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Disclosure Rate and the Associated Factors Among Adolescents Living with the Human Immunodeficiency Virus in Gombe Metropolis, Nigeria

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Abstract

Background: Disclosure of Human Immunodeficiency Virus (HIV) status is one of the major challenges in the management of children and adolescents living with HIV (CALHIV). Disclosure has been shown to positively impact adherence to antiretroviral therapy and retention in the care of CALHIV. With the increasing number of adolescents living with HIV (ALHIV) and the peculiarities of adolescence, there is a need for local data on the disclosure of HIV status among ALHIV.

Objectives: To determine the disclosure rate in HIV infection and the associated factors among ALHIV in Gombe Metropolis.

Methods: This cross-sectional study was conducted over ten months among 130 ALHIVs aged 12-18 who attended Antiretroviral Therapy Clinics at the Federal Teaching Hospital and the State Specialist Hospital in Gombe, Nigeria. Disclosure of HIV status was assessed using a pre-tested semi-structured questionnaire administered to adolescents and their respective caregivers.

Results: The HIV status disclosure rate by caregivers' report and self-report was 66.2% and 63.1%, respectively. Older adolescents' age and higher level of education were significantly associated with disclosure ($p < 0.05$). The commonest reason for disclosure was 'increasing curiosity' (23/130; 26.7%), while 'being too young' was the commonest reason for non-disclosure (19/44; 43.2%).

Conclusion: The disclosure rate among ALHIV in Gombe Metropolis was relatively high. Caregivers should be encouraged to disclose early.

Keywords: Adolescents, Antiretroviral Therapy, Disclosure, HIV infection.

Introduction

Human Immunodeficiency Virus (HIV) infection is a significant cause of morbidity and mortality among adolescents, especially in sub-Saharan Africa.[1,2] About 1.7 million adolescents (aged 10-19 years) live with HIV/AIDS globally.[3] In Nigeria, over 120,000 adolescents live with the virus.[4] The increase in survival of children with perinatally acquired HIV has significantly contributed to the high proportion of adolescents living with HIV (ALHIV).[5] As the children grow, disclosure of their HIV status becomes an

essential challenge in the management of the condition.[6-8]

Disclosure is the process of providing information or ongoing discussion on HIV status to an infected child.[9] Full disclosure entails stating the name of the disease as 'HIV/AIDS'.[10] Disclosure of HIV status has been shown to have a positive impact on the general well-being of HIV-infected children.[10] Due to its relevance, the World Health Organisation, the American Academy of Paediatrics (AAP) and the African Network for the Care of Children Affected by HIV/AIDS (ANECCA) strongly recommended full disclosure to ALHIV.[9-11] Despite the increasing numbers of ALHIV, there appears to be a paucity of studies on HIV disclosure exclusively among adolescents.[12] More so, findings from previous studies have shown inconsistencies in reported HIV disclosure rates and its associated factors.[12-15] Therefore, the study was conceived to provide local data for evidence-based recommendations on status disclosure among ALHIV in a typical sub-Saharan setting. This is essential in view of the psycho-social peculiarities of adolescence.[16]

Therefore, the study aimed to assess the prevalence of full status disclosure and the factors associated with HIV status disclosure among ALHIV in the Gombe Metropolis.

Methods

Study design

The descriptive, cross-sectional study was conducted between July 2020 and May 2021.

Study area

The study was conducted at the Antiretroviral Therapy (ART) Clinics of the Federal Teaching Hospital (FTH), Gombe and the State Specialist Hospital (SSH), Gombe in Gombe Metropolis, North-East Nigeria. The two facilities were the only public facilities providing paediatric ART care in the metropolis. Each of the two clinics has a side laboratory, a counselling unit, a nursing bay, consulting rooms and the ART pharmacy. The number of registered paediatric and adolescent patients in FTH and SSH (as at the time of the study) were 660 and 922, respectively. There were 112 and 96 adolescents (aged 10-19) who were actively attending the follow-up care available in the two clinics at the time of the study.

