

Understanding the role of age in HIV disclosure rates and patterns for HIV-infected children in southwestern Uganda

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Highly active antiretroviral therapy has enabled HIV-infected children to survive into adolescence and adulthood, creating need for their own HIV diagnosis disclosure. Disclosure has numerous social and medical benefits for the child and family; however, disclosure rates tend to be low, especially in developing countries, and further understanding of the barriers is needed. This study describes the patterns and correlates of disclosure among HIV-infected children in southwestern Uganda. A cross-sectional study was conducted in a referral hospital pediatric HIV clinic between February and April 2012. Interviews were administered to caregivers of HIV-infected children aged 5–17 years. Data collected included socio-demographic characteristics of the child and caregiver, reported disclosure status, and caregivers' reasons for full disclosure or non-full disclosure of HIV status to their children. Bivariate and multivariate analysis was done to establish the socio-demographic correlates of disclosure. Caregivers provided data for 307 children; the median age was eight years (interquartile range [IQR] 7–11) and 52% were males. Ninety-five (31%) children had received full disclosure (48% of whom were >12 years), 22 children (7%) had received partial disclosure, 39 (13%) misinformation, and 151 (49%) no disclosure. Full disclosure was significantly more prevalent among the 9–11 and 12- to 17-year-olds compared to 5- to 8-year-olds (p -value < 0.001). The most frequently stated reason for disclosure was the hope that disclosure would improve medication adherence; the most frequently stated reason for nondisclosure was the belief that the child was too young to understand his/her illness. There was an inverse relationship between age and full disclosure and partial disclosure was rare across all age groups, suggesting a pattern of rapid, late disclosure. Disclosure programs should emphasize the importance of gradual disclosure, starting at younger ages, to maximize the benefits to the child and caregiver.

Keywords: HIV; AIDS; children; disclosure; Uganda

Introduction

Worldwide, approximately 3.2 million children below 15 years of age are living with HIV, 90% of whom live in sub-Saharan Africa (UNAIDS, 2014).

Widespread access to highly active antiretroviral therapy (HAART) has lengthened the survival of children born with HIV into adolescence and adulthood (Elise et al., 2005), creating need for their own HIV diagnosis disclosure. The World Health Organization (WHO) and other guidelines generally recommend a step-by-step disclosure process, in which information on disease is delivered gradually based on its complexity and the child's cognitive development. Nevertheless, disclosure should be considered in children of school-going age, and all adolescents should be fully disclosed to (AAP, 1999; MOH-Uganda, 2005; WHO, 2011). Studies have documented social and health benefits of disclosure such as improved social behavior, self-esteem

and school performance, and medication adherence (Biobele et al., 2011; Blasini et al., 2004; Sherman, Bonanno, Wiener, & Battles, 2000).

Several studies, however, have shown that full disclosure rates range between 3% and 29% in sub-Saharan settings, including in Uganda (Bikaako-Kajura et al., 2006; Biobele et al., 2011; Kallem, Renner, & Ghebremichael, 2011) compared to 10% and 75% in Western countries (Wiener, Mellins, Marhefka, & Battles, 2007).

To further explore this important issue, we examined the prevalence of child HIV disclosure, reasons for either disclosure or nondisclosure, and factors associated with full HIV disclosure among children in southwestern Uganda.

Methods

We conducted a cross-sectional study at a tertiary pediatric HIV clinic of Mbarara Regional Referral

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Hospital in southwestern Uganda. This clinic provides free HIV care to HIV-infected children from Mbarara municipality and the surrounding districts. At the time of the study, the clinic did not follow a structured HIV disclosure protocol.

The participants in the study were the primary adult caregivers. A primary caregiver was defined as an adult (age ≥ 18 years) who lived with the child and was responsible for their daily care, including daily medications and bringing them to the clinic. Caregivers were eligible if they cared for an HIV-infected child aged 5–17 years and if they attended the clinic between 23 February and 20 April 2012. All eligible caregivers were consented for their participation. Caregivers could respond for more than one child, if appropriate, and were consecutively enrolled to participate in the study.

