

Full Length Research Paper

Disclosure of HIV diagnosis to infected children receiving care in University of Uyo Teaching Hospital, Uyo, Nigeria

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Disclosure of human immunodeficiency virus (HIV) diagnosis to infected children is still a challenge despite proven evidences that it has numerous social and medical benefits for the child and family. The aim of this study was to document the disclosure rate of HIV diagnosis to children in Uyo, Nigeria and determine the factors influencing disclosure or non-disclosure to these children. This was a descriptive cross-sectional study. A pre-tested and validated semi-structured questionnaire was administered to consenting parents/caregivers of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) infected children aged 6 to 17 years in care at the Paediatric Infectious Diseases Unit of the University of Uyo Teaching Hospital, Uyo (UUTH) from January to June, 2015. One hundred and twenty-two caregivers (26 males and 96 females), giving a male to female ratio of 1:3.7, aged 20 to 60 years, were interviewed. Sixty-eight (55.8%) of them had post secondary education. Twenty (16.4%) of the children aged 9 to 17 years (13.3±2.4 years) had been disclosed to. Age of the children, gender, orphan status, their level of schooling and their socio-economic class positively affected disclosure. Also, caregivers between ages 30 and 49 years who were more educated were more likely to disclose the HIV status of their children. Commonest reason for non-disclosure was child being sad (29.5%). Others were blaming the parents (18.0%), not understanding the import of the diagnosis (9.8%) and 6.6% feared child disclosing to others. Forty-four (37.7%) did not give reasons for non-disclosure. Sixty-seven (54.9%) of the caregivers who did not disclose said they would do so after 10 years of age. A national protocol for paediatric HIV disclosure is desirable.

Key words: Disclosure, diagnosis, children, human immunodeficiency virus (HIV), Nigeria.

INTRODUCTION

Nigeria still stands as the country with the second highest burden of HIV in the world, only after South Africa with a national prevalence of 3.4% according to the National HIV/AIDS and Reproductive Health Survey of 2012

(UNAIDS Global Report, 2014). Over the past three decades, after the first two cases of HIV and AIDS were reported, a number of programmes have been set up to reduce the incidence and prevalence of the infection in

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the country. Prevention of Mother to Child Transmission (PMTCT) has been one of such, with a goal of eliminating Mother to Child Transmission (MTCT) by 2015 (UNAIDS Global Report, 2014). The coverage for PMTCT still remains low at 30.1% (UNAIDS Global Report, 2014), although there has been a slight appreciation from the 25.9% of the preceding 2 years, based on the 2014 estimates. An estimated 69,400 Nigerian children were newly infected with HIV in 2011, and an unprecedented 440,000 children lived with this infection as at 2012 (AVERTing HIV and AIDS, 2012).

The provision of treatment and care for HIV/AIDS with increased availability and use of cost effective antiretroviral drugs has had a significant positive impact on the people living with HIV including children. Consequently, more perinatally infected HIV children now live longer into adolescence and adulthood.

Disclosure of an HIV diagnosis to school-aged HIV infected children has been documented to be beneficial to them and their caregivers spanning from better adjustment to their chronic illness and less psychological distress (Bachanas et al., 2001), lower rates of depression (Lipson, 1994) to greater success of highly active antiretroviral treatment (HAART) (Paterson et al., 2000; Chi-Ling and Rosemary, 1999). Disclosure rates have been reported to range from 17 to 100% in resource-rich settings (Gerson et al., 2001). Arun et al. (2009) reported 14% in New Delhi, India, while Kallem et al. (2011) reported 21% in Ghana and Feinstein et al. (2010) reported a range of 3 to 77% from Soweto, South Africa. In Nigeria, there is paucity of data on the disclosure rates of HIV diagnosis to children and up till now, no disclosure guidelines exist. As at 2012, the only available data is a disclosure rate of 13.5% to children in an HIV Care Programme in South-West Nigeria (Brown et al., 2011).

