

## Does Disclosure of HIV/AIDS Status to Children with HIV/AIDS Affect their Mental Health?

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### Abstract

**Objectives:** The paper assessed the prevalence of disclosure, factors responsible for awareness and effect of disclosure on the mental health of HIV-infected children at the HIV clinic of the University of Ilorin Teaching Hospital, Nigeria (UITH).

**Methodology:** It was a descriptive cross-sectional study involving 196 HIV-positive children between 6-17 years at the HIV clinic of UITH. A two-staged study was carried out: a first stage in which a questionnaire designed by the researchers was administered followed by a screening instrument- the Child Behaviour Questionnaire (CBQ) to parents/caregivers and children; and a second stage interview using the K-SADS-PL. In the second stage, a score of seven or more and approximately 30% of those scoring less than seven were selected on the CBQ as this represents the best trade-off between a high sensitivity and low false positive rate.

**Result:** About Eighteen percent (18%) of the children were aware of their HIV/AIDS status. Among the 19.4% of the study population with mental health problems, 11% were aware of their status. However, the children's awareness of HIV status was not associated with mental health problems, Pearson  $X^2$  (1.93, N=196),  $p=0.16$ . Children who were aware of their HIV status were more likely to be adolescents, were in secondary schools, were more likely to be from the Hausa tribe, had younger fathers and had mothers who were HIV positive, Pearson  $X^2$  (16.514, 31.836, 7.877, 15.393 and 10.149 respectively, N=196),  $p \leq 0.01$ ,  $<0.01$ ,  $0.01$ ,  $<0.01$  and  $0.006$  respectively.

**Conclusion:** Despite the fact that disclosure of a child's HIV status did not necessarily result in development of psychiatric disorders in the present study, awareness of HIV status is still relatively low among the age group. However, it delineates the role of socioeconomic and demographic factors in determining the level of awareness of children about their HIV status.

**Keywords:** Disclosure; Mental health; Children and adolescents

### Introduction

Human immunodeficiency virus infection/Acquired immune deficiency Syndrome (HIV/AIDS) is a chronic medical condition associated with a high rate of stigma and discrimination [1]. The highly stigmatizing nature may be as a result of the association of HIV/AIDS with social activities like commercial sex work and illicit drug use. As a result of this, many parents of children with the disease do not divulge their child's HIV status to them. The parents of children with HIV may also be concerned about the impact the disclosure may have on the child's health like the psychological health [2]. Parents are particularly worried that a child's awareness of his/her HIV status may negatively affect the child's will to live [2]. In spite of the fact that healthcare professionals are aware of the importance of disclosure, they respect the parents or caregiver preference about disclosure.

Disclosure of HIV status to children is particularly a difficult task for parents/caregiver and professionals taking care of children with HIV infection. There has been mixed findings on the relationship between disclosure and psychiatric morbidity in children with HIV [3]. While some studies reported that children who were aware of their HIV status were rated as having more psychiatric problems [3], other investigators discovered that disclosure may actually contribute positively in some ways to their psychological wellbeing and may have no adverse psychosocial effects [4]. Furthermore, other works found little or no differences in psychological functioning between children who are aware of their HIV status or not. Disclosure have been found to influence social support especially from family members, subsequently playing a role in coping, self-esteem and also enhancing involvement with health promoting behavior [5].

There is paucity of data on disclosure and its impact on the mental health of children with HIV in resource limited settings, where majority of these children live. Thus, this study assesses the level of disclosure, the factors associated with disclosure and the impact of disclosure on the mental health of children with HIV/AIDS.

### Objectives

The study assessed the prevalence and determinant of disclosure in 196 HIV infected children at the HIV clinic of the University of Ilorin Teaching Hospital, Ilorin (UITH), Kwara State, Nigeria. The study also determined the impact of disclosure on the mental health of HIV infected children.

### Materials and Methods

#### Study population

It was a descriptive cross-sectional study which included 196

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consecutive HIV positive children at the HIV clinic UITH Kwara State, Nigeria. The population for the study was gotten from the pediatrics HIV clinic and the adult HIV clinic where some adolescents for the study were recruited.

**Inclusion criteria:** Children who were eligible were between 6 and 17 years, tested HIV positive and had a parent/caregiver present at the clinic.

**Exclusion criteria:** Patients were excluded if they were too ill to be interviewed, had other chronic medical illnesses like sickle cell diseases and patients who had a prior history of psychiatric disorder before the diagnosis of HIV infection.