A one-time, pretested, standardized structured questionnaire was administered to each caregiver by a trained research assistant. The questionnaire was completed in the local language (Runyankole) in a private room without children present to ensure confidentiality and avoid unplanned disclosure. We collected data regarding the caregiver and child's socio-demographic characteristics, what the caregiver had told the child about his/her (child's) HIV status, and why the caregiver had or had not provided information. Potential responses were offered based on literature (Biadgilign, Deribew, Amberbir, Escudero, & Deribe, 2011; Blasini et al., 2004; Kallem et al., 2011; Lester et al., 2002; Malobika, Anand, & Mahesh, 2011; Wiener et al., 2007) and our personal experiences. Finally, the child's medical records were reviewed to collect data on his/her HIV infection, diagnosis, and treatment.

The children's disclosure status was classified basing on a disclosure status pattern first described by Funck-Brentano and Costagliola (1997) as follows:

Full disclosure: The caregiver reported telling the child that he/she has HIV/AIDS, mentioning the disease specifically as HIV/AIDS or any of its local translations, describing how he/she acquired it and how it can be transmitted to others, and explaining that HIV infection is the reason he/she attends the clinic and takes medicines.

Partial disclosure: The caregiver reported telling the child some, but not all the information above or saying the child has the disease described in a way that is consistent with HIV/AIDS but not mentioning HIV by name.

Misinformed: The caregiver reported telling the child that he/she has another medical condition, like asthma or tuberculosis with the intention of deviating the child's attention from HIV.

No disclosure: The caregiver reported telling the child nothing about his/her illness.

Descriptive statistics were used to describe the socio-demographic characteristics of caregivers and children, as well as establish the prevalence of each type of disclosure and reasons for disclosure or nondisclosure. Bivariate analysis with logistic regression was performed to determine which factors were significantly associated with full disclosure. For the multivariable model, we considered variables with a significant (<0.05) univariable p -value as well as prior confounders. We excluded from the multivariable model, variables which were significant in the univariable models, but when included in the multivariable model, restricted the data-set to small sub-groups, increasing standard errors. A p -value of <0.05 was considered significant in both analyses. All statistical analyses were performed in STATA (version 11).

The research proposal was reviewed and approved by the Mbarara University of Science and Technology Institutional Review Committee. Informed consent was obtained from all caregivers. Consent/assent was not obtained from children to avoid potential unintended disclosure.

Results

A total of 312 caregivers were screened for eligibility. Ten were excluded because they were minors ($N = 2$) or were not the primary caregivers of the children they accompanied ($N = 8$). Three hundred and two caregivers were interviewed. No caregivers refused or withdrew consent.

As shown in Table 1, the median age of the caregivers was 36 (interquartile range [IQR] 30–43) years and 261 (85%) were female. The majority (182 [59%]) were the child's mother, 150 (50%) were married, 145 (48%) had only primary school education, and 160 (53%) lived in a rural setting. Information was provided for one child per caregiver with the exception of ten caregivers (3%) who provided information for two children each.

The caregivers provided data for 307 children, whose characteristics are shown in Table 2. The children's median age was eight (IQR 7–11) years and 158 (52%) were males. One hundred and twenty-six (41%) lived with both parents, while 93 (30%) lived with a single mother. Sixty-six (22%) children had lost their mothers, 93 (30%) had lost their fathers, and 60 (20%) had lost both.

The children had been in continuous HIV care for a median of 4.0 years (IQR 2.6–5.9), with a median age at diagnosis of 4.4 (IQR 2.4–5.8) years. The majority of the children (144 [47%]) were in WHO clinical stage III at entry into care. Two hundred and sixty-three (86%) children were taking HAART at the time of the study.

