

Mukhtar-Yola M  
Kuczawski M



## Barriers and impact of disclosure of HIV status to children at the National Hospital, Abuja Nigeria

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Mukhtar-Yola M (✉)  
Department of Paediatrics,  
National Hospital Abuja, Nigeria  
Email: mariyamukhtar@yahoo.com

Kuczawski M  
School of Health and Related  
Research  
University of Sheffield, England

**Abstract:** *Background:* HIV infected children survive to adolescence because of anti retroviral therapy, however, only a small proportion know their diagnosis. Disclosure is critical to long-term disease management, yet little is known about if, how, and when disclosure takes place and the barriers associated with it, and its impact on children in resource-limited settings.

*Objective:* This study set out to determine the process of and barriers to HIV disclosure in children as well as the immediate impact of this on children and their caregivers.

*Methods:* A cross-sectional study was done June-July 2016 using a structured questionnaire, convenience sampling and quantitative methods at the infectious disease clinics of National Hospital Abuja. A sample of 164 caregivers of HIV positive children aged 5 to 16 years receiving antiretro-

viral therapy for at least one year were enrolled.

*Results:* Prevalence of full disclosure was 24.5%, partial 22.7% with overall prevalence of 47.2%. Main barrier to disclosure was child's age and fear of informing others. The impact of disclosure on caregivers was relief in 45.5% but emotional and difficult for others. Immediate reactions by children were sadness; tearfulness and worry in 28.6%, some showed no reaction while others even expressed relief. On a longer term, disclosure had several effects. Main predictors of disclosure on regression were the child's age and caregiver's opinion on disclosure.

*Conclusion:* The prevalence of full disclosure is low and several barriers affect disclosure. Caregiver's and HCWs need empowerment and support with culturally appropriate skills and platforms to deal with the barriers, process and impact of disclosure.

### Introduction

Children with Human Immunodeficiency Virus (HIV) are surviving to adolescence and adulthood because of the increasing long-term use of antiretroviral therapy. Disclosure to the child about his HIV status is an important component of long-term disease management, yet there is limited knowledge of when and how this takes place in developing countries as well as the barriers and impact of disclosure on children.<sup>1,2</sup>

Nigeria with a HIV prevalence of 3.2 % has the second highest numbers of people living with HIV/AIDS in the world.<sup>3,4</sup> An estimated 3.4 million people are living with the virus including 380,000 children aged 0 to 14 years.<sup>3</sup>

Disclosure simply means to “reveal, to make known, to make public or share an information on an issue.”<sup>5</sup> Disclosure in the context of HIV could be about informing children about their own HIV status or the HIV status of their caregivers.<sup>2</sup> In this context however, disclosure refers to the former. Disclosure can be full where the child is informed that he has HIV/AIDS or partial in which case the child is informed that he has a

chronic illness for which he needs to be on treatment for a long time. It's prevalence in children and adolescents from sub-Saharan African studies ranges between 1.7-56.7%.<sup>1-8</sup> These are generally low considering the benefits of disclosure which have been reported to result improved adherence to medications, higher CD4 counts, higher self-esteem and fewer symptoms of depression.<sup>6-8</sup>

Additionally, disclosed adolescents may be better able to seek social support, have improved coping skills and improved communication with caregivers<sup>9,10</sup> as well as practice safer sexual practices to prevent secondary transmission.<sup>8</sup> Disclosure to children and adolescents also reduces the stress, burden and depression parents feel by hiding the diagnosis from their children.<sup>1,11</sup> Care givers often require a step by step guide or support from HCW or others on how to conduct disclosure. Lack of these skills often lead to non-disclosure.<sup>1,14</sup>

