

# Factors affecting disclosure of serostatus to children attending Jinja Hospital Paediatric HIV clinic, Uganda

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## Abstract:

**Background:** Disclosure of HIV status is important for optimal adherence to antiretroviral therapy in children. Identifying factors that affect disclosure of sero-status to children will help improve the process of disclosure. The purpose of the study was to determine the rate of HIV disclosure by the parents/caretakers to their children and other factors affecting disclosure.

**Methods:** A cross sectional study among 174 caretakers of children age 5-18 years, twenty children and all (ten) health workers at Jinja Hospital paediatric HIV clinic. Data was collected with standardized questionnaires on socio-demographic factors, disclosure status, health facility factors, fears and perceived benefits of disclosure.

**Results:** We found disclosure rates in 56% of the children. Among those not disclosed to, non-disclosure was 19% and deception 25%. Factors associated with disclosure of sero-status to a child were age of child (X<sup>2</sup> 37.4 df 1 p< 0.001), child being on antiretroviral therapy (OR 2.0 CI 1.1-3.6 p=0.024) and child attending psychosocial support group (OR 7.4 CI 3.6-15.3 p < 0.001). There were no appropriate guidelines on disclosure and only half of health providers had training on disclosure of HIV serostatus to children.

**Conclusion:** The overall prevalence of disclosure was low. Psychosocial support groups promoted disclosure.

**Keywords:** Serostatus, Paediatric HIV Clinic, Uganda

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## Introduction

The Joint United Nations Programme on HIV and AIDS (UNAIDS)<sup>1</sup> estimates that 260 000 children became newly infected with HIV worldwide by end of 2012. UNICEF<sup>2</sup> estimates that about 190,000 children aged 0-14 years in Uganda are infected with HIV. According to Ministry of Health (MOH), of the 130,000 new infections that occur, about 18% is through mother to child transmission of HIV (MTCT).<sup>3</sup> The availability of HIV counseling, testing, and treatment with Antiretroviral Treatment (ART) during pregnancy has led to a dramatic drop in the rate of perinatal transmission, as well as significantly improved morbidity and mortality.<sup>4</sup> With increased survival, parents and caregiv-

ers of perinatally HIV infected children face the challenge of disclosure of HIV serostatus to their infected children.<sup>5</sup> Benefits of disclosure include good adherence,<sup>6</sup> improved healthcare and better dialogue among the adolescents, caregivers, and healthcare providers.<sup>7</sup> The challenges of disclosure include concerns that the child might be psychologically harmed or may not keep the secret<sup>8</sup> and fear that the stigma of AIDS will have a negative impact on their children and families Weiner et al.<sup>9</sup> Although sub Saharan Africa has one of the highest numbers of children with HIV, disclosure of HIV status to infected children has received relatively little attention.<sup>10</sup> With a high burden of HIV in children, disclosure is an issue that families, practitioners, and researchers need to address.<sup>5</sup> As an increasing number of children born infected with HIV live to older ages, the question of when and how to talk with them about their HIV status becomes more crucial. Despite the benefits of disclosure, many parents/caretakers do not disclose to the children.<sup>11,12,13</sup> There are few studies describing the development and evaluation of interventions to facilitate disclosure.<sup>5</sup>

In the MOH guidelines for HIV counseling and testing, it is stated that disclosure should be done at the judgment of the counselor and parent/guardian.<sup>14</sup> The

guidelines recommend that counselors should aim at disclosing the status of children by 10 years,<sup>14</sup> and yet there are no guidelines on how this should be achieved. World Health Organization recommends that children of school age should be told their HIV positive status but the specific age appropriate counselling advise for health workers and child's parents/caregivers are not provided.<sup>15</sup> In Jinja Hospital, efforts have been made to encourage caretakers to disclose to children by ongoing counseling and establishing psychosocial support groups. This study explored factors affecting disclosure, its consequences and prevalence of disclosure. Identifying factors that affect disclosure of sero status in children will help improve disclosure by assisting caregivers and children deal with this difficult process.