Study population, sample size and sampling technique

The respondents were ALHIV on follow-up care in the two facilities. A documented disclosure rate of 29.6% in Abuja-Nigeria was used to calculate the sample size.[15] The sample size was calculated and adjusted to 131 using the Cochrane formula $n = z^2pq/d^2$ and $S = n \div [1+(n-1) \div N]$, respectively.[17] The adjustment was necessary because the number of the study population was less than the initially calculated minimal sample size.[17] The number of respondents recruited per facility was estimated by simple proportion. Seventy-one respondents were recruited from the FTH Gombe, and 60 respondents were recruited from the SSH Gombe. A purposive sampling method was used to recruit the respondents from each facility. Adolescents who were <12 years old, those whose parents refused consent, and those who were >18 years old were excluded. According to the WHO guidelines, full disclosure should be achieved by the 12th year, thus the exclusion of those <12 years.

Ethical consideration

Ethical clearance was obtained from the Ethics and Research Committee of the Federal Teaching Hospital, Gombe, and permission was obtained from the Gombe State Ministry of Health (Certificate Number: HREC25/10/2013). Written informed consent was obtained from every caregiver of the study participants. Assent was also obtained from all the adolescents who were yet to turn 18. Confidentiality was also ensured.

Study tool and data collection

A pre-tested, semi-structured questionnaire adapted from the work of Turissini *et al*. [18] on disclosure of HIV status was used to obtain data from both the parents and the adolescents. The biodata, socioeconomic status (using the Oyedeji classification system), information on disclosure of HIV status, parental perception on disclosure, and reasons for disclosure and non-disclosure were obtained. Relevant clinical details available in the clinical records of the study participants, like WHO clinical stage, viral load, and adherence, were also retrieved.

Data management

The questionnaires were numbered serially and cross-checked for completeness. One returned questionnaire was excluded from the final analysis because it contained incomplete data. Data were extracted and entered into SPSS version 24 for analysis. Categorical variables were expressed in frequency and percentages, while the mean was calculated for quantitative variables that were normally distributed. The Chi-Square test was used to assess the level of association between categorical variables with a significant level of association set at p-value <0.05.

Results

Out of the 130 adolescent participants with complete data, 73 (56.2%) were males with a male-to-female ratio of 1.4:1. The mean age of the adolescents was 14.9±1.7 years. Twenty-six (20.0%) were late adolescents, while the rest were almost equally distributed as either early or mid-adolescents. Ninety-seven (74.1%) belonged to the low socioeconomic class (SEC), while 67 (51.5%) were either single or double orphans. The sociodemographic characteristics of respondents are shown in Table 1.

The HIV-related clinical characteristics of the adolescents are presented in Table II. Mother-to-child transmission of HIV accounted for 123 (94.6%), and 95 (73.1%) were diagnosed with HIV between the ages of 1 and 9 years, while 23 (17.7%) were diagnosed in adolescence.

Those with advanced disease - World Health Organization (WHO) Stages III and IV - represented 23.8% of the cohort. Adherence to Antiretroviral Therapy (ART) was good in the majority (84.6%), and 98 (75.4%) of the adolescents were virologically suppressed with viral loads of ≤ 1000 copies/ml.

HIV status disclosure rate

The rate of HIV status disclosure based on the caregivers' report was 66.2% (86/130), while the rate based on the adolescent respondents (self-report) was 63.1% (82/130). This is illustrated in Figure 1 below.

Responses of caregivers on the disclosure process

The responses of caregivers on the disclosure process are shown in Table III. Of the everyday caregivers' reasons for disclosure, 'increasing curiosity' by the adolescents was the commonest reason that led to disclosure of HIV status in 23 (26.7%), followed by 'worsening illness' in 14 (16.3%). Mothers were responsible for the disclosure process in about half (48.8%) of the cases, while health workers did the disclosure process in 15 (17.4%). Nearly half (45.3%) of the subjects had no reported change in attitude after knowing their HIV status, 28 (32.6%) were reported to be scared, and 15 (17.4%) were reported to have been angry. The minimum age of subjects at disclosure was eight years, while the mean age at disclosure was 13.2 ±1.7 years. Most (89.5%) of the respondents had disclosure after their 12th birthday.

Caregivers' reasons for non-disclosure of HIV diagnosis

The commonest reason given by the caregivers for not disclosing to the subjects their HIV status was 'being too young' in 19 (43.2%), followed by 'not knowing how to go about it' in 13 (29.5%). The reasons are represented in Figure 2.