Despite all these identified benefits, the prevalence of disclosure is low due to several barriers. In rural Zambia,<sup>12</sup> Mweeba et al reported the fear of stigma and discrimination to the child as a significant barrier to disclosure. Other reported barriers include the fear of the

child's reaction, the fear of blame on the parents and the reaction of others in the community if the child is unable to keep the secret.<sup>2, 13-19</sup> The age when the child will be old and mature enough to be able to understand what the mother disclosed was a significant barrier reported across several studies.<sup>2, 11, 15, 16, 20-22</sup>

There is limited literature on the impact of HIV status disclosure on children and little is known about the quality of life thereafter. In a survey in South Africa involving caregivers of children aged 4-17 years, 61% of the children showed no reaction on disclosure while 36% were sad and withdrawn and 10% were worried and tearful.<sup>15</sup> Similarly, Mutumba in Uganda reported that Adolescents in their cohort had both negative and positive reactions. Negative reactions included hopelessness, fear of death, sadness, anger, and even suicidal considerations.<sup>16</sup> On the contrary, a small number reported positive reactions such as relief and happiness at learning their diagnosis or discovering the family secret. Reactions to disclosure were closely related to knowledge about HIV and ART, respondent's health status at the time of disclosure, prior experiences with HIV-infected persons, age, and gender.<sup>16</sup> For instance, respondents who were well, described their initial reactions to disclosure as shock and disbelief, while adolescents who were frequently ill were not surprised at the diagnosis, and even experienced relief at learning the cause of their illness.

Disclosure is crucial to long-term disease management, several reports have associated it with improved medication adherence, self esteem and improved communication with caregivers.<sup>6-10</sup> This study aims to determine the process of and barriers to HIV disclosure in children as well as determine the immediate impact of disclosure on children and their caregivers.

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## Methodology

**Study design:** A primary study with a cross-sectional design was conducted over 6 weeks in June - July 2016 using convenience non-randomized sampling and quantitative methods. A structured pre-piloted questionnaire prepared in English with closed-ended questions and pre-coded responses in some sections was used. Questions were structured into five sections to cover: socio-demographic characteristics, disclosure and its processes, facilitators and barriers to disclosure as well as type of support received during disclosure as well as immediate impact of disclosure.

Interpreters were used where necessary and the questionnaire applied to those who found filling it challenging. It was administered in a private room away from the children to ensure confidentiality and avoid unplanned disclosure.

**Study Participants and setting:** Participants were recruited from the paediatric antiretroviral clinic of National Hospital Abuja, a tertiary center that serves as a referral hospital not only to the district hospitals within

town but also from neighboring states and beyond. These participants were caregivers of HIV positive children aged 5 to 16 years receiving antiretroviral therapy for at least one year who had read the patient information sheet and consented to participate in the study.

**Sample size:** As this was a prevalence study, the confidence interval formula for surveys was used to determine the estimated sample size of 180. Ethical approvals were obtained from ethical review boards of both the University of Sheffield, UK and the National Hospital Abuja Nigeria.

**Data Management:** Respondents were assigned a unique identifier and the questionnaire was anonymised with no personal identifiers collected. The data was extracted from the questionnaires by the researcher, cleaned and validated and stored electronically in a folder in a password-encrypted computer. This was done simultaneously as the data was being collected. Analysis was done within a month following completion of data collection. The paper forms of the data were stored away in a securely locked cupboard and will be destroyed 6 months after the completion of the study.

### *Information, verbal consent and confidentiality*

A month prior to the onset of the study, poster containing information about the study was posted on the notice boards of both clinics. The purpose was to sensitize caregivers about the study before it started. Subsequently, Participant information sheet were also provided highlighting the aims and importance of the study. The researchers assured them of full confidentiality and anonymity as well as data protection. Additionally, participants were informed of their right to withdraw from the study

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## Results

Although a sample size of 180 was projected, 170 were enrolled because of industrial action in the hospital. Of the 170 participants that were eligible, 164 participants consented to participate giving a response rate of 96.5 %.

