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## Disclosure of HIV status to infected children in a Nigerian HIV Care Programme

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With increasing survival of HIV-infected children, parents face the challenges of disclosure to the children. The aim of this study was to assess the rate of HIV disclosure to children in Ibadan and the factors influencing it in order to guide design of strategies for successful disclosure. A semi-structured questionnaire was administered to consecutive consenting caregivers of HIV-infected children aged  $\geq 6$  years attending the Paediatric Infectious Disease Clinic of the University College Hospital, Ibadan, between November 2008 and October 2009. Caregivers of 96 children (46 boys, 50 girls) infected with HIV were interviewed. The ages of the children ranged from 6 to 14 years with a mean (SD) of 8.8 (2.2) years. Disclosure had been done in only 13 (13.5%) of the children; ages at disclosure ranged from 4.5 to 13 years with a mean of 8.7 (SD = 2.2). Disclosure was associated with age above 10 years. Reasons given by carers for non-disclosure in 83 caregivers included inability of the children to understand in 53 (63.9%), fear of disclosure to other children 34 (41.0%), fear of disclosure to family/friends in 28 (33.7%), fear of psychological disturbance of the children in 26 (31.3%) and fear of blaming the parents in 22 (26.5%). Twenty (20.8%) of the children have asked questions relating to their diagnosis and the responses are often evasive. Caregivers felt disclosure had helped adherence to antiretroviral therapy in 7 (63.6%) of the 11 children on antiretroviral drugs in whom there was disclosure but no effect on the remaining. There is a need to assist parents and health care providers in successfully disclosing HIV status to infected children without adverse consequences.

**Keywords:** disclosure; paediatric HIV; Nigeria

### Background

In high resource settings, the use of highly active antiretroviral therapy (HAART) has led to increasing survival of HIV-infected children. In the UK and Ireland, 1313 vertically infected children had been enrolled in the Collaborative HIV Paediatric Study by 2007 of whom about half were aged 10 years or over and 8% already enrolled in adult services (Foster et al., 2009). With the recent availability of antiretroviral therapy in Nigeria, survival of children is expected to improve. Although there are no longitudinal studies on perinatally infected Nigerian children, age spectrum of HIV-infected children in a cross-sectional study included children up to the age of 16 years most of whom were perinatally infected (Ugochukwu, 2006). With increased survival, one challenge that parents and caregivers of perinatally HIV-infected children face is disclosure of HIV serostatus to their infected children and many caregivers fear that such communication may create

distress for the child. The American Academy of Pediatrics encourages disclosure of HIV infection status to school-aged children (American Academy of Pediatrics [AAP], 1999). Studies have examined the psychological impact of both disclosure and non-disclosure with mixed results. While some workers have reported more psychological disturbances in children and families where disclosure had not taken place (Bachanas et al., 2001), others (Mellins et al., 2002) found little or no difference in psychological functioning between disclosed and non-disclosed children. Similar research on disclosure and adherence to antiretroviral therapy has revealed mixed findings (Hammami et al., 2004; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004).

Nigeria has the second highest number of people living with HIV in the world after South Africa. HIV seroprevalence rate among antenatal clinic attendees was 4.6% in the year 2008 and 220,000 children less than 15 years were estimated to be living with HIV in 2007 (National Agency for the Control of AIDS

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[NACA], 2010; UNAIDS/WHO, 2008). Yet there is a dearth of information on HIV disclosure in the country. This study assessed the rate of HIV disclosure to children in an HIV Care Programme in Nigeria and the factors influencing it in order to guide design of strategies for successful disclosure.

## Methods

This study took place in the Paediatric Infectious Disease Clinic of the University College Hospital, Ibadan, Nigeria. It involved interviews with caregivers of children enrolled in the HIV Care Programme in the Hospital. All caregivers gave consent and ethical approval obtained from the Joint Ethics Committee of the University of Ibadan and University College Hospital Ibadan, Nigeria.

Caregivers of HIV positive children aged six years or more were invited to participate in the study. A semi-structured questionnaire was administered to consecutive consenting caregivers in the absence of the children to ensure confidentiality and avoidance of unplanned disclosure. The study took place between November 2008 and October 2009. The questionnaires contained 42 questions and were administered by trained HIV counsellors who were staff of the clinic, after additional training on the use of the questionnaire. Approximate time taken to administer each questionnaire was 20 minutes. Data obtained included socio-demographic variables, whether or not disclosure had taken place, age at disclosure if it had been taken and preferred age of disclosure and reasons for either disclosure or non-disclosure. Disclosure in this study referred to telling the child specifically that he/she had AIDS or a viral infection called HIV. Data analysis was done using SPSS version 15.0 software.