## Prevalence and patterns of disclosure

Disclosure of HIV serostatus is when the child is given information about their illness (HIV and/or AIDS). There are various patterns of disclosure, ranging from non-disclosure, partial disclosure to full disclosure. Although complete nondisclosure (no mention of HIV or of any illness) does take place, in the child's early years, partial disclosure is more common. Partial disclosure<sup>16</sup> is the term used for describing situations in which children are given some but not all information about their illness. When full disclosure occurs, children are told the name of the illness (HIV and/or AIDS), disease specific information, and how they acquired the disease. The rates of disclosure ranged from a low of 17 to 70% as reported in several studies,<sup>4,8,17,18,19,20,21,22,23,24</sup> non-disclosure 23% and deception 20% particularly in young children.<sup>17</sup> Partial disclosure was reported to vary between 35-40% by Gortmarker et al,<sup>4</sup> and Weiner et al.<sup>9</sup> Partial disclosure often occurs in conjunction with illness deception.<sup>4</sup>

There is controversy about the age of disclosure with some people advocating for disclosure as early as 5-7 years.<sup>8,23</sup> Age has been reported to be the most important predictor of whether or not the child is disclosed to.<sup>8,9</sup>

## Methodology

**Study setting:** The study was conducted at Jinja Regional Referral Hospital Paediatric HIV clinic.

**Study design:** This was a cross sectional study.

**Sampling and procedure:** Recruitment was by consecutive enrolment. Sample size was calculated using

the formula developed by Kish and Leslie<sup>26</sup>, 1965 and using 67% as the proportion of children who had been disclosed to.<sup>6</sup> Written informed consent was obtained from caretakers. The interview was conducted by the principal investigator using a questionnaire. Inclusion criteria was primary caretakers (parent or guardian who provides majority of child's ongoing daily care) of children with HIV aged 5 to 18 years. Exclusion criteria was if the caretaker was not able to give all the required information especially with regards to disclosure. The dependent variable was disclosure of HIV sero status to the child. The independent variables were child related factors including socio demographic factors like age, sex and level of education of the child, primary caretaker factors like socio-demographic factors and relationship with the child. Health facility service factors including type of pre and post test counseling, psychosocial support groups, ongoing counseling and health service provider factors. Other independent variables included perceived benefits, reasons for disclosure, fears and problems encountered, right person to disclose and health facility factors.

Children and health workers were interviewed to supplement what caretakers reported. Assent from children above 10 years old whose caretakers had consented and to whom HIV serostatus was disclosed and caretaker thought the child could discuss issues of HIV. They were interviewed using a simplified semi-structured questionnaire to assess the level of understanding of the disease and disclosure. To avoid inadvertent disclosure, caregivers were required to confirm the child's disclosure status before the interview. Health care workers in the paediatric HIV clinic were interviewed using an interviewer administered questionnaire to explore their opinions, experiences and attitudes regarding paediatric HIV disclosure, training on disclosure to children, existence and need for guidelines. The data was entered using EPIINFO and analysed using the SPSS version 12.0.1. To assess prevalence of disclosure, results obtained for prevalence were expressed as a percentage (the number of patients disclosed to was the numerator and total number enrolled was the denominator). Data was summarized using frequency tables for categorical data. Means and standard deviation were used to summarize continuous variables. Confidence interval of 95% was obtained and Chi-squared test was used to ascertain statistical significance of association between categorical variables and disclosure. Odd's ratio was used to determine the relative risk. P-values of below

0.05 were considered significant. Predictors of disclosure were determined using binary logistic regression analysis. Variables significantly associated with disclosure in the bivariate analysis were entered into the subsequent multivariate logistic regression models with disclosure as the dependent variable. Thematic analytic approach was used to analyse the responses to the answers by the health service providers.

**Ethical clearance:** Approval was obtained from Makerere University School of Public Health Higher Degrees Research and Ethics committee and Uganda National Council for Science and Technology. Permission was obtained from Jinja Hospital

**Limitations:** The study involved obtaining self reported information from respondents so there might have been bias in reporting by the caretaker especially with regards to disclosure status. We overcame this by asking probe questions to increase rigour.

## Results

### Profiles of the study sample

Between March and June 2009, interviews were conducted for 174 primary caretakers of children attending Jinja Hospital Paediatric HIV clinic and 20 children who had been disclosed to and whose primary caretaker had consented and thought the child was able to discuss issues related to HIV. Ten health workers were also interviewed.

Results for the three groups interviewed are presented together. Mean age of the children was 9.9 years (sd ±3.3), median 9 years and range was 5 to 18 years. Eighty three (47.7%) of the children were male. Eighty three (47.7%) of the caretakers were male. Only 21.3% and 11.5% had achieved tertiary and no education respectively. Considering relation of the caretaker to the child, 36% was mother, 15.5% was father and another 15.5% was both. Only 28% of caretakers were salaried employees, 24% subsistence farmers and 35% were in petty business.