### *Socio-demographic characteristics*

The children's age ranged between 1-16 years with a mean of 10.5 years (SD 3.58) while the mean age at diagnosis was 3.5 years (SD 2.98) with a range of 0- 13 years. The mean age at enrolment into care was 3.8 years (SD 3.89). The majority of children had been on ART for more than 4 years (119; 72.6%), 3-4 years in 22 (13.4%) and for at least one year in 9 (5.5%). The mean duration on ART was 4.4 years (SD 1.12). The male to female ratio of 1.6:1 and 70% of the children were either in primary or Junior Secondary School. Majority of the caregivers, 162 (98.8%) lived in the same household as the child. Forty-three (30.7%) of biological fathers had died compared to 6 (4.3%) biological

mothers. Fathers had higher levels of education and more professional jobs compared to the mothers.

### Prevalence of disclosure

The prevalence of formal disclosure was 47.2% of which full disclosure was done in 24.5%, and partial disclosure was done in 22.7%. About 52.8% of the participants did not have any formal disclosure. The mean age of the children at full disclosure was 11.87 SD 2.065. Details of these have been reported earlier.<sup>23</sup>

### Disclosure process

Disclosure was considered a process by 62 (81%) of the caregivers as they reported informing the children gradually about the chronic illness they had before eventually telling them that they had HIV/AIDS. However, for 15 (19%) caregivers, disclosure was considered a one-time event as they informed the children of their status at one sitting. Caregivers along with HCW (28; 36.1%) or both parents together (24; 31.2%) mainly undertook the process of disclosure (table 1).

Support prior to disclosure was received by 40 (51.9%) caregivers while 37 (48.1%) reported not receiving any support. Of those that were supported, 38 (95%) reported that the process was explained to them. Support was provided by Healthcare workers (HCW) in 36 (90.0%) cases, by a support group in 3(7.5%), by family members in 1(2.5%).

**Table 1:** Responsible person for disclosure (n=77)

Responsible person	Frequency	Percent (%)
Father	9	11.7
Mother	10	13.0
Parents together	24	31.2
HCW	5	6.5
Parents and HCW	28	36.1
Others	1	1.3
Total	77	100

### Barriers to disclosure

One hundred and sixty three responders identified several reasons for not disclosing or for delaying disclosure to children. The single most common reason was the fear that the child will inform others (51; 31.3%), followed by the child was too young in 30 (18.4%). Additional barriers identified include fears that the parent will be blamed for transmission, fear of the child's resentment, feeling unprepared for the questions that will follow disclosure and feeling unprepared for the disclosure process. A combination of reasons were also identified such as child was too young and can inform others 20 (12.3%). (Table 2)

### Impact of disclosure

#### Impact on caregiver

Of the 77 caregivers that either partially or fully disclosed to their children, 35 (45.5%) reported feeling

relieved after disclosing, 9 (11.7%) described the process as very emotional, 7 (9.1%) felt it was a realistic thing to do while 8 (10.4%) felt it was both emotional and difficult. Other caregivers reported a combination of feelings or responses such as empowering, practical and valuable.

### Impact on the child

The immediate reactions to disclosure by the children are shown in Table 3

**Table 2:** Identified barriers to disclosure

Barriers	Frequency (n=163)	Percent (%)
Fears of child informing others	51	31.3
Child too young	30	18.4
Fear of child's resentment	7	4.3
Feeling unprepared for questions	12	7.4
Feeling unprepared for disclosure	14	8.6
Parental fear of blame for transmission	8	4.8
<i>Combined reasons</i>		
Too young and may inform others	20	12.3
Too young and fear child's condition may deteriorate	12	7.4
Too young, may inform others and condition may deteriorate	9	5.5
Total	163	100

**Table 3:** Immediate reaction of children following disclosure (n=77)

Response	Frequency	Percent %
Tearful or cried	15	19.5
Withdrawn and unresponsive	15	19.5
Relief	5	6.5
Anger	2	2.5
Inquisitive and asked questions	4	5.2
Sad, tearful and worried	7	9.1
Surprised	7	9.1
No reaction	22	28.6
Total	77	100

There were mixed reactions, as some were tearful and cried (15; 19.5%), some were relieved (5; 6.5%) and others showed no reaction (22; 28.6%).