Means and standard deviations were computed for continuous variables and categorical variables presented as frequencies. Association between categorical variables was tested using Chi-square test and Fisher exact as appropriate: statistical significance set at  $p < 0.05$ .

## Results

There were 262 children aged 0–14 years that were being followed up in the clinic comprising 166 (63.4%) aged 0–5 years and 96 (36.6%) aged 6–14 years.

Caregivers of all 96 HIV-infected children aged  $\geq 6$  years were interviewed. The children comprised 46 boys and 50 girls yielding a male:female ratio 0.92:1. The ages of the children ranged from 6 to 14 years with a mean (SD) of 8.8 (2.2) years. The caregivers interviewed were the mothers in 54 (56.3%) cases, fathers in 16 (16.7%) cases, stepmothers in 5 (5.2%) cases, grandmothers in 10 (10.4%) cases and grandfathers in 3 (3.1%) cases. Others were aunts in 2 (2.1%) cases, uncles in 3 (3.1%) cases, sisters in 2 (2.1%) cases and a cousin in 1 (1.0%) case.

Mode of HIV acquisition was vertical in 82 (85.4%), through blood transfusion in 8 (8.3%) and unknown in 6 (6.2%) of the children.

Based on caregiver reports, disclosure had been carried out in only 13 (13.5%) of the children; ages at disclosure ranging from 4.5 to 13 years with a mean of 8.7 (SD = 2.2) years. Table 1 shows the relationship between socio-demographic variables in the children and disclosure.

Disclosure had been carried out in 11 (14.5%) of 76 children on antiretroviral therapy compared to

Table 1. Relationship between socio-demographic variables in children and disclosure.

Variable	HIV status disclosed	HIV status not disclosed	Total	Fisher exact test (two-sided significance)
Sex	Male	4	42	0.238
	Female	9	41	
	Total	13	83	
Age (years)	6–10	7	69	0.026*
	11–14	6	14	
	Total	13	83	
Education	Nursery/primary	9	75	0.055
	Secondary	4	8	
	Total	13	83	
Orphanhood	Both parents alive	6	40	1.00
	Orphan	7	43	
	Total	13	83	

\*Significant.

2 (10%) of 20 children yet to start antiretroviral therapy (Fisher exact two-sided significance  $p = 1.0$ ). Mean duration of antiretroviral therapy in the 11 children disclosed to was 20.9 months compared to 21.6 months in 63 children to whom their HIV status had not been revealed ( $t$ -test  $p = 0.897$ ).

Disclosure had been done for 6 (13.0%) of the 46 non-orphans, 4 (16.0%) of the 25 maternal orphans, 1 (5.3%) of the 19 paternal orphans and 2 (33.3%) of the 6 double orphans.

Disclosure was done by the mother in 6 (46.2%) cases, by the father in 3 (23.1%) cases, and by the step-mother, maternal aunt, paternal grandfather in 1 (7.7%) case each. One child (7%) became aware of his HIV status during a conversation between his caregiver and doctor. Disclosure took place in the hospital in only two children and at home in the remaining children. Three of the children expressed sadness following disclosure and the remaining 10 showed no reaction.

The decision of the caregivers to disclose was based on questioning by the children regarding the reason for the use of the drugs in three cases, questions on what illness they were suffering from in three cases, the caregivers' perceived need to disclose when the children were ill in two cases, the need to facilitate adherence to antiretroviral therapy in one case and the belief that the child was mature enough to know in one case. The reasons for disclosure to the remaining three children were not specified. The reasons given by caregivers for non-disclosure are shown in Table 2.

Twenty (20.8%) of the children have asked questions relating to their diagnosis and the responses by the carers have included silence, evasive responses and sometimes lies. Sample questions from children and responses from caregivers are shown in Table 3.

The age of the child believed to be most appropriate for disclosure ranged from 5 to 20 years with a mean (SD) of 13.4 (3.1) years. Caregivers' suggestions of preferred persons for disclosure are shown in Table 4. Parental disclosure was preferred by 63.5%

of caregivers followed by disclosure by both health workers and parents in the same setting (14.6%).

When asked if disclosure of HIV status to the children was important, 91 (94.8%) said it was important, 4 (4.2%) caregivers said it was not important and 1 (1%) was not sure if it was important. Eighty-nine (92.7%) believed disclosure was important in achieving adherence to antiretroviral therapy while the remaining 7 (7.3%) said it was not important.

Seventy-six (79.2%) children were on antiretroviral therapy and caregivers felt that disclosure had helped adherence in 7 (63.6%) of the 11 children on antiretroviral drugs in whom there was disclosure but no effect on the remaining 4 (36.4%). Adherence was said to have improved in 4 (66.7%) of the 6 children aged 10 years or less and in 3 (60%) of the 5 children aged above 10 years (exact significance  $p = 1.0$ ).

