4)	58 (46.7)	62 (54.0)		
No/Unknown	413	44	64 (15.5)	93 (22.7)	164 (40.6)	222 (57.5)	241 (75.5)		
Someone at school or crèche knows child's HIV status									
Yes	102	16	20 (19.6)	31 (30.3)	42 (41.2)	51 (50.0)	55 (53.9)		
No/Unknown	446	32	54 (12.1)	84 (18.8)	160 (35.9)	229 (51.4)	248 (55.6)		
Number of children living in the home									
1–2	331	25	41 (12.4)	67 (20.2)	123 (37.2)	170 (51.4)	186 (56.2)		
2	217	23	33 (15.2)	48 (22.1)	79 (36.4)	110 (50.7)	117 (53.9)		
Child sometimes goes hungry									
Yes	63	10	13 (20.6)	18 (28.9)	29 (47.1)	41 (71.4)	44 (80.2)		
No/Unknown	485	40	61 (12.6)	97 (20.2)	173 (36.7)	239 (52.9)	259 (68.3)		

Abbreviations: ESRU: Empilweni Services and Research Unit; PHRU: Perinatal HIV Research Unit.

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Table 3. Hazard ratio of disclosure over time, by baseline sociodemographic characteristics (n=498).

Study site	HR	(95% CI)	P-value	Adjusted HR ^d	(95% CI)	P-value
ESRU (Ref)	1.0	–	<.0001	1.0	–	0.4049
PHRU	1.7	(1.3, 2.2)		0.9	(0.7, 1.2)	
Child characteristics						
Sex						
Male (Ref)	1.0	–	0.0594	1.0	–	0.0563
Female	1.3	(1.0, 1.6)		1.3	(1.0, 1.6)	
Age						
4–5 years old (Ref)	1.0	–	<.0001	1.0	–	<.0001
6 years old	3.0	(1.9, 4.6)		3.2	(2.0, 5.1)	
7 years old	6.1	(4.1, 9.1)		6.4	(4.1, 10.1)	
8–9 years old	8.8	(5.7, 13.4)		9.4	(6.0, 14.5)	
Family and social characteristics						
Adult lives in home who does not know the child's HIV status						
Yes (Ref)	1.0	–	0.0585	1.0	–	0.1345
No/Unknown	1.3	(1.0, 1.8)		0.8	(0.6, 1.1)	
Someone at school or crèche knows child's HIV status						
Yes	0.9	(0.6, 1.3)	0.5517	0.9	(0.6, 1.2)	0.3542
No/Unknown (Ref)	1.0	–		1.0	–	
Number of children living in the home						
1–2 (Ref)	1.0	–	0.2270	1.0	–	0.8127
2	0.9	(0.7, 1.1)		1.0	(0.8, 1.3)	
Child sometimes goes hungry						
Yes	1.5	(1.1, 2.2)	0.0262	1.6	(1.1, 2.3)	0.0152
No/Unknown (Ref)	1.0	–		1.00	–	

Abbreviations: CI: confidence interval; ESRU: Emptilweni Services and Research Unit; HR: hazard ratio; PHRU: Perinatal HIV Research Unit.

Note: Statistically significant p-values <0.05 are bolded.
The Cox regression model was adjusted for the other variables in the table.

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