## Measures

The Parent Version of the Child Behaviour Questionnaire (CBQ) (Rutter scale A2) was the screening instrument used for assessing psychiatric morbidity in this study. It has been used extensively both in developed and developing countries. The scale consists of 31-item on a 3- point scale concerning the child's behaviour in and around the home during the last 12 months. The parents indicate the extent to which each item applies to the child. Each item is scored 0, 1, 2, ("does not apply", "applies somewhat" and "certainly applies") respectively, producing a total score within the range 0-62. In the initial study by Rutter et al, children with a total score of 13 or more are designated as having some disorders. However, a study carried out in a Nigerian paediatric primary care service, a teaching Hospital in Ibadan, discovered that a total score of 7 on the scale gave the best trade-off between a high sensitivity and a low false positive rate. At this score, sensitivity and specificity was 0.61 and 0.74 respectively with misclassification of 0.29 [6]. This cut-off was used in this study.

Schedule for Affective Disorders and Schizophrenia for School Aged Children Present and Lifetime Version (K-SADS-PL) was used for the diagnostic aspect of the study. It is a semi- structured interview for assessing psychiatric disorders in children and adolescents. It assesses current and past episodes of psychopathology in children and adolescents and has been adapted to the DSM-IV diagnostic criterion.

K-SADS-PL has strong content and concurrent validity and in comparison to other child diagnostic instruments, the K-SADS-PL compares favourably with test-retest reliability estimates and has excellent inter-rater reliability and results comparable to semi-structured and fully structured child diagnostic interviews [7,8].

A questionnaire designed by researcher was used in assessing the socio demographics of the participants like child's characteristics (age), home environment, parental characteristics (wellbeing, education and occupation) and family characteristics (income, social support and family relationship). This questionnaire also included some questions about disclosure such as "Is your child aware of their HIV status?"

The medical data sheet was used to extract data from the case note. It included health variables such as CD4 count, complications arising from HIV, stage of the disease and the type of anti-retroviral drugs (ART) used by the respondents.

## Procedure

The study was a two stage one. In the first stage, the caregivers and their children were given the information about study and caregivers who gave their informed consent and children who gave assent were interviewed. A questionnaire designed by the researcher and the CBQ were administered to all consecutive parents/caregivers of the

respondents at the HIV clinics who met the inclusion criteria. Though CBQ is supposed to be a self-administered questionnaire, it was read to each participant because of the relatively low level of literacy of the people. The medical data sheet was used to extract some medical parameters (like CD4) from the case notes of the respondents. Children scoring 7 or more on Rutter Scale A2 and 30% of those scoring <7 were selected for the second session of the interview using the K- SADS-PL. The parent/ caregiver, then their children were interviewed and rated concurrently by the researcher who was unaware of the scores obtained by the children in Stage 1.

Approval for the study was obtained from the Ethics and Research Committee of UITH, Ilorin. Informed and written consent were obtained from the caregivers and assent from the children.

## Data analysis

Data from this study were presented in tables. Means and standard deviation of numeric variables were also presented. Epi-Info version 6.04d was used for the analysis. Chi-square test was used to determine the significant association between variables. Statistical significance was set at  $p < 0.05$ . Multiple logistic regression analysis was used to eliminate mutual interference between independent variables.

## Results

### Patient characteristics

Table 1 shows the characteristics of the participants in the study. Of the 196 children and adolescents enrolled for the study, 71.9% were between 6 and 10 years while 28.1% were between 11 and 17 years. Seventy-four percent of the study population were Yoruba, 19% Hausa and other tribes like Igala and 7% Igbo. Eighty-two percent of the children and adolescents were on antiretroviral drugs (ART); 68% of them had been on the ART for about 3 years and 75% were on first line drugs. More than three-quarter had a CD4 count greater than 350 cell/mm<sup>3</sup>, 74% were in stage 1 and 2 while 83% had no complications from HIV/AIDS.

### Disclosure and mental health outcome

The study showed that 18.4% of the children and adolescents were aware of their HIV/AIDS status (Table 1). About 63% of the caregiver of the respondents gave reasons like fear of impact on the emotional health of the child as being a reason for not disclosing the children's HIV status to them. Furthermore, 37% of the caregiver did not disclose the child or adolescent's HIV status because of fear the child may tell others about their HIV status. Among the 19.4% of the participants with mental health problems, 89% were not aware of their HIV status while 11% were aware of their status. However, the awareness of HIV status was not significantly associated with mental health problems ( $X^2=1.933, p=0.164$ ).