### Prevalence and patterns of disclosure

Table 1 shows prevalence and patterns of disclosure. The patterns of disclosure were initially categorized as disclosed to and not disclosed to. This was further disaggregated into complete, partial disclosure, complete non-disclosure and deception. We found disclosure rates in 56% of the children. Among those not disclosed to, non-disclosure was 19% and deception 25%. For the younger children, caretakers said that much as they had been told that they had HIV, they did not seem to understand the illness well. Among children not disclosed to, 19% had been told nothing related to HIV/AIDS and about 25% overall had been told lies (table 1). In the group that had been told lies, care takers preferred to use non-stigmatizing chronic and/or co-morbid illnesses like asthma, tuberculosis, sickle cell or skin disease.

**Table 1: Prevalence and patterns of disclosure**

Type of Disclosure	Number (%)	Patterns of disclosure within disclosure category	Number (%)
Disclosed to	98 (56.3%)	Complete disclosure	75 (43.1%)
		Partial disclosure	23 (13.2%)
Not disclosed to	76 (43.7%)	Complete non-disclosure	33 (19%)
		Deception	43 (24.7%)

Bivariate analysis of factors associated with disclosure Bivariate analysis of the child related factors was done and the results are presented in table 2. There is a statistically significant relationship between disclosure of HIV serostatus to children and age of the child ( Chi Square 37.4 with 2 df . p<0.000 (Table 2). Disclosure is not distributed similarly across the different age groups (the older children are likely to be disclosed to). Sixty

eight percent of the children were attending the psychosocial support group and they were seven times more likely to be disclosed to (Table 2).

About 58% of the children were on ART. A child on ART was twice as likely to be disclosed to (p=0.024). When the duration on ART was considered, those who had been on ART for more than 12 months were more likely to be disclosed to and this was statistically significant. (Table 2)

**Table 2 Child characteristics in the disclosed and non-disclosed groups**

Variable	Disclosure status		OR	CI	p-value
	Yes Number (%)	No Number (%)			
<b>Sex</b>					
Male	45 (41.8)	38 (50 )	0.9	0.5-1.6	0.6
Female	53 (58.2)	38 (50)			
<b>Age</b>			X <sup>2</sup> 37.4	df = 2	0.000*
5-7 ψ	14 (14.3)	32 (42.1)	14.8	5.6-39.0	0.000*
8-10	32 (32.7)	36 (47.4)	7.3	3.0-17	0.000*
>10	52 (53.1)	8 (5)	1		
<b>On ART</b>					
Yes	63 (64.9)	36 ( 48.6)	1.9	1.0-3.6	0.03*
No	34 (35.1)	38 (51.4)			
<b>Duration on ART</b>			X <sup>2</sup> 8.6	df 3	0.000
0 months Ж	31 (33)	37 (52.9)	2.3	1.0-5.1	0.04
0-12 months	19 (20.2)	14 (20.0)	1.4	0.6-3.7	0.04
13-24 months	17 (18.7)	5 (5)	0.5	0.2-1.7	0.5
>24 months	27 (28.7)	14 (20.1)	1		0.04*
<b>Ariel Club</b>					
Yes 1	84 (85.7)	34 (44.7)	7.4	3.6-15.3	<0.001*
No 2	14 (14.3)	42 (55.3)			

\* Represents the significant factors

X<sup>2</sup> We used the Chi Square to analyse for statistical significance

> 10 years Ψ Is the reference category for age

> months Ж is the reference category for ART

Average age at disclosure to children was 9.22 years (s.d 3.0).

Average duration from testing to disclosure was 1.1 years with a range of zero to five years.

Bivariate analysis was done for caretaker factors and information was collected about caretaker characteristics and this is presented in table 3. Those who had tested for HIV were 2.6 times more likely to disclose com-

pared to those who had not tested. This was significantly associated with disclosure to the child as illustrated in table 4 above. Relationship to the child, level of education of the caretaker were not significantly associated with disclosure status of the child (Table 3).