## Discussion

The disclosure rate of 13.5% observed in this study is low. It is similar to 14% reported by Arun, Singh, Lodha, and Kabra (2009) in India but lower than 30.1% in school-aged children in Thailand (Oberdorfer et al., 2006). However, in the latter study, the caregivers' understanding of "knowing" did not always mean that the children were told the name of "HIV" or "AIDS" unlike in our study in which all the children to whom their HIV status had been revealed were told they had HIV infection. A study in South Africa revealed a much lower disclosure rate (9%) than our study but their study population was much younger, 74% of them were younger than 6 years of age (Moodley, Myer, Michaels, & Cotton, 2006). A disclosure rate of 37.8% in adolescents aged 11–15 years was reported by Menon, Glazebrook, Campain, and Ngoma (2007) in Zambia. In a study based in the United States, Cohen et al. (1997) observed that disclosure had been carried out in 42% of school-aged children at a mean age of 8 years. The higher disclosure rate observed in the United States may reflect a better enlightenment of the parents and understanding of the importance of disclosure. The mean age at disclosure in our children was 8.7 years and similar to 8 years reported by Cohen et al. (1997) in the United States, 8.1 years by Moodley et al. (2006) in South Africa and 9.2 years reported by Oberdorfer et al. (2006) in Thailand. On average, disclosure seems to occur between 8 and 9 years of age.

Our findings support those of previous studies that identified a child's age as a determining factor for HIV disclosure in children (Cohen et al., 1997; Oberdorfer et al., 2006): children older than 10 years were more likely to have been disclosed to than those

Table 2. Reasons for non-disclosure in 83 children.

Reasons*	Number	Percentage
Child too young to understand	53	63.9
Fear of disclosure to other children	34	41.0
Fear of disclosure to family and friends	28	33.7
Fear of psychological disturbance in children	26	31.3
Fear of blaming parents	22	26.5
Fear of refusal of drugs	10	12.0

\*Multiple response.

Table 3. Sample questions and comments from some children and caregivers' responses.

Questions/comments	Responses
For how long shall I continue these drugs?	The doctor will decide at the right time.
I am tired of taking the drugs.	The doctor insists you take them.
I am tired of taking drugs.	No response.
What are the drugs for?	The drugs are for treatment of malaria.
When will I stop the drugs.	You need to continue using them to remain strong.
When will I stop using the drugs?	Pray that God speaks to the doctor.
Why do I always come to the hospital?	To be treated for pneumonia.
Why am I taking drugs daily?	Your type of illness killed your father, refusal leads to death.
Won't these drugs get finished.	I do not know.
What is wrong with me?	Something is wrong with your blood.

who were younger. However, in the study of Cohen et al. (1997), 95% of children older than 10 years were aware of their status in contrast with disclosure in only 30% of children of that age group in our study reflecting our generally lower disclosure rate.

In the present study, the most common reason for non-disclosure was the belief that the child was too young to understand followed by fear of disclosure to other persons. Similar reasons have been reported in various studies but having different weightings in different parts of the world. In a study in London based on 13 families with children who acquired HIV by vertical transmission, the most frequently given reason for delay in talking to the children about HIV was fear that the children may accidentally reveal their diagnosis, thereby simultaneously revealing maternal HIV status and exposing the family to potential stigmatisation, discrimination and prejudice (Waugh, 2003). The most common reason for non-disclosure reported by Oberdorfer et al. (2006) was the fear that disclosure might have negative psychological consequences to the child; this was the fourth most common reason in our study.

Most caregivers in the present study said that disclosure was important but would rather delay it till the child is older. The preferred age of disclosure ranged from 5 to 20 years with a mean age of 13.4 years. Majority of the caregivers in the study by Arun

et al. (2009) preferred mid-teen age as the appropriate time for disclosure. Teenagers are at risk of engaging in sexual activities and yet lack the experience to do so in a safe manner that may result in the spread of HIV (Bamidele, Abodunrin, & Adebimpe, 2009). Therefore, whilst caregivers may like to delay disclosure to teenage, they need to be counselled on the risks of their children engaging in sexual activities before disclosure. None of the caregivers in our study however, raised this issue as a source of concern.

An important reason for which disclosure is advocated is its perceived facilitation of adherence to antiretroviral therapy. In our study, most caregivers opined that disclosure would help in improving adherence. In almost two thirds of the children on antiretroviral therapy in whom their HIV status had been revealed, caregivers reported improved adherence but no effect on the rest. In a study based in Uganda, adherence to antiretroviral therapy was reported to be better in children for whom disclosure had been done (Bikaako-Kajura et al., 2006). In another study, while some children became more cooperative after disclosure, others became more difficult, refusing to go the hospital (Hammami et al., 2004). There is, therefore, need to exercise caution in the process of disclosure so it will only lead to desirable effects.