Table 1. Correlation between caregivers' socio-demographic characteristics and full disclosure.

Variable	N	Percent (%) with full disclosure	Unadjusted OR (95% CI)	p-value
Gender				0.910
Male	46	31.3	1	
Female	259	30.4	1.0 (0.5–2.1)	
Marital status				0.043
Married	150	24.7	1	
Widowed	73	35.6	1.7 (0.9–3.1)	
Separated	54	33.3	1.5 (0.8–3.0)	
Single/never married	28	50.0	3.1 (1.3–7.0)	
Highest education level				0.033
None	49	36.0	1.8 (0.9–3.5)	
Primary	145	23.8	1	
Secondary	66	32.8	1.5 (0.8–2.9)	
Tertiary	45	46.5	2.7 (1.3–5.6)	
Relationship with child				0.006
Mother	182	26.0	1	
Father	38	27.0	1.1 (0.5–2.4)	
Grandparent	31	29.0	1.2 (0.5–2.7)	
Other relation	54	51.9	3.1 (1.6–5.8)	
Occupation				0.166
Peasant	122	24.8	1	
Trader	109	32.4	1.5 (0.8–2.6)	
Formal employment	45	40.0	2.0 (1.0–4.2)	
Other	30	40.0	2.0 (0.8–4.7)	
Monthly income				0.278
None	37	40.5	1.9 (0.9–4.0)	
<USD \$40	151	26.3	1	
USD \$40–200	100	34.7	1.5 (0.9–2.6)	
>USD \$200	17	35.3	1.5 (0.5–4.4)	
Type of residence				0.143
Rural	160	27.3	1	
Semi-urban	91	39.3	1.1 (0.6–2.2)	
Urban	54	29.1	1.7 (1.0–3.0)	
Type of housing/dwelling				0.057
Permanent	139	34.5	1	
Semi-permanent	95	22.1	0.5 (0.3–1.0)	
Other	71	37.1	1.1 (0.6–2.0)	

OR, Odd's ratio; CI, confidence interval.

Note: Bold indicates p -values < 0.05.

As per caregiver reports, 95 (31%) children had received full disclosure, 22 (7%) had received partial disclosure, 39 (13%) were misinformed, and 151 (49%) had received no disclosure. Sixteen (10%) of the 159 children in the 5- to 8-year-old age group had full disclosure, while 46 of 62 (74%) children of the 12–17 years age group had full disclosure. The majority of the children who had received partial disclosure (14 [64%]) were in the 5–8 years age group, 5 (23%) were in the 9–11 years age group, and 3 (14%) were in the 12–17 years age group. [Figure 1](#) shows the distribution of the patterns of the children's disclosure status by age.

Results of the bivariable analyses are shown along with the caregiver and child characteristics in [Tables 1](#)

and [2](#). After controlling for the effects of other variables in the multivariate analysis, only the child's age and disclosure of their status to other household members were shown to be independently associated with full disclosure ([Table 3](#)). Older children (9–11 years) and teenagers (12–17 years) were 6.9 and 15.4 times more likely to have been disclosed to than younger children (5–8 years), respectively ($p = 0.001$ each). Similarly, children whose diagnosis had been disclosed to other people within their households were 6.0 times more likely to have had full disclosure than their counterparts whose diagnosis had been kept secret from household members ($p = 0.009$, 95% CI 1.6–23.4).

Table 2. Correlation between the children's characteristics and full disclosure.