**Table 3 Caretaker characteristics in disclosed and non-disclosed groups**

Variable	Disclosure		OR	CI	P value
	Yes N (%)	No N (%)			
<b>Relationship to child</b>					
Biological parents					
Yes	66 (67.3)	51 (67.1)	1.1	0.5-1.9	0.97
No	31 (32.7)	26(32.6)			
<b>Highest Level of education</b>					
0 (None + Primary)	84 (86.7)	65 (43.6)	1.2	0.5-2.8	0.684
1 (Post primary)	13 (13.3)	12 (15.8)			
<b>Occupation</b>					
Salaried + Business	36 (37.5)	24 (32.9)	1.2	0.7-2.3	0.54
Other	60 (62.5)	49 (67.1)			
<b>Caretaker ever tested</b>					
Yes	80 (81.6)	48 (63.2)	2.6	1.2-5.2	<b>0.006*</b>
No	18 (18.4)	28 (36.8)			
<b>Sex of caretaker</b>					
1 Male	19 (19.4)	22 (28.9)	0.6	0.3-1.2	0.14
2 Female	77 (80.6)	55 (71.1)			

### Multiple logistic regression of factors associated with disclosure

Multiple logistic regression was used to control for confounding. All risk factors that were found to be significantly associated with disclosure of HIV serostatus to children at bivariate analysis ( $p$  value  $< 0.05$ ), and all plausible factors that were not significant during bivariate analysis were put into logistic regression analysis (Table 4). Age of the child, being a member of the psy-

chosocial support group and caretaker having tested for HIV remained significantly associated with disclosure even on multivariate analysis. Being on ART was not significant on multivariate analysis. Each unit increase in the age of the child increases the Odds of being disclosed to by a factor of 1.5. Attendance at a psychosocial support groups shows a positive relationship indicating that the more a person attends the psychosocial support group the higher the likelihood that the child is disclosed to.

deception 25%. Factors associated with disclosure of sero-status to a child were age, being on antiretroviral therapy, attending psychosocial support group, and parents/caretakers having tested for HIV.

The rates of complete disclosure among HIV infected children aged 5 to 18 years in this study was 43.1% which is similar to that reported by Mialky et al<sup>27</sup> in Philadelphia where the rate of disclosure was 43%. This is possibly because the age groups studied were similar. However, the rate of disclosure in this study is higher than 19.8% reported in Thailand by Boon-Yashidi et al.<sup>8</sup> This could be because the age group he studied was younger. Secondly, the rates of disclosure could be higher in this study because many of the children are attending the psychosocial support groups where HIV is discussed.

In this study, partial disclosure was about 12% and this is lower than that reported by Gortmarker et al.<sup>4</sup> who reported partial disclosure as the most common with rates of 40%. This could be so because in our study, the children who were told lies about their diagnosis were categorized under non-disclosure. Gortmarker et al reported that a similar pattern of partial disclosure often occurred in conjunction with illness deception.<sup>4</sup> Partial disclosure may be considered as part of the process of disclosure. Among children that were told lies about their illness, most of the lies were about co-morbid conditions, which seemed more acceptable and less stigmatizing. This is similar to a study reported by in which deception often entailed caregivers telling their children only about a co-morbid condition, and attributing all medical needs to that less-stigmatized condition.<sup>17</sup>

Average age at disclosure was about 9.2 years. This is similar to other studies<sup>8,27</sup> where the mean age of disclosure was 9.6 years and 9 years respectively. This is probably because at this age, cognitive development of illness begins.<sup>28</sup> The youngest age of disclosure in this study was 5 years and this is in line with what some experts are advocating for, disclosure as early as 5 to 7 years.<sup>25,29,30</sup> However, in this study, most of the caretakers thought that younger children did not seem to understand the implications of HIV diagnosis. Most of the children thought the optimal age for specific discussions about an HIV infected child's health should be conducted at an average age of 10 years. This is similar

to the thoughts of the care takers who suggested that specific discussions regarding HIV infection should be delayed to a median of 10 years.<sup>10</sup> It is also in agreement with the theory of child's cognitive understanding of illness, which considers the age from 9 to 10 years and older as the best time for HIV infected children to know about their sickness as at this age children can understand about causes of illness and its consequences.<sup>28</sup>

Attending the psycho social support group was significantly associated with disclosure and this could be because caretakers share their experiences and lessons learnt, including passing of information on HIV to children. This is similar to a study in Italy where family group psychotherapy had a positive impact on the environment of HIV-infected children, promoting psychological well-being and the disclosure of the HIV status to children.<sup>31</sup> Being on ART and duration on ART was significantly associated with disclosure. It is similar to a study by Menon et al.,<sup>32</sup> in Zambia who reported that children on antiretroviral therapy were most likely disclosed to. However the findings in this study are different from what was reported in Thailand where being on ART and duration on ART were not significantly associated with disclosure.<sup>33</sup> This could be explained by the counseling that is done prior to starting ART in which the caretakers are given information and encouraged to disclose hence empowering the caretaker with knowledge to discuss with the child. Caretaker having tested him/herself was associated with disclosure. This is related to studies by Mellins et al., Weiner et al. and Ledlie.<sup>9,13,34</sup> which showed that those caretakers who were HIV negative were likely to disclose. This is possibly because of the pre and post test counseling that the caretaker could have received when he/she had her own-test.