Sometimes, when children do not feel sick, they do not understand why they have to take medications. Therefore, caregivers gradually explain to their children that they had to take the medication to prevent the onset of illness, but they preferred not to mention HIV until the child would understand the meaning. The fear is "the child is too young to understand; he would possibly start talking about it at school" (Hammami et al., 2004). This is tantamount to partial disclosure of HIV status. A similar approach was used by some caregivers in the present study in response to HIV related questions raised by children. Responses such as "there is something wrong with your blood", "the same illness killed your father" and

Table 4. Caregivers' preferred persons to perform disclosure.

Person	Frequency	Percentage
Parents	61	63.5
Health worker and parents at the same instance	14	14.6
Health worker with parental consent	11	11.5
Other family members	2	2.1
Others	8	8.3
Total	96	100

the need to continue using drugs “to avoid relapse” represent partial disclosure.

Apart from the burden of prolonged use of drugs, children also become curious of frequent hospital visits. Some of the responses given by parents when asked by their children about frequent hospital visits included deception or attributing the illness to another medical condition such as pneumonia or malaria. A particular caregiver said HIV drugs are used for treatment of malaria. Similar observations of deception have been reported by Funck-Brentano et al. (1997) and Oberdorfer et al. (2006). Some other caregivers are at a loss as to how to respond to questions from children and rather remain silent. Of greater concern, however, are responses that may instil fear such as telling the child that he is afflicted with the same kind of illness that killed his father and refusal of drugs would lead to death. Even though, this might make the child take the drug, it has a great potential for psychological disturbances in the child. Other methods employed by caregivers to ensure adherence to drug usage include the use of bribes and force on the children as reported in Uganda (Bikaako-Kajura et al., 2006). Lack of disclosure, therefore, seems to make adherence difficult for both the caregiver and the child.

Most caregivers (63.5%) believed that the parents should be responsible for disclosure. This is similar to observations by Arun et al. (2009) in India and Oberdorfer et al. (2006) in Thailand where 42% and 57%, respectively, of caregivers believed the parents were the most appropriate persons to carry out disclosure. However, unlike in the study by Oberdorfer et al. where 43% of caregivers preferred disclosure to be done by the health care provider, in the present study only about a quarter of caregivers agreed that support by health workers is needed in the process of disclosure, this comprises 14.6% who preferred disclosure by parents and caregivers at the same instance and 11.5% who preferred disclosure by health workers after parental consent. In keeping with caregiver preferences, disclosures in our study were done most commonly by parents especially mothers followed by other family members. The unexpected disclosure to a child during a conversation between a parent and a doctor calls for caution in discussions during medical consultations.

Clinicians can aid with disclosure issues in several ways. First, providers can help parents think about disclosure as a process, rather than a single event or point in time. In this regard, caregivers may require education about the possibility of *partial* disclosure – gradually increasing the child’s understanding over time. Parents may also benefit from peer support, speaking with other caregivers concerning disclosure

to an HIV-infected child – either individually or in a group (Klitzman, Marhefka, Mellins, & Wiener, 2008). There is, therefore, need for specific programmes to prepare families and children for disclosure. This is in view of the importance of disclosure such as improved adherence (Bikaako-Kajura et al., 2006), better psychological adjustment (Bachanas et al., 2001) and avoidance of risky sexual practices to prevent spread of the infection.

Disclosure has some ethical and legal issues. Whilst physicians often advocate disclosure due to the possible psychological and medical benefits for the child as well as public health concerns (i.e., the possibility of transmission to sexual partners), parents often fear that disclosure may distress the child and other family members (Klitzman et al., 2008). The laws of Nigeria protect the privacy of information regarding a person’s HIV status and may, therefore, prevent health care workers from informing a child that he or she was perinatally infected with HIV since such a disclosure would result in violating the confidentiality of the mother’s HIV diagnosis (The Federal Government of Nigeria, 2003). This is an ethical dilemma that needs to be weighed against the child’s rights and public health implications.

## Conclusion

Disclosure is a challenge to parents and caregivers and done only in a minority of cases of school children. It is often delayed because of perceived immaturity of the children, risk of disclosure to others and fear of unacceptable reaction to disclosure. Health care providers can aid disclosure by helping caregivers see it as a process of gradually increasing children’s understanding based on their cognitive development and developmental maturity and facilitation of peer support. Counselling of caregivers on the benefits of disclosure and the possible adverse effects of non-disclosure is necessary. There is also need for guidelines to assist health workers when counselling parents and guardians on disclosure. All these may be incorporated into a special programme aimed at preparing children and families for disclosure.

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