Variable	<i>N</i>	Percent with full disclosure	Unadjusted OR (95% CI)	<i>p</i> -value
Age (years)				<0.001
5–8	159	9.5	1	
9–11	86	40.0	6.4 (3.2–12.6)	
12–17	62	74.2	27.4 (12.6–59.7)	
Gender				0.0741
Male	158	26.6	1	
Female	149	36.1	1.6 (1.0–2.5)	
Family setting				0.109
Living with both parents	106	23.1	1	
Living with single parent	99	33.3	1.7 (0.9–3.1)	
Living with other relative	62	33.9	1.7 (0.9–3.4)	
Other	40	42.5	2.5 (1.1–5.3)	
Mother alive				0.002
No	66	47.0	1	
Yes	241	27.0	0.4 (0.2–0.7)	
Father alive				0.001
No	93	44.4	1	
Yes	214	25.1	0.4 (0.3–0.7)	
Child knows mother's HIV positive				0.000
No	147	3.5	1	
Yes	94	74.3	81.1 (28.8–227.8)	
Child knows father's HIV positive				0.000
No	180	10.1	1	
Yes	34	79.4	34.3 (11.9–98.8)	
Child's status disclosed to people outside household?				0.0006
No	274	34.7	1	
Yes	33	10.5	0.8 (0.1–0.7)	
Is the child on HAART?				0.007
No	53	14.3	1	
Yes	254	34.0	3.1 (1.3–7.6)	
WHO clinical stage at entry into care				0.981
I	22	28.6	1.0 (0.3–2.6)	
II	88	31.4	1.1 (0.6–2.0)	
III	150	29.5	1	
IV	47	28.3	0.9 (0.5–2.0)	

OR, odd's ratio; CI, confidence interval.

Note: Bold indicates *p*-values < 0.05.

Table 4 presents caregivers' reasons for full and less than full disclosure. Caregivers of the majority of the children (61 [64.2%]) disclosed with the hope that disclosure would motivate adherence to treatment. The other frequently mentioned reasons were that the caregivers wanted the children to know why they were suffering (40 [42%]) and that they feared the children might transmit the infection to others (23 [24%]). The majority of these caregivers (140 [66%]) had not fully disclosed because they perceived the children as being too young to understand their illness. The other frequently mentioned reasons were the fear of inadvertent disclosure to others (66 [31%]) and fear of negative psychological and emotional effects of disclosure on the child (61 [29%]).

Discussion

We found a prevalence of full disclosure of 31% among children attending a pediatric HIV clinic in a rural, Ugandan clinic. This rate is close to that reported from an earlier study done in Kampala, Uganda of 29% (Bikaako-Kajura et al., 2006), although studies in other African settings have reported somewhat lower overall rates of 17–21% (Biadgilign et al., 2011; Biobele et al., 2011; Kallem et al., 2011). The differences in disclosure rates may be at least partially explained by age, as two of the other studies involved younger children of 0–14 years (Biobele et al., 2011) and 1–14 (Kallem et al., 2011) compared to the 5- to 17-year-olds in our study.