This study set out to document the disclosure rate of an HIV diagnosis to infected children in care at the Paediatric Infectious Diseases Unit of a tertiary hospital in Akwa Ibom state, south-south Nigeria with a prevalence rate of 6.5% which is above the national average (3.4%). It also attempted to determine the factors influencing disclosure or non-disclosure of the diagnosis of this widely stigmatized chronic infection to these children.

METHODOLOGY

This was a descriptive cross-sectional study involving interviews of consenting parents and caregivers of children managed for HIV/AIDS at the Paediatric Infectious Diseases Unit of the University of Uyo Teaching Hospital, Uyo, Akwa Ibom State of Nigeria. The study was carried out from 21 January to 3 June, 2015. The Paediatric HIV/AIDS Programme started in the unit in 2005 and it caters mainly for infected children from the state. Prior to commencement of the study, clinicians and expert clients of the Paediatrics HIV Care Programme team were previously trained on administration of a semi-structured questionnaire to the parents and other related caregivers of these children. Consenting related caregivers of HIV/AIDS patients aged 6 to 17 years were

interviewed. Parents and caregivers who did not give informed consent and institutional caregivers who do not reside with the children were excluded.

A pre-tested and validated questionnaire with 40 questions which required an average of 15 min to complete was used. The main questions included caregivers' socio-demographic variables and the relationship between them and the children, whether or not the child has been disclosed to specifically as being infected with HIV. Where children were not specifically informed that they had HIV/AIDS, their parents/caregivers were not included in the category of the 'disclosed' children. The child's social class was determined using the parents/caregivers social class according to the social classification scheme proposed by Oyediji (1985). The scheme classifies educational level on a scale of 1 to 5 with level 1 being the most educated and 5 as those who can just read and write or not literate. The occupation of parents is also graded from 1 to 5 with class 1 being senior public servants or equivalent and 5 being unemployed, students, full time house wives and so on. The child's social class is determined by addition of each of parents' educational and occupational points and dividing by 4 with result taken as nearest whole number. The highest social class so determined is 1 and the lowest social class is 5.

Parents/caregivers were interviewed in a separate room, which was not within hearing distance from the consulting rooms as a precaution against unplanned disclosure to the children. Waiting children were entertained with some snacks.

Data analyses were done with Statistical Package for Social Sciences (SPSS) version 20.0 software. Categorical variables were presented as frequencies and mean values, while standard deviation were computed for continuous variables. Associations between categorical variables were tested with Chi-square or Fisher exact test where appropriate and $p < 0.05$ was used as significant values.

Ethical clearance was obtained from the Ethics and Research Committee of the University of Uyo Teaching Hospital, Uyo. Informed consent was obtained from parents/caregivers of the children.

RESULTS

One hundred and ninety-eight (198) children with HIV/AIDS, 84 females and 114 males were in care at the Paediatric Infectious Diseases unit of the hospital. Of these, 130 were above 5 years of age, of which 8 had institutional caregivers who were excluded, leaving 122 eligible caregivers, 26 males and 96 females giving a male to female ratio of 1:3.7. All of them gave informed consent for the interview. Mothers 78 (63.9%) and fathers 21 (17.2%) comprised the majority of the study population; the remaining 18.9% were other relatives. The caregivers' age ranged between 20 and 60 years with the majority being 30 to 39 years of age (49.2%). Sixty-eight (55.7%) of the caregivers were educated beyond secondary school level. Table 1 shows the characteristics of caregivers in the study population, while Table 2 shows the socio-demographic characteristics of the children. Children aged 6 to 8 years were 56 (45.9%) and constituted the largest group, while the least represented were 15 (12.3%) from the 12 to 14 years age group. There were 55 (45.1%) females and 67 (54.9%) males, giving a female to male ratio of 1:1.2. Majority of the children belonged to the lower social classes 3 to 5. Table 3 shows that Caregivers of 20 (16.4%) of the

Table 1. Socio-demographic parameters of caregivers.

