



ISSN: 2476-8642 (Print)

ISSN: 2536-6149 (Online)

www.annalsofhealthresearch.com
Indexed in: African Index Medicus,
Index Copernicus & Google Scholar
Member of C.O.P.E and D.O.A.J

Annals of Health Research



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**PUBLISHED BY THE MEDICAL
AND DENTAL CONSULTANTS ASSOCIATION
OF NIGERIA, OOUTH, SAGAMU, NIGERIA.**

ORIGINAL RESEARCH

Determinants of HIV serostatus disclosure and assessment of the competence of health care personnel in HIV serostatus disclosure

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Abstract

Background: Disclosure of HIV serostatus is essential for the care and eradication of HIV infection. The World Health Organization recommends disclosure to school-age children and younger children but this practice is commonly hindered by stigmatization and other presumed psychosocial effects of the disease.

Objective: To identify limitations to the disclosure of serostatus in HIV-infected children, outcomes of disclosure as well as compare the outcomes of disclosure by either parents/caregiver only with the involvement of health care personnel.

Methods: A questionnaire-based study of primary caregivers of children aged 6 years to 18 years with HIV infection who were enrolled at two government-owned tertiary institutions in Lagos State, Nigeria. The healthcare personnel directly involved in the care of these children also participated in the study.

Results: A total of 190 primary caregivers participated in the study. In all, 29 health care personnel completely filled the questionnaires. Disclosure (partial and full) was recorded among 31.0%. Older children and children with single parents were more likely to know their HIV status. Similar positive and negative impacts of disclosure were observed irrespective of the individuals involved in the processes. In all, 62.1% of healthcare personnel have had training on disclosure.

Conclusion: Disclosure rate in HIV-infected children was low. There is a need for more training of health personnel and education of caregivers on the benefits of disclosure as well as the introduction of effective measures to tackle the barriers to disclosure.

Keywords: *Childhood, Disclosure, Healthcare Personnel, Human Immunodeficiency Virus, Lagos.*

Introduction

Improvement in access to antiretroviral drugs has made HIV infection a chronic disease.^[1] Unlike other chronic diseases, discrimination and stigmatization are major consequences of HIV infection which hinder HIV serostatus disclosure.^[2] Disclosure of HIV serostatus is crucial to the continuum of care and eradication of HIV infection. ^[3] Hindrances to the disclosure of HIV serostatus in sub-Saharan Africa are a major factor for its high burden. In Nigeria, 170,000 adolescents are living with HIV and only 12% of persons within this age group know their HIV status in the country.^[4, 5] Lack of disclosure of HIV serostatus amongst persons of the age group who are likely to practise unsafe sexual practices will inadvertently contribute to the risk of further spread and impact of HIV infection.

Reports have shown that age-appropriate disclosure of HIV serostatus is beneficial. It increases adherence to medications, access to care and reduces the death rate. However, stigmatization and fear of psychosocial harm are some of the reasons parents refuse to disclose HIV serostatus to their wards.^[6]

The World Health Organization recommends disclosure to school-age children and younger children using age-appropriate information provision and full disclosure when the child is emotionally matured to receive the information.^[6] In addition to determining age, limitation and disclosure outcomes as done in previous studies, this study aimed to compare the outcomes of serostatus disclosure by either parents/caregiver alone with those that involved health care personnel. This will help in suggesting individuals that should be involved in serostatus disclosure to children with HIV infection.

The objective of this study was to evaluate the determinants and effects of serostatus disclosure in children with HIV infection and assess the

competence of health care personnel on disclosure of HIV serostatus in HIV Clinics in Lagos state, Nigeria.

Methods

Study Design

This was a questionnaire-based study of the caregivers of HIV-infected children. It also included health personnel directly involved in the care of these children.

Study Setting, Population and Duration:

The study was done in the two tertiary Government institutions in Lagos State (Lagos State University Teaching Hospital (LASUTH), Ikeja and Massey Children's Hospital (MCH), Lagos Island). The two facilities have well-established clinics for children with HIV infection.