When the caregivers were asked about the effect that disclosure has had on the children over time, several responses were obtained (Table 4) with the majority reporting that disclosure improved medication adherence (44; 57.1%) while 4 (5.2%) refused medications after disclosure.

### Bivariate Analysis

To identify if there was an association between disclosure and some independent variables, bivariate analysis was done. There was no statistically significant difference between those that disclosed and those that did not in relation to gender (Pearson's  $\chi^2$  1.676, P 0.196), religion (Pearson's  $\chi^2$  0.32, P 0.858), ethnicity ( $\chi^2$  for trend 0.690, P 0.406) or if a child had any siblings (Pearson's  $\chi^2$  2.402, P 0.121). However there was a significant rela-

relationship between disclosure and the child's level of education ( $\chi^2$  for trend 26.710,  $P < 0.001$ ), support for disclosure ( $\chi^2$  4.399,  $P = 0.036$ ) and if caregiver held the opinion that children should have disclosure done (Pearson's  $\chi^2$  30.174,  $P < 0.001$ ) (Table 5).

An independent sample T test was also done to find any association between the age of the child at his last birthday and disclosure. The mean age at disclosure was 11.87 (SD 3.290) while for the non disclosed 9.07 (SD 3.154). The mean difference was 3.158  $P < 0.001$ ; SE 0.507; 95% CI 2.156-4.159.

**Table 4:** Effect of disclosure on children and adolescents (N=77)

Response	Frequency	Percentage
Coping better in school	10	13.0
Taking medications regularly (adherence)	44	57.1
Refused medications	4	5.2
Protection of self and others	4	5.2
<i>Multiple responses</i>		
Coping better and improved medication adherence	5	6.5
Improved adherence, positive outlook to life and self protection	6	7.8
Coping better, improved adherence and a positive outlook to life.	4	5.2
Total	77	100

**Table 5:** Relationship between disclosure and some independent variables

Independent Variable	Disclosure		Chi square $\chi^2$	P Value
	Yes (%)	No (%)		
<i>Socioeconomic status (n=163)</i>				
Upper	24(48.0)	26(52.0)	0.246#	0.620
Middle	27(42.0)	37(58.0)		
Lower	26(53.0)	23(47.0)		
<i>Mothers Education (n=151)</i>				
University	18(72.0)	7(28.0)	2.818#	0.093
National Diploma	18(39.0)	28(61.0)		
Secondary school	25(48.0)	27(52.0)		
Primary school	6(27.0)	16(73.0)		
No formal education	4(67.0)	29(33.0)		
<i>Duration on ART (years) n=163</i>				
At least 1	0(0.0)	9(100.0)	4.360#	0.037*
1-2	5(71.0)	2(29.0)		
2-3	2(29.0)	5(71.0)		
3-4	10(46.0)	12(54.0)		
>5	60(51.0)	58(49.0)		
<i>Do you think the child should be told his status n=162</i>				
Yes	75(58.0)	55(42.0)	30.174\$	<0.001*
No	1(3.2)	30(96.8)		
<i>Support for disclosure =163</i>				
Yes	40(53.0)	35(47.0)	4.399\$	0.036*
No	37(42.0)	51(58.0)		
<i>Would you recommend disclosure to other parents n=163</i>				
YES	73(51.0)	71(49.0)	5.917\$	0.015*
NO	4(21.0)	15(79.0)		

**Table 6:** Logistic regression model showing predictors of disclosure

Characteristic	Coefficient B	Standard Error	Wald	Significance	Odds ratio	95% Confidence Interval.	
						Lower	Upper
Age of the child	2.83	0.62	20.837	0.000	1.328	1.176	1.499
Caregivers perception on disclosure	3.649	1.049	12.090	0.001	38.424	4.914	2.542
Support for disclosure	0.153	0.398	0.148	0.700	1.166	0.534	2.542
Constant	-6.42	1.244	26.989	0.000	0.002		