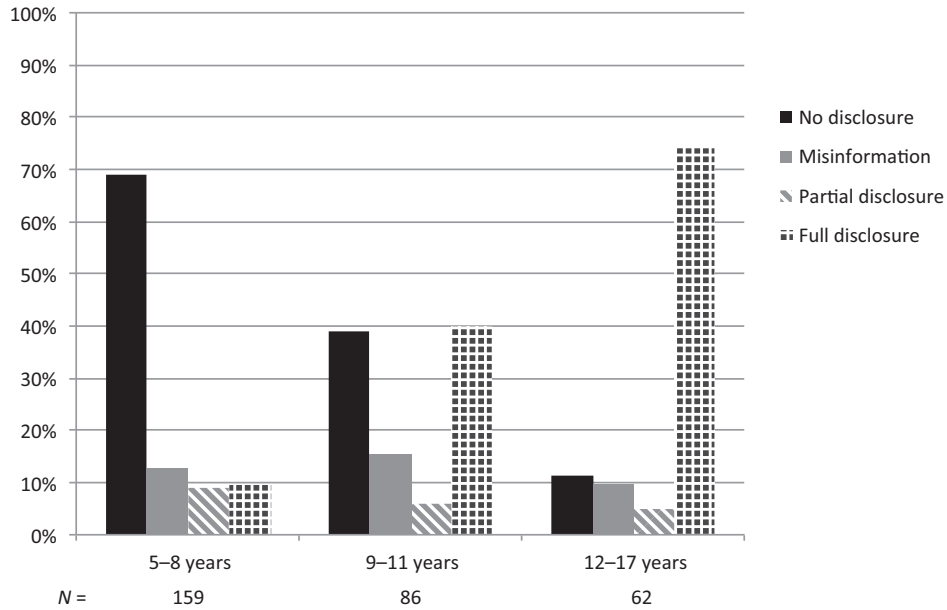


Figure 1. The distribution of patterns of disclosure among the different age groups.

Table 3. Factors independently associated with full disclosure.

Variable	N	Percent with full disclosure	AOR (95% CI)	p-value
Age (years)				<0.001
5-8	159	9.5	1	
9-11	86	40.0	5.0 (2.1-11.9)	
12-17	62	74.2	17.2 (6.3-46.8)	
Gender				0.263
Male	158	26.6	1	
Female	149	36.1	1.5 (0.7-3.2)	
Child's status disclosed to people in household?				0.009
No	274	34.7	1	
Yes	33	10.5	6.0 (1.6-23.4)	
Child on HAART?				0.073
No	53	14.3	1	
Yes	254	34.0	4.0 (0.9-18.4)	
Caregiver's level of formal education				0.566
None	49	36.0	1.6 (0.6-4.6)	
Primary	145	23.8	1	
Secondary	66	32.8	1.7 (0.8-2.9)	
Tertiary	45	46.5	1.5 (0.5-4.2)	
Caregiver's residence				0.443
Rural	161	27.3	1	
Semi-urban	89	39.3	1.5 (0.6-3.6)	
Urban	55	29.1	0.7 (0.3-2.1)	

AOR, adjusted odds ratio; CI, confidence interval.
 Note: Bold indicates p-values < 0.05.

Table 4. Reasons for full disclosure (95 children) and less than full disclosure (212 children).

Reason	Frequency (%)
Caregivers' reasons for full disclosure^a	
I hoped that disclosure would improve adherence	61 (64.2)
I wanted the child to know why he/she's suffering	40 (42.2)
I feared he/she would transmit it to others	23 (24.2)
Child repeatedly asked me why he/she was taking medicines	13 (13.7)
I thought child was old enough to understand his/her illness	12 (12.6)
Health workers insisted I should disclose	7 (7.4)
I feared that the child might know from elsewhere	3 (3.2)
It's the child's right to know his/her status	3 (3.2)
Caregivers' reasons for non-full disclosure^a	
The child's too young to understand his/her illness	140 (66.0)
I fear that the child will disclose to others	66 (31.1)
I fear negative emotional impact	61 (28.8)
I do not know how to tell the child	16 (7.5)
Health worker discouraged disclosure	12 (5.7)
I am waiting for someone else to disclose	3 (1.4)
I feel guilty about how the child was infected	2 (1.0)
I fear the child will blame me for the illness	2 (1.0)

^aMultiple responses were possible per caregiver.

Full disclosure in young children is neither expected nor often possible.

The low rates of disclosure in African settings may also be attributable to limited resources available for support to caregivers and families through this expectedly difficult communication. Additional contributors may be lack of skills and appropriate recommendations and guidelines tailored to specific settings to support health care workers who offer care to HIV-infected children. For example, at the time of the study, there was no specific disclosure policy in our clinic.