The study population comprised of caregivers of HIV-infected children aged six years to 18 years who volunteered to partake in the study. It also involved the health personnel (doctors, nurses, and counsellors who primarily cared for children with HIV infection) who consented to partake in the study. The caregivers of children enrolled in the HIV Clinics were consecutively recruited until the desired sample sizes were met (which was determined based on the number of registered children in each study centre). Only HIV-infected children with encephalopathy were excluded from the study. The study was carried out over a three-month period (January to March 2018).

Tool Validation

Identification of items clarity was done by administering the questionnaire to ten people followed by a pilot study that involved thirty people.

Content validity was assessed by a review of the questionnaire by expertise which included an

epidemiologist and specialist in Infectious Diseases.

Test-retest for tool internal consistency was done for the caregiver and the health personnel by administering the same questionnaire to ten of them and similarity in responses was observed. The Cronbach's alpha coefficient was 0.85 and 0.70 for the health personnel and the caregivers respectively. Partial disclosure was defined as telling a child about the disease without using the word "HIV or AIDS" while full disclosure was defined as the use of the word HIV or AIDS while explaining the disease to the HIV-infected child. [6] Non-disclosure was described as a lack of awareness about his or her HIV status, the reasons for daily medication or clinic visits.

Socioeconomic Class: The classification of caregivers into different socio-economic classes was done using the model recommended by Ogunlesi *et al.* [7] The subjects were classified into upper, middle and lower socio-economic classes.

Ethical Consideration: Ethical approval for the study was obtained from the Health Research and Ethics Committee of Lagos State University Teaching Hospital, Ikeja (NHREC04/04/2008).

Data Analysis

The socio-demographic, anthropometric, clinical data and the responses to the questions were analysed using the Statistical Package for Social Sciences (SPSS) version 20 (IBM Inc., Chicago, USA).

Descriptive and inferential statistics were conducted using the Chi-Square test, Fisher's Exact test, and logistic regression analysis. Probability values less than 0.05 at 95% confidence interval were considered statistically significant.

Results

A total of 190 primary caregivers of HIV-infected children participated in the study (150 from LASUTH and 40 from MCH). In both centres, most of the caregivers surveyed were mothers (68.7%; n = 103 in LASUTH and 65%; n = 26 in MCH).

The age ranged from 6 years and 18 years with a mean age of 10.7±2.9 years. The mean age of the children at MCH and LASUTH was 11.6±3.9 years and 10.5±2.6 years respectively (t = -2.314, p<0.001). In all, 114 (60%) of the children were males; majority of the subjects in both centres were also males respectively (52.5%; n = 21 and 62 %; n = 93).

Disclosure of HIV status (partial and full) of the affected children to them had been done for 14 (35%) and 45 (30%) of subjects at MCH and LASUTH respectively. Full disclosure was done for 10 out of 40 (25.0%) and 39 out of 150 (26%) of the children disclosed to at MCH and LASUTH respectively.

The minimum and maximum age at serostatus disclosure were 6 years and 16 years respectively. The mean age at serostatus disclosure to affected children was 11.1±2.3 years. Children attending LASUTH had a significantly lower mean age at disclosure compared to those attending MCS (10.5±1.9 years vs. 13.1±2.6 years; t = -3.718, p = 0.06). For children who were yet to have HIV serostatus disclosure, the caregivers intended disclosing between the age range of 8-21 years with a mean age of planned disclosure of 14.2±3.1 years. The caregivers of children attending LASUTH had a lower mean age they intended to disclose the wards' HIV serostatus to them compared to those attending MCH (13.3±2.5 years vs. 16.2±3.2 years; t = -5.137, p = 0.62).

Individuals involved in the disclosure and the effect of disclosure

The disclosure of HIV serostatus to affected children was mostly done by the mothers

(35.6%; n = 21). The fathers solely disclosed to their wards in 9 (15.2%) cases. Both parents were involved in the disclosure to only 2 (3.4%) children. The effect of disclosure was observed among 55 (93.2%) out of the 59 subjects that had

disclosure. No significant difference was observed in responses to the disclosure and individuals involved in disclosing as shown in Table I.