### Binary Logistic regression

Independent variables found to be significantly associated with disclosure were further subjected to a binary logistic regression model (Table 6). In the final model, only the age of the child ( $P < 0.001$ , 95% CI 1.176-1.499) and the caregiver's opinion ( $P = < 0.001$ , 95% CI 4.914-2.542) on whether disclosure should be done or not were significant. The odds of being disclosed per year of increasing age were 1.35 times the odds of not being disclosed i.e as the age increased, odds of being disclosed increased by 0.35 (35%). Similarly, for one unit change (opinion child should be told), the odds of being disclosed to are 38.4 times the odds of not being disclosed.

### Discussion

This primary cross-sectional study, set out to determine the process of HIV disclosure to children, identify barriers influencing disclosure as well as explore the immediate impact of disclosure on children.

Most of the Caregivers (81%) perceived disclosure as a gradual process, informing children they had a chronic illness requiring long-term treatment to encourage medications while waiting not only for the child to get older but also to prepare themselves for disclosure. However, 19% considered it a one-time event, informing the children at one sitting. Vaz et al<sup>19</sup> reported that even though parents reported disclosure as a gradual event, the children saw it as a discrete event. Madibba et al<sup>20</sup> found that biological parents approached disclosure as a process after dealing with their own personal fears over the child's diagnosis while non-biological caregivers often blurted out the diagnosis impulsively often during moments of emotional outbursts. This study did not explore children's opinion on disclosure and did not find any difference in the type of disclosure between different caregivers.

In this study, both parents (31.2%), the parent or caregiver assisted by the HCW (36.1%) or the mother alone conducted disclosure most of the time. Support on how to conduct disclosure was provided to 51.9% of the caregivers and 95% of them were confident that the process was explained to them. Caregiver support for disclosure seemed statistically significant towards disclosing, however, contrary to expectations; in the final regression model this was not sustained. This effect may be better assessed in a larger study. Several reports from resource-poor countries have identified that parents did not feel

adequately prepared for disclosure, due to limited skills<sup>14,19,24</sup> and most requested the support of HCWs. In Tanzania,<sup>25</sup> where disclosure was mainly carried out by HCWs, the need for training and provision of simple to follow step-by-step guidelines was recommended. Several disclosure models appropriate to developing countries<sup>26-29</sup> have been developed to provide the much-needed guidance by HCWs as the guideline by WHO<sup>30</sup> does not provide a step-by-step approach. The Integrated Nigerian National guideline for HIV prevention treatment and care does have a section on disclosure but it is very brief and inadequate.

The most common reasons caregivers identified as barriers to disclosure were the fear that the child may inform others and being too young. This is understandable because in Nigeria, the extended family system is very vibrant with the large family living in one big compound and the children sharing meals and playing together. Should the young child share the “secret” of HIV status with friends it almost automatically discloses parental status to the rest of the family and friends leading to stigma, discrimination and loss of respect. Other barriers identified by the caregivers included feeling unprepared to disclose, fear of blame for transmission as well as concern for the child’s physical, mental and emotional health. Several other studies reported similar findings from Africa<sup>2,16,20,21,31,32,38</sup>. Additionally, Madibba<sup>21</sup> identified barriers such as caregivers not knowing what, how and the right time to tell as well as the fear of associating the diagnosis with death and dying.

Clearly, many of these barriers can be addressed by provision of early counseling by HCWs and provision of support services as well as mass media education on stigma reduction.

Disclosure had an impact both in the short and long term on the child and the caregivers. It brought a feeling of relief to a majority (45.5%) of caregivers and for others, it was very emotional and difficult. This is not unexpected as parents often carry a heavy burden of guilt especially with mother to child transmission of HIV.