Table I: Sociodemographic characteristics of the participants

Variables	Frequency (n = 130)	Percentage
Age groups		
Early adolescents	49	37.7
Mid Adolescents	55	42.3
Late adolescents	26	20.0
Gender		
Male	73	56.2
Female	57	43.8
Socio-economic status		
Low	97	74.1
Middle	29	22.3
High	04	3.1
Level of education		
Not enrolled	02	1.5
Primary	22	16.9
Secondary	102	78.5
Tertiary	04	3.1
Primary caregivers		
Biological parents	99	76.1
Uncles/Aunts	17	13.1
Older Sibling	8	6.2
Grandparents	6	4.6
Orphancy		
Single-orphan	47	36.2
Double orphan	20	15.3
Non-orphan	63	48.5

Table II: HIV-related clinical characteristics

Variables	Frequency	Percentage
Mode of transmission		
Vertical	123	94.6
Horizontal	3	2.3
Unknown	4	3.1
Age at diagnosis of HIV		
≤1 year	12	9.2
>1 – 9 years	95	73.1
10-18 years	23	17.7
Disease stage (WHO)		
Stage I	32	24.6
Stage II	67	51.6
Stage II	25	19.2
Stage IV	6	4.6
Previous HIV-related hospitalisation		
None	84	64.6
Once	32	24.6
Twice or more	14	10.8
Adherence to ART		
Good (≥95%)	110	84.6
Poor (<95%)	20	15.4
Recent viral load (copies/ml)		
< 20	58	44.6
20-1000	40	30.8
>1000	32	24.6

Adolescents' perception of disclosure and self-disclosure of HIV status

The majority (90.2%) of the 82 subjects who knew their HIV status liked the fact that they were disclosed. Only 9 (11%) of them reportedly disclosed their HIV status to a third party, most of whom (55.6%) were their family members. Table IV shows the perception of the adolescents on knowing their HIV status and pattern of self-disclosure to a third party.

Factors Associated with HIV Diagnosis Disclosure

The disclosure rate was significantly higher in late and mid-adolescents than in early adolescents ($p<0.001$). Similarly, the disclosure rate was significantly higher among ALHIVs who were enrolled in secondary or tertiary educational institutions than those in primary schools or those who were not ($p = 0.037$). Adolescents who were

ever hospitalised had a higher disclosure rate compared to those with no history of hospitalisation, even though the difference was not significant (X^2= 5.227, p = 0.073). Similarly, ART adherence, viral suppression and WHO disease stage were not significantly associated with disclosure (shown in Tables Va and Vb).