Table I: Relationship between types of individuals involved in serostatus disclosure and the types of responses obtained

Responses to disclosure	Individuals involved in sero-status disclosure				Total (%)
	Parents (%)	Relatives (%)	Caregiver with healthcare personnel (%)	Healthcare personnel only (%)	
Positive	16 (44.4)	8 (22.2)	4 (11.1)	8 (22.2)	36 (100)
Negative	8 (72.7)	0 (0)	1 (9.1)	2 (18.2)	11 (100)
No response	2 (50)	0 (0)	0 (0)	2 (50)	4 (100)
Both positive and negative	6 (75)	0 (0)	1 (12.5)	1 (12.5)	8 (100)
Total	32 (54.2)	8 (13.5)	6 (10.2)	13 (22.0)	59 (100)

$\chi^2 = 9.408, p = 0.400$

Out of 44 children that had positive responses to disclosure, better adherence to medication (79.5% n = 35), better relationship with caregiver (13.6%; n = 6) and less frequent questioning (2.3%; n = 1) were the observed responses. In 2 (4.5%) children, a combination of better adherence to ARVs and better relationships with caregivers was observed.

Negative responses to disclosure were observed in a total of 19 (32.2%) children. Anger (52.6%; n = 10), withdrawal (21.0%; n = 4), sadness (5.3%; n = 1), loss of trust (10.5%; n = 2), fear (5.3%; n = 1) and questioning the source (5.3%; n = 1) were the various negative impacts responses recorded.

The duration of negative responses was reported by 17 (89.5%) out of 19 subjects. The majority of negative responses were observed for less than one week (64.7%; n = 11). In 4 children (23.5%), these impacts lasted between one week and a month while in 1 (5.9%) child, it lasted longer than a month but less than a year.

In one other child, the caregiver observed this impact for over a year (5.9%).

Reasons for Disclosure and non-disclosure

The maturity of affected children was the most frequent reason for serostatus disclosure (28.8%; n = 17) as shown in Figure 1. The reasons for serostatus disclosure in 5 (8.5%) cases were multiple including maturity, frequent questioning and poor drug adherence to antiretroviral therapy.

The commonest reasons for HIV serostatus non-disclosure to HIV-infected children included being too young (56.5%; n = 74) and risk of stigmatization (31.3%, n = 41) as shown in Figure 2. A combination of children who were considered too young and stigmatization was observed in 2 (1.5%) children.

Healthcare Personnel and HIV disclosure

A total of 29 health care personnel (8 from MSCH and 21 from LASUTH) who were primarily involved with the care of HIV-

infected children were surveyed. These included 17 doctors, 7 counselors, and 5 nurses. The

median duration of practice was 84 months (IQR 24months, 120 months).