### Factors associated with awareness

The study showed that more males were aware of their HIV status but the gender was not significantly associated with disclosure (Table 2). The participants who knew their HIV status were more likely to be adolescents between 11 and 17 years ( $p \leq 0.01$ ), were more likely to be secondary school students ( $p \leq 0.01$ ) and were more likely to be from Hausa tribe and other tribes like Igala ( $p=0.01$ ).

The fathers of children who were aware of their HIV status were more likely to be between 20 and 34 years while the fathers of participants who were not aware of their HIV status were more likely to be between 50 and 65 years ( $p \leq 0.01$ ). Seventy-one percent of the

Characteristics of Participants	N=196
Mean age y (SD)	9.2 (± 2.82)
Age y	
6-10	141 (71.9%)
11-17	55 (28.1%)
Gender	
Male	93 (47.4%)
Female	103 (52.6%)
Level of Education	
None	4 (2%)
Primary	169 (86.3%)
Secondary	23 (1.7)
Ethnicity	
Yoruba	145 (74.0%)
Igbo	14 (7.1%)
Hausa and others	37 (18.9%)
Residence	
Both Parents	93 (47.4%)
Single Parent	64 (32.7%)
Other relatives	39 (19.9%)
Disclosure	
Aware of HIV status	36 (18.4%)
Unaware of HIV status	160 (81.6%)
Mental health problems	
Presence	38 (19.4%)
Absent	158 (80.6%)
Receiving ARV	
Yes	161 (82.1%)
No	35 (17.9%)
Stage of disease	
Stage 1 and 2	146 (74.5%)
Stage 3 and 4	50 (25.5%)

**Table 1:** Characteristics of participants.

participants in the study had mothers who were not aware of their HIV status during their antenatal period. Children who knew their HIV status were more likely to have mothers who were HIV positive during the antenatal period. ( $p=0.006$ ) (Table 2).

When multiple logistic regression was conducted to determine the relationship between disclosure of HIV status to children (as the dependent variable) and the children's age, ethnicity, level of education, father's age and maternal HIV status (as the independent variables); the relationship between disclosure of HIV status and the independent variables became insignificant ( $p$  values ranging between 0.99, 0.13, 1.00, 0.81, and 0.70 for child's age, ethnicity, level of education father's age and maternal HIV status respectively). The Hosmer-Lemeshow (H-L) Goodness of Fit test was also not significant,  $X^2(6, N=196) = 3.222$ ,  $p=0.78$ . Since the H-L Goodness of Fit statistics is non-significant, we fail to reject the null hypothesis; implying that the model's estimates of the relationship between disclosure and the children's age, ethnicity, level of education, father's age and maternal HIV status fit the data at an acceptable level.

## Discussion

The study showed that 18.4% of the children were aware of their HIV status. The disclosure rate of 18.4% found in the current study falls within the disclosure rate of 13 to 60% in HIV-infected children between 5 to 17 years from Asia or Southern-Eastern Africa [9]. The

findings from this study correlates with finding from resource- limited settings that generally found that the prevalence of disclosure of HIV status to children is low, even among adolescents [10]. The disclosure rate in the current study is slightly higher than the rate found in a cross sectional study carried out in Ibadan, a similar socio cultural zone by Brown et al., found a disclosure rate of 13.5% [11]. Studies in other African countries like Zambia [12] and Uganda [13] reported a higher disclosure rate of 31.8% and 29% respectively in HIV infected. While the Zambian study had predominantly adolescents in their study, the present study included children and adolescents between 6 and 17 years. The inclusion of children between 6 and 17 years in the current study may have been responsible for a lower rate of disclosure of HIV status. This is because studies have shown that most children know their HIV status at an older age [10]. The findings on disclosure in this study is also within the range (18% to 77%) reported in studies from resource rich countries like the United States [3]. The reasons for non-disclosure in the current study were: fear that the child may tell others about their HIV status (leading to stigmatization and discrimination of the child and family), fear that the knowledge of HIV by the child may have psychological impact and parents' guilt about transmitting the virus to their child. These findings is not unusual because studies have shown that caregivers in resource limited settings express fear of stigma and negative effect on children's wellbeing when considering disclosure of HIV status to children [10]. Some parents did not give any reason for not disclosing their child's HIV status.