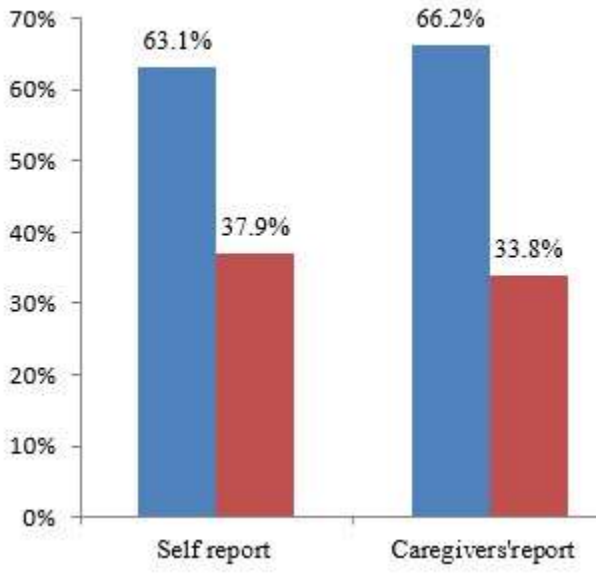

Figure 1: Disclosure rate based on self-report and caregivers' report

Discussion

The HIV status disclosure rate of 66.2% provided by the caregivers in this study is higher than the 19.6% rate reported by Ikpeme *et al*. [19] in Uyo, Southern Nigeria, 29.6% reported by Okechukwu *et al*. [15] in Abuja, North-central Nigeria and 13.5% reported by Brown *et al*. [20] in Ibadan, Southwest Nigeria. The higher prevalence in this study is not surprising as the study was conducted exclusively among adolescents, who, by recommendation, should have full disclosure of their HIV status as against the inclusion of younger ages in the Uyo, Abuja and Ibadan studies. Similarly, the disclosure rate in the present study is greater than the findings in similar studies by Gyamfi *et al*. [8] in Ghana and Tsuzuki *et al*. [21] in Zambia, who reported disclosure rates of 33.3% and 29.8%, respectively. The present study assessed disclosure during real-time questioning of the caregiver and the adolescents, while other studies, like the Zambian study by Tsuzuki *et al*. 20, assessed disclosure using prior clinical records, which could have been affected by poor and incomplete documentation. The comparable rates of HIV status disclosure observed in the present study and that of Grubman *et al*. [22] and Bachanas *et al*. 23, all in the USA, who reported rates of 57.1% and 64%, could suggest improvement in adherence to the various recommendations on disclosure in our area of practice. Also, improved counselling services and the availability of a differentiated model of care for adolescents (like the influence of the Operation Triple Zero club) could have contributed to disclosure practices among caregivers and healthcare workers.

This study revealed that increasing adolescent curiosity was the commonest reason for caregivers to disclose information. Adolescents are known for their curiosity as they explore the boundaries of independence from their parents or caregivers.[16] This suggests that the risk of accidental/unplanned disclosure of diagnosis to these adolescents is increased as their curiosity increases, hence the need for continuous advocacy on early disclosure. This finding is similar to that of Brown *et al*[20] who also reported 'frequent questioning on what illness they are suffering from' as the commonest reason for disclosure. Adolescents have been shown to manifest various reactions and attitudes following disclosure of their HIV status.[24]

Table III: Responses of caregivers on the disclosure process

Variables	Frequency	Percentage
Reasons for disclosure		
Increasing curiosity	23	26.7
Worsening illness	14	16.3
Commencement of antiretroviral therapy	9	10.5
Hospitalisation	4	4.7
Parental demise	3	3.5
School enrolment	3	3.5
Others*	30	34.8
Persons responsible for disclosure		
Mother	42	48.8
Father	9	10.5
Other relation	19	22.1
Health workers	15	17.4
Others**	1	1.2
Reaction during the disclosure period		
No noticeable change	39	45.3
Scared	28	32.6
Angry	15	17.4
Others***	4	4.7
Age at disclosure (years)		
<12	9	10.5
12-18	77	89.5

***Change in caregivers; Accidental disclosure; Healthcare providers' counsel**
****Neighbour; ***Withdrawn, can't describe.**

Table IV: Perception on disclosure of HIV status and self-disclosure to a third party

Variables	Frequency	Percentage
Perception on disclosure		
Liked being told	74	90.2
Disliked being told	8	9.8
Total	82	100.0
Self-disclosure to third party		
Yes	9	11.0
No	73	89.0
Total	82	100.0
Third-party (persons) disclosed to		
Family member	5	55.6
Friends	3	33.3
Neighbour	1	11.1
Total	9	100.0

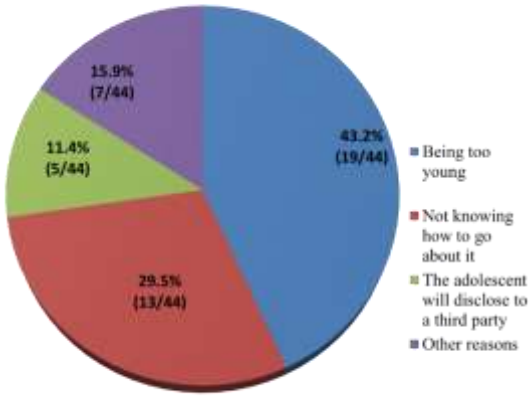

Figure 2: Caregivers' reasons for not disclosing the HIV diagnosis to ALHIV
****Others: No reason; Waiting for the father to do the disclosure; Not important**

Table Va: Associations between sociodemographic profile and disclosure of HIV status