Reasons for HIV status disclosure

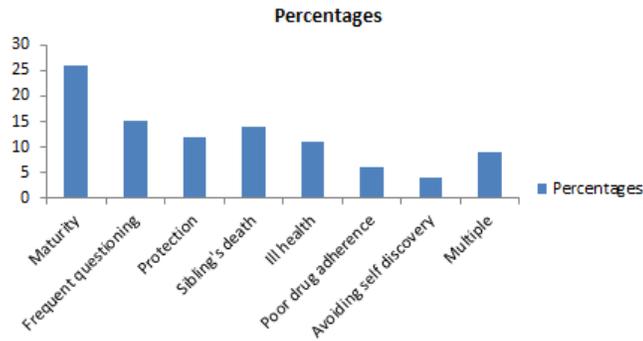


Figure 1: Reasons for HIV serostatus disclosure

Reasons for non-disclosure of HIV status

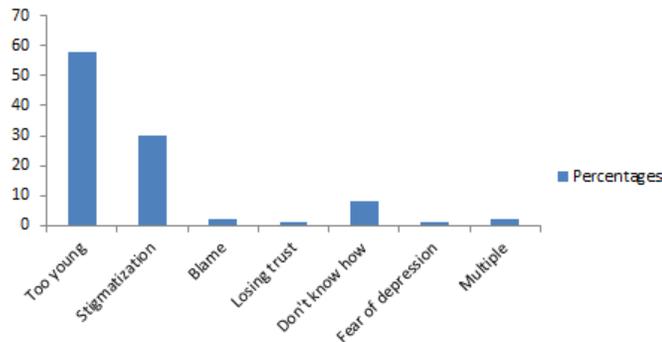


Figure 2: Reasons for HIV serostatus non-disclosure

The mean age expected for serostatus disclosure by healthcare providers was 11.2±4.5 years. The majority believed serostatus disclosure should be done at age twelve years and above (n =10; 34.5%). A total of 5 (17.2%) and 6 (20.7%) health workers expected serostatus disclosure to be done between 5 and 6 years and between 7 and 12 years respectively. Over a quarter (n = 8;

27.6%) of them had no idea on when serostatus disclosure should be done in HIV-infected children.

In all, 18 (62.1%) healthcare workers have had training on how to disclose HIV serostatus to affected individuals. Majority of individuals with training on disclosure were recruited from

MSCH (87.5%; n = 7 vs 52.4%; n = 11). The need for routine training on disclosure was strongly recommended by the majority (72.4%) of the health care personnel. When counseled to disclose the serostatus of HIV-infected children to them, the commonest reasons caregivers gave for negative responses included the inability to keep information, stigmatization and being too young to understand.

Determinants of HIV status disclosure

Table II shows the determinants of serostatus disclosure to affected children. Adolescents (10 to 18 years) were more likely to know their HIV status compared to the younger ones.

Multivariate logistic regression tests showed that the child's age and caregiver's marital status are independent determinants of disclosure as shown in Table III.

Table IIa: Determinants of HIV sero-status disclosure

	HIV Status Disclosure		Statistics
	No (%)	Yes (%)	
Age Group (years)			$\chi^2 = 41.606; p = 0.001$
6 to < 10	87 (66.9)	10 (16.9)	
10 to 18	43 (33.1)	49 (83.1)	
Gender			$\chi^2 = 0.692; p = 0.405$
Male	76 (58.0)	38 (64.4)	
Female	55 (41.9)	21 (35.6)	
Social Class			$\chi^2 = 6.259; p = 0.043$
Upper	30 (22.9)	12 (20.3)	
Middle	40 (30.5)	9 (15.3)	
Lower	61 (46.6)	38 (64.4)	
Marital status of caregivers			$\chi^2 = 8.823; p = 0.003$
Married	94 (72.3)	29 (50.0)	
Not Married	36 (27.7)	29 (50.0)	
Couples' Discordance			$\chi^2 = 3.275; p = 0.195$
Discordant couple	32 (35.5)	20 (24.7)	
Not discordant	58 (64.4)	61 (75.3)	
Family size			$\chi^2 = 2.912; p = 0.09$
< 4	31 (23.7)	21 (35.6)	
≥ 4	100 (76.3)	38 (64.4)	
Demise of family member to HIV infection			$\chi^2 = 3.035; p = 0.219$
No	78 (60.5)	29 (49.2)	
Yes	51 (39.5)	30 (50.8)	

FE - Fisher's Exact Test

Discussion

In the present study, a higher proportion of HIV-infected children were males. This observation agreed with the findings in a study conducted in Kano, Nigeria by Obiagwu *et al.* [8]

where male preponderance was reported among affected children. HIV infection in children mainly occurs through mother-to-child transmission and the gender predilection for HIV infection occurring through this route is unknown. [9] Partial HIV serostatus disclosure

had been done in about one-third of the study population and in one-quarter, full serostatus disclosure had been achieved. A similarly low rate of serostatus disclosure was reported in Ghana by Hayfron-Benjamin *et al.*^[10] In Nigeria, the disclosure rate to HIV-infected children has also been previously documented to be as low as 13.5% to 33%.^[11-14]