There was no association between disclosure and psychiatric morbidity in this study. It is possible that disclosure may act through interaction with other factors in order to have an impact on the mental health of children. The children in the present study have a good immune status as evidenced by the fact that most had a high CD4 count, most were in stage 1 and 2 of the illness and most of them did not have complications from HIV infection. These factors may have been protective because a study by Misdrahi et al. noted a significant relationship between worsening immune function and psychiatric morbidity [10]. There have been different findings on the relationship between disclosure in HIV children and psychiatric disorders [3]. Mellins et al. [14] reported that there was no association between disclosure and psychiatric morbidity in children with HIV. In the study by Gadov et al. [15], the younger youths who were aware of their HIV status had more symptomatology, supporting the notion that HIV creates adjustment problems [15]. While also essential for the secondary prevention of HIV transmission and improved adherence [5,16], disclosure for adolescents may increase emotional and behavioral disorders, family conflicts or social stigma perception and may hinder confidentiality [17,18]. However, other investigators have reported that disclosure may actually contribute positively in some way to psychological well-being [9]. Riekert et al. [19] found that children with HIV who knew of their HIV status scored lower on depression and anxiety measures than children who do not know their HIV diagnosis [19]. Other studies found little or no difference in psychological functioning between disclosed and non-disclosed children [5]. Inconsistencies on the impact of disclosure on psychological and emotional wellbeing of children may be attributable to limited sample size and use of cross-sectional designs.

The present study showed that more of the participants who were aware of their HIV status were adolescents (11-17 years) and were more likely to be in secondary schools which was similar to the study by Mellins et al. and Kallem et al. [9,14]. This may infer that parents may be more comfortable disclosing HIV status to adolescents. Studies have noted that most children become aware of their HIV status at an older age [20]. Furthermore, in developed countries, disclosure of HIV status

Variables	HIV status Known (n= 36)	HIV status unknown (n=160)	Chi square	p-value
Age			16.514	<0.01
06-Oct	16 (11.3)	125 (88.7)		
Nov-17	20 (36.4)	35 (63.6)		
Sex			1.162	0.28
Male	20 (21.5)	73 (78.5)		
Female	16 (15.5)	87 (84.5)		
Level of Education			31.836	<0.01
None	0 (0.0)	4 (100.0)		
Primary	22 (13.0)	147 (87.0)		
Secondary	14 (60.9)	9 (39.1)		
Ethnicity			7.877	0.01
Yoruba	20 (13.8)	125 (86.2)		
Igbo	4 (28.6)	10 (71.4)		
Hausa/others	12 (32.4)	25 (67.6)		
Maternal HIV in Pregnancy			10.149	0.006
Positive	2 (40.0)	3 (60.0)		
Negative	16 (31.4)	35 (68.6)		
Unknown	18 (12.9)	122 (87.1)		
Father's age (in years)			15.3933	<0.01
20-34	2 (100)	0 (0)		
35-49	12 (18.5)	53 (81.5)		
50-65	2 (4.9)	39 (95.1)		
Antiretroviral therapy			0.043	0.836
Yes	30 (18.6)	131 (81.4)		
No	6 (17.1)	29 (82.9)		
Stage of disease			1.815	0.178
1 and 2	30 (20.5)	116 (79.5)		
3 and 4	6 (12.0)	44 (88.0)		
Complications			0.733	0.392
Yes	4 (12.9)	27 (87.1)		
No	32 (19.4)	133 (80.6)		

**Table 2:** Factors associated with disclosure in children with HIV/AIDS.

to children depends on the age [3]. In a multivariate analysis Kallem et al. noted that a higher level of education was a predictor of disclosure in children with HIV [9].

The study found an ethnic disposition to disclosure. Most of the children who were aware of their HIV status belonged to the Yoruba tribe (predominant tribe in the study area). Cultural and educational considerations may have been responsible. Furthermore in this study, the mothers of children who were aware of their HIV status had mothers who were HIV positive during their pregnancy. The disposition of HIV positive mothers to disclose to their children may have been as a result of their awareness of the peculiarities of being HIV positive. Petersen et al. also noted that caregiver who were HIV positive stated that disclosure was much easier if they were HIV positive and could educate the child that it was possible to have HIV and still remain healthy [21].

This study is one of the few studies to assess the effect of awareness of HIV status on the mental health of HIV-infected children and also used standard instrument in assessment of mental health problems in children in Nigeria. In addition, a relatively large sample was used. It is limited by the fact that it was a cross-sectional study and a hospital-based study thus may not generalized finding to the populace.

## Conclusions

The study suggests that awareness of HIV status in HIV-infected children does not have a negative effect on their mental state. Disclosure of the HIV status is occurring at an older age. In spite of the above findings, it is imperative for children to be aware of their HIV status for maintenance of their health and subsequently HIV prevention.

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## Conflict of interest

The author declares that there is no competing interest.

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