A significant finding of this study was the low rates of partial disclosure (7%), especially considering that most of the children were of school age (5–12 years), for whom WHO and other guidelines recommend partial disclosure (AAP, 1999; MOH-Uganda, 2005; WHO, 2011). A study by Malobika et al. (2011) in Northern India involving children aged 5–17 years found that no children had received partial disclosure; however, studies elsewhere in sub-Saharan Africa, which also included school-aged children, found higher partial disclosure rates of 58% (Kallem et al., 2011) and 38% (Bikaako-Kajura et al., 2006). Instead, most (61%) children in our study either had nondisclosure or misinformation, especially in the young children (5–8 years). These differences may be explained by the fact that all these studies used definitions of “partial disclosure” different from what our study used. For example, Bikaako-Kajura et al. (2006) defined partial disclosure as, “a situation in which the child is suspicious and asks questions of the caregiver about the disease and the drug.”

The patterns of disclosure stratified by age in this study reveal high levels (74%) in the 12–17 years age group and high rates (63%) of nondisclosure and misinformation among the younger children (5–11 years) and yet low overall rates (7%) of partial disclosure. This may suggest that disclosure may be conducted over a relatively short period of time, rather than a gradual process of incremental delivery of information. Although our study did not explore the disclosure process, our findings seem to suggest that children in our settings are brought rapidly from a point of nondisclosure or misinformation to full disclosure, as they advanced in age. Such an abrupt disclosure process would be in keeping with findings of two previous studies (Malobika et al., 2011; Vaz, Eng, Maman, Tshikandu, & Behets, 2010). A single disclosure conversation without adequate preparation is concerning, as it may have adverse outcomes in the child, such as loss of hope and depression (Hardy, Routh, Armstrong, Albrecht, & Davis, 1995).

In addition to the child's age, disclosure of the child's HIV status to other people within the household was significantly associated with full disclosure to the child. To the best of our knowledge, this association has not previously been reported in the literature. Since our

study was cross-sectional, we do not know if the disclosure to other people influenced disclosure to the child or whether disclosure to the child put the caregivers at liberty to disclose to other people within the household. Further qualitative research would be useful in understanding these dynamics.

Consistent with other studies (Biobele et al., 2011; Kallem et al., 2011; Vaz et al., 2010), the majority of the caregivers disclosed to their children in the hope that it would improve the children's adherence to their treatment. Other reasons included a desire to let the child know why he or she was suffering and the fear that he/she may transmit the infection to others. These reasons may be related to increased age and independence of the child. As children grow older, they tend to want to know what they are suffering from and why they take medication. Caregivers perceived older children as being both cognitively and emotionally ready and able to handle the knowledge of their illness and its implications. Older children possess a considerable risk of transmitting the infection to their friends sexually or through use of sharp instruments like razor blades.

Consistent with prior disclosure studies (Biobele et al., 2011; Kallem et al., 2011; Wiener et al., 2007) the most commonly mentioned reasons for nondisclosure in this study were the belief that the children were too young and cognitively immature to understand their illness, and fear that the child would inadvertently disclose to other people. Disclosure of a child's HIV infection to other people would, by implication, reveal the HIV status of other family members, especially the parents, since the vast majority (91%) of pediatric infections in our study setting result from mother-to-child transmission (UNAIDS, 2014). Disclosure of parental HIV status could lead to discrimination and ostracization of the family, thus creating social disharmony. As long as there is widespread stigma against people living with HIV, the fear of disclosure to other people will likely continue to hinder disclosure of HIV diagnosis to children.

A strength of this study is the inclusion of a large sample size of school-age children and adolescents, in whom disclosure is encouraged and practical. This study is limited by its cross-sectional design, which limits our interpretation of results and the fact that it focused on what the children had reportedly been told by their caregivers and not what they themselves possibly knew.

Recommendations

In sum, the low overall rate of disclosure seen in this study suggests the need for increased interventions to encourage and support caregivers. In particular, caregivers need to be educated to understand disclosure as a process and supported to recognize and act on

opportunities to initiate discussions about HIV status with their children from an early age. Health-care workers, too, need to be supported with clear, locally appropriate guidelines and training to build skills to support families through the disclosure process. These efforts will help ensure that the benefits of disclosure are realized by the children and their caregivers.

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