The mean age at serostatus disclosure in the current study was 11.1 years. This is slightly

higher than the mean age reported in Tanzania and Ethiopia. ^[15,16] A similar mean age of 11.5 years was reported by Ubesie *et al* ^[12] in the south-eastern part of Nigeria. The mean age at disclosure in the current study was, however, higher than the reported value of 8.7 years by Brown and colleagues ^[11] in Ibadan, Nigeria. The involvement of children less than five years could account for the lower mean age observed in the study by Brown *et al.*^[11]

Table IIb: Determinants of HIV sero-status disclosure

	HIV Status Disclosure		Statistics
	No (%)	Yes (%)	
Demise of family member to HIV infection			
No	78 (60.5)	29 (49.2)	$\chi^2 = 3.035; p = 0.219$
Yes	51 (39.5)	30 (50.8)	
Stage of Disease			
1	44 (34.1)	17 (30.9)	*FE = 11.388; p = 0.077
2	32 (24.8)	23 (41.8)	
3	35 (27.1)	14 (25.4)	
4	18 (13.9)	1 (1.8)	
TB Treatment			
No	99 (72.8)	35 (59.2)	$\chi^2 = 5.636; p = 0.06$
Yes	37 (27.2)	22 (40.7)	
Drug			
First line	113 (85.6)	46 (78.0)	$\chi^2 = 1.798; p = 0.407$
Second line	19 (14.4)	13 (22.0)	
Viral suppression			
Suppressed	107 (81.7)	47 (79.7)	$\chi^2 = 0.326; p = 0.849$
Not suppressed	24 (18.3)	12 (20.3)	

*FE - Fisher's Exact Test

Table III: Predictors of HIV status disclosure

Variables	p-value	95% CI for EXP (B)
Age of child	0.001*	3.450 to 69.885
Social Class	0.138	-.290 to -1.156
Marital status of caregiver	0.005*	1.301 to 4.641

The caregivers of HIV-infected children who were yet to know their HIV serostatus planned disclosure at the mean age of 14.2 years in the current study. Bearing in mind the importance

of disclosure of HIV serostatus to care, there is a need for more strategic efforts that will encourage age-related serostatus disclosure as well as address the hindrances to disclosure.

Parents were mostly responsible for the disclosure in the present study. This is similar to the report by Naidoo *et al* [17] in South Africa. HIV serostatus disclosure had a similar outcome irrespective of who was involved in the disclosure process. This shows that the disclosure of serostatus to HIV-infected children may be done by caregivers who know how to. Studies have shown difficulties in serostatus disclosure by both parents and health care providers. [18,19] With the adoption of the guidelines on serostatus disclosure, all the participants involved in the care of HIV infected children should be able to handle serostatus disclosure in children.

Positive impacts of serostatus disclosure in the current study included better antiretroviral drug adherence, a better relationship with the caregiver and less questioning. Improvement in drug adherence following disclosure is one of the most consistent positive impacts reported in previous studies. [11,20-23] Adherence to antiretroviral medications is crucial to the attainment of treatment goals in paediatric HIV. Therefore, improvement in the disclosure rate may also contribute to the achievement of the required goals.

In the present study, about one-third of the children with serostatus disclosure had negative responses such as anger, withdrawal, and sadness. Negative responses following serostatus disclosure have been previously documented. [24,25] These negative impacts have been realised to be inconsequential compared to the benefits. [26] In the present study, the negative responses lasted mostly within a month. There is a need to encourage caregivers on the significant benefits of serostatus disclosure compared to the negative responses which are mostly transient.

Maturity in age and understanding was the major reason for serostatus disclosure in the

present study. Frequent questioning, the demise of a sibling and poor drug adherence were prominent reasons for serostatus disclosure in the present study. The caregivers' perception of affected children being too young, stigmatization and lack of how to disclose, mostly accounted for the failure of serostatus disclosure. In some previous studies, similar barriers to serostatus disclosure have been reported. [22,27] Stigmatization is a major social problem faced by HIV-infected individuals. It is a major hindrance to the care and disclosure of HIV serostatus, hence, it requires more education of the populace. The lack of know-how was the third leading reason for non-disclosure of serostatus in the current study. There is a need for more parental education and support on disclosure of their wards' HIV serostatus.