The investigators found that most of the caretakers (90%), children (85%) and all health workers thought that disclosure had improved adherence. Paediatric HIV providers believe that disclosure is important for helping children understand the need for ART and create trusting relationships that facilitate adherence,<sup>6,35</sup> In Mildmay Centre Uganda, complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence.<sup>6</sup> In Brazil, Marques et al. 2006 found that despite its initial negative impact, disclosure resulted in improved healthcare and better dialogue among the adolescents, caregivers, and

**Table 4: Adjusted Odds Ratios from multivariate analysis**

Variable	Unadjusted Odds Ratio	Unadjusted p value	Unadjusted 95% CI	Odds Ratio	95% CI	p-value
Member of psychosocial support group	7.4	0.001	3.6-15.3	5.0	2.1-10.8	< 0.001*
Age of the child	X <sup>2</sup> 37.4	0.000	df=1	1.5	1.2-1.6	< 0.001*
Caretaker having tested for HIV	2.8	0.005	1.4-5.6	0.5	0.2-0.9	0.03*
Whether patient is on ART or not.	1.9	0.03	1.0-3.6	0.9	0.33-2.5	0.79

Eighty seven percent of the primary caretakers 87% (85/98) said that disclosing serostatus had helped the child to take drugs better, and about 10% (9/98) felt relieved for telling the truth. Like the caretakers, 85% (17/20) of the children thought it was good to be disclosed to. All health workers (10/10) interviewed thought that the possible benefits of disclosure were to improve adherence, positive living, improve quality of life and build self esteem and confidence among the HIV positive children. Problems encountered by caretakers during the process of disclosure included not knowing what to say 36 (40%), no problem 30 (34%), guilt of transmission 6 (7%) and other problems 17 (19%) included fear of many questions from the children, fear to hurt the child, not in position to handle the depression resulting from disclosure and thoughts of dying after disclosure.

### Health service factors

Ten health workers in the HIV clinic were interviewed and these included; three paediatricians, one medical officer, one clinical officer, four nurse counselors and one dispenser. They handle issues of disclosure but without reference to any specific guidelines. Only five of the health workers had training directly addressing issues

of disclosure in children and this was included in the counseling course for paediatric HIV.

The health workers said they were not aware of guidelines for disclosure in children except for one who had seen those adopted locally for an institution. All health workers thought there was need for these guidelines at National level. All health workers thought that caretakers should be supported during the process of disclosure especially in cases where the parents have failed to disclose. If they completely fail, then the health worker should do the disclosure.

### Discussion

Mother to child transmission (MCT) accounts for about 18% of the new infections in Uganda. Standard antiretroviral therapy has lead to improved quality of life, reduced morbidity and mortality. Despite benefits of disclosure, some caretakers do not disclose to children their own HIV status. The study was designed to identify prevalence of disclosure and factors affecting disclosure of HIV sero status to children aged 5 to 18 years attending Jinja Hospital Paediatric HIV clinic. We found disclosure rates in 56% of the children. Among those not disclosed to, non-disclosure was 19% and

healthcare providers.<sup>7</sup> This could also be explained by the fact that when a child knows the reason why he/she is taking the medication, he is likely to co-operate.

Only half of the health workers had been trained in disclosure to children and there were no guidelines to refer to. This is similar to the situation in Thailand where there were no guidelines for disclosure.<sup>36</sup> The consequences of not having guidelines are that healthcare providers would approach disclosure issues differently with uncertainty. In this study, health workers thought that the health workers role was to support the disclosure process. This is similar to a study conducted by Myer et al. 2006 in South Africa.

**Conclusions:** The overall prevalence of disclosure was low. Parents and health workers should be adequately empowered to deal with the process of disclosure. Establishing psychosocial support groups, adequate counseling for the care takers, training health workers and developing/disseminating culturally appropriate and age-specific guidelines on disclosure of serostatus to children would help deal with the difficult process of disclosure.

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