The immediate reactions to disclosure by the children were mixed and probably age and maturity related. Possibly, the majority of those that showed no reaction might be younger children who are yet to comprehend what they are being told. Some of the children expressed surprise while others expressed relief. A small proportion were inquisitive and asked questions. Similar findings were described in other studies.<sup>15, 21,22</sup> There were no reports of hopelessness or suicidal ideations in this study compared to reports by Mutumba.<sup>16</sup> Clearly, there is a need for the person conducting disclosure to be prepared on how to handle the multiple ways these children can react. As such the need for training and retraining on disclosure strategies and responses.

On a longer term, many caregivers expressed that disclosure had helped the children improve on medication adherence some were coping better in school and had a more positive outlook on life. Caregivers also expressed that disclosure had empowered the adolescents to protect

themselves and others. In the report by Brown et al,<sup>2</sup> caregivers reported improvement in adherence by up to 63.6%. Other authors reported that disclosure reduces the children’s anxiety, allows them to communicate better with family and peers as well as reducing the impact of stigma.<sup>20,21, 25</sup>

Although there are limited studies on potential negative consequences of full disclosure, Lesch et al<sup>11</sup> showed that there was no evidence that disclosure had a long term negative impact on children’s psychological and emotional health outcomes. Additionally, Phuma et al<sup>17</sup> explored the experiences of disclosed 10-14-year-olds and concluded “children move from being worried about taking life-long medications to acceptance of their diagnosis. They also expressed unhappiness that their parents delayed disclosure.” Inston<sup>33</sup> also reported that children that are not disclosed to tend to internalize problems and become poor communicators. On the contrary, Zhao et al<sup>34</sup> found that there was no difference in psychological measures between disclosed and undisclosed children. Clearly, there is a need for more studies to determine these effects in African Children.

No matter the argument, the subject of disclosure of HIV status to children is a very sensitive one. As pointed out by some researchers,<sup>35-36</sup> although clinical guidelines can enhance the quality of clinical decisions and the consistency of care, it is essential for HCW to consider the culture in which the patient is immersed, as culture is the basis for understanding social interactions, behaviours, and the meaning of actions.<sup>37</sup> This is very relevant to the African society, where parents are often seen as authority figures and communication between a parent and child is often unidirectional and directive. This may explain the wide disparities between the more developed nations<sup>38-39</sup> with disclosure rates of up to 75% and low resource settings. Due to such traditional hierarchies in African settings, parents are likely to experience some loss of control and respect from their children when they disclose. It is essential for the HCWs to be sensitive and recognize this while trying to teach the parents new sets of communication skills that will provide a platform for open discussion with their children. The study has several identified strengths. A sample of 164 participants and a response rate of 96.5% is a good number with sufficient power for a cross-sectional study. Secondly, the study was conducted in a national referral centre for Pediatric HIV care based in the Nigerian capital city. This provides a good representation of participants from different ethnic groups and social classes. Thirdly, the questionnaire was piloted prior to sample collection. This allowed adjustment of questions to make them clearer to participants.

The study also had several limitations. Like all cross-sectional designs, there was potential for selection and information bias. The research was conducted in a treatment centre and one of the inclusion criteria was being on ART for at least one year. Being on ART may have a compounding effect on disclosure, even though in this study, the duration on ART was not found to be signifi-

cantly associated with disclosure. Additionally, because of the cross-sectional design, only associations could be ascertained and not causal relationships.

Secondly, because of industrial action that took place at the hospital, the desired sample size of 180 could not be reached and 164 caregivers were interviewed.

It is recommended that the Nigerian National guidelines should be reviewed to provide adequate, step-by-step age-appropriate guide to healthcare workers on disclosure. Pictorial Job aids should also be developed to

capture the various stages of disclosure. These guidelines should be disseminated to all treatment centres and used to train HCWs. Support groups should be empowered with adequate, appropriate knowledge and skills to support each other.

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