The need for serostatus disclosure at a stage in life was unanimously accepted by the healthcare workers. The majority of healthcare workers in the care of HIV-infected children believed disclosure of serostatus to affected children should be carried out from the age of twelve years while over a quarter of them had no idea of the age disclosure should be done. This observation revealed the need for training of health care providers on how to disclose HIV serostatus to affected children. This requirement for training was also requested by almost three-quarters of the participants in the current study. Lack of training was identified as a barrier to serostatus disclosure by Kalembo *et al*. [19] WHO recommends training for healthcare providers and provides counselling guideline on serostatus disclosure.[28]

In the present study, children aged ten years and above were more likely to know their HIV serostatus compared to the younger age group. This is in keeping with the findings in some previous studies. [11,15,16] The caregivers within the low social class were more forthcoming with

the disclosure of the HIV status to their wards compared to those in high social class. This is in keeping with the finding reported by Ubesie *et al.* [12] and also in keeping with the report that uneducated parents had a higher rate of serostatus disclosure compared with educated parents. In contrast, Nzota *et al.* [29] in a Tanzanian study reported a higher rate of serostatus disclosure to children of higher-income earners than those with lower monthly income. The need for dependence on relations and the extended family system for supports, which is commoner in the lower social classes, could account for the less inhibition over divulging of serostatus of affected children.

Orphans, children of separated parents and children of single parents were more likely to know their HIV serostatus than those whose parents lived together. Higher likelihood of disclosure to orphaned children was also reported by Negese *et al.* [16] The finding of a higher rate of serostatus disclosure to children with single parents observed in the current study, had earlier been reported by Kodyalamoole *et al.* [27] in India. Single parenthood and orphanhood are liable to financial challenges and this may account for the higher rate of serostatus disclosure in these groups of people. Dependence on others for supports as well as incentives commonly provided in the Adolescent Clinic at the study centres (for which serostatus disclosure is a pre-requisite for enrolment) could account for the higher rate of serostatus disclosure in these individuals with the likelihood of financial dependence. Sero-status disclosure was more likely, though not in a significant proportion, among children with a history of the demise of a family member unlike its significant determinant for serostatus disclosure as reported by Negese *et al.* [16]

A non-significantly lower proportion of discordant couples have disclosed their ward's

HIV serostatus to them compared to seropositive couples. The rate of disclosure of HIV status among non-discordant couples is low in Nigeria. [30] This is expected to reflect on the serostatus disclosure of children in these circumstances. As observed in the present study, independent determinants of serostatus disclosure included the age of the child and the marital status of the caregiver. Children with single parents were more likely to know their HIV serostatus compared with those with married parents who lived together. This is similar to the finding of a higher rate of serostatus disclosure to children living with their mothers only by Tsuzuki *et al.* [31]

Conclusion

Overall, the serostatus disclosure rate to a population of HIV-infected Nigerian children is low. The disclosure by all individuals involved in the care of affected children has similar effects. Children aged ten years and above and with unmarried parents are more likely to know their HIV serostatus compared with younger age groups or those with married parents. There is a need for training and support for parents on the disclosure of HIV serostatus. Knowledge of age-appropriate disclosure for younger children with HIV infection is required. Routine training of healthcare personnel in the care of affected children as a strategic tool for the increase in the rate of HIV serostatus disclosure to affected children cannot be overemphasized.

Acknowledgment: All the healthcare personnel, HIV-infected children and their primary caregivers who participated in the study.

Authors' Contributions: AMO, AMA, and OOA gathered the data while AMO analysed and interpreted the data. AMO, UPO, AAB drafted the

manuscript. All the authors approved the final version of the manuscript.

Conflict of Interest: None.

Funding: Self-funded.

Publication History: Submitted 19 July 2019; Revised 14 September 2019; Accepted 25 September 2019.

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