Variables	**Disclosure of HIV status**				
	Yes	*No*	*Total*	X^2	*p-value*
	n (%)	*n (%)*	*n (%)*		
Age group					
Early adolescents	20 (40.8)	29 (59.2)	49	17.06	<0.001*
Mid – adolescents	41 (74.5)	14 (25.5)	55		
Late adolescents	21 (80.8)	5 (19.2)	26		
Gender					
Male	45 (54.9)	28 (45.1)	73	0.145	0.702
Female	37 (64.9)	20 (35.1)	57		
Level of Education					
Not enrolled	1 (50.0)	1 (50.0)	2	8.481	0.037*
Primary	8 (36.4)	14 (63.6)	22		
Secondary	70 (68.6)	32 (31.4)	102		
Tertiary	3 (75.0)	1 (25.0)	4		
Socioeconomic status					
Low	61 (62.9)	36 (37.1)	97	0.369	0.831
Middle	19 (65.5)	10 (34.5)	29		
High	2 (50.0)	2 (50.0)	4		
Parental demise					
Both parents	14 (70.0)	6 (30.0)	20	1.870	0.393
Single parent	32 (68.1)	15 (31.9)	47		

In the present study, 45.3% of the adolescents reported no noticeable change in their actions following disclosure. The finding is, however, contrary to that of Okawa *et al*[25] in Zambia, who reported that only 9% of the population had no noticeable reaction following disclosure and that of Ekop *et al*. 13, who studied a similar population with the same study design and also reported a high parental concern on the reactions of their children following disclosure process.[26] While those studies documented 'parental reports', our study reported the 'adolescents' self-report, which may be more reliable in assessing adolescents' reactions. Among the many reasons proffered for non-disclosure by the caregivers, 'being too young' (43.2%) was the commonest reason in the present study, followed by 'not knowing how to go about it'. This is similar to the observations made by Orji *et al*[27] in Abakaliki, Southern Nigeria and Gyamfi *et al*[8] in Ghana, even though their study subjects included pre-adolescents. On the other hand, Ekop and colleague[13] whose study population were adolescents reported 'fear of subsequent disclosure by the adolescents to a third party' as the commonest reason for non-disclosure.

Table Vb: Associations between clinical characteristics and disclosure of HIV status

Clinical characteristics	**Disclosure of HIV status**				
	Yes	*No*	*Total*	X^2	*p-value*
	n (%)	*n (%)*	*n (%)*		
Disease stage (WHO)					
I	20 (62.5)	12 (37.5)	32	1.173	0.760
II	41 (61.2)	26 (38.8)	67		
III	16 (64.0)	9 (36.0)	25		
IV	5 (83.3)	1 (16.7)	6		
Adherence to Antiretroviral therapy					
Good	70 (63.6)	40 (36.4)	110	0.096	0.757
Poor	12 (60.0)	8 (40.0)	20		
Previous HIV-related hospitalization					
Twice or more	11 (78.6)	3 (21.4)	14	5.227	0.073
Once	24 (75.0)	8 (25.0)	32		
None	47 (56.0)	37 (44.0)	84		
Viral load (copies/ml)					
<20	35 (61.4)	22 (38.6)	57	0.398	0.820
20-1000	27 (67.5)	13 (32.5)	40		
>1000	20 (62.5)	12 (37.5)	32		

With the restriction of the study participants to 12 years of age or higher (as in the AAP recommendation)[11], this study revealed the need for continuous engagement with caregivers in encouraging early disclosure. It also shows the need for developing culturally acceptable ways of initiating HIV status disclosure in the study's locality.

This study also revealed that older adolescents and the increasing level of education of the adolescents were significantly associated with HIV status disclosure. The association between disclosure and the age of adolescents agrees with several studies.[19-21,28] As adolescents grow toward adulthood, disclosure becomes eminent, possibly due to the increasing knowledge and curiosity that comes with age.[16] Similarly, the report of Ikpeme and colleague[16] in Uyo, southern Nigeria, supports the significant association between disclosure and the level of education of the adolescents in this study. This may suggest a positive impact of health education on the disclosure of HIV status to ALHIV who attend schools. Other factors like HIV-related clinical characteristics were not significantly associated with disclosure in this study, in contrast to the reports of Okechukwu *et al*.[15] and Arrive *et al*.[28].

Conclusion

The HIV status disclosure rate was relatively high and significantly associated with older age and a high level of education among the adolescents studied. Increasing curiosity among adolescents was the most common reason for disclosure. It is recommended that caregivers of ALHIV should be engaged and encouraged by clinicians on early disclosure of HIV status.

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