Parameter		Frequency	Percentage
Sex	Male	26	21.3
	Female	96	78.7
	Total	122	100.0
Age (years)	20-29	10	8.2
	30-39	60	49.2
	40-49	32	26.2
	50-59	15	12.3
	60+	5	4.1
	Total	122	100.0
Education	1	65	53.3
	2	3	2.5
	3	31	25.4
	4	17	13.9
	5	6	4.9
	Total	122	100
Employment	1	29	23.8
	2	1	0.8
	3	12	9.8
	4	55	45.1
	5	25	20.5
	Total	122	100.0

Table 2. Parameters of infected children.

Parameter		Frequency	Percentage
Sex	Male	67	54.9
	Female	55	45.1
	Total	122	100.0
Age (years)	6-8	56	45.9
	9-11	33	27.0
	12-14	15	12.3
	15-17	18	14.8
	Total	122	100.0
Social class	I	29	23.8
	II	7	5.7
	III	35	28.7
	IV	41	33.6
	V	10	8.2
	Total	122	100.0
Disclosure status	Disclosed	20	16.4
	Not disclosed	102	83.6
	Total	122	100

Table 3. Relationship of disclosure rate to children's variables.

Variable		HIV status disclosed	HIV status not disclosed	Total (%)	p value
Sex	Male	7	60	67 (54.9)	0.044*
	Female	13	42	55 (45.1)	
	Total	20	102	122 (100)	
Age (years)	6-8	0	56	56 (45.9)	0.0001
	9-11	3	29	32 (26.2)	
	12-14	5	10	15 (12.3)	
	15-17	12	7	19 (15.6)	
	Total	20	102	122 (100)	
Orphan status	Complete orphan	6	7	13 (10.7)	-
	Maternal orphan	1	17	18 (14.7)	
	Paternal orphan	5	23	28 (23.0)	
	Parents alive	8	55	63 (51.6)	
	Total	20	102	122 (100)	
Schooling	Nursery	0	22	22 (18.0)	0.0001
	Primary	4	64	68 (55.7)	
	Junior secondary	4	9	13 (10.7)	
	Senior secondary	10	5	15 (12.3)	
	Post secondary	2	2	4 (3.3)	
	Total	20	102	122 (100)	
Social class	I	3	26	29 (23.8)	0.004
	II	0	7	7 (5.7)	
	III	2	33	35 (28.7)	
	IV	10	31	41 (33.6)	
	V	5	5	10 (8.2)	
	Total	20	102	122 (100)	

*P – Fisher's exact test was used.

children were certain that the children knew their HIV serostatus. The age at disclosure ranged from 9 to 17 years with a mean age of 13.3 ± 2.4 years and a gender distribution of 13 females and 7 males. Of the 13 females who knew their serostatus, one did not know the route of transmission, while 5 and 7 said their routes were sexual and mother-to-child transmission (MTCT), respectively. Of the 7 males, 4 had MTCT and 3 did not know their route of transmission. There was a statistically significant association between disclosure and the gender of the children ($p = 0.044$, using Fisher's exact test), their age ($p = 0.0001$), level of schooling ($p = 0.0001$), orphan status ($p = 0.014$) and their socio-economic class ($p = 0.004$). For parents/caregivers, the variables with significant statistical association were age ($p = 0.004$) and educational level ($p = 0.001$). Other variables which however had no statistically significant association with the rate of disclosure were gender ($p = 0.94$), relationship with child ($p = 0.053$), marital status ($p = 0.094$) and employment status ($p = 0.298$). This is shown in Table 4.

For parents/caregivers whose children/wards did not know that they were HIV positive, the common reasons for non-disclosure were that the child will be sad 36 (29.5%), blame the parents 22 (18.0%), not understand the import of the diagnosis 12 (9.8%) and 8 (6.6%) respondents feared the child disclosing to others. As many as 44 (37.7%) of the respondents did not want to give their reasons for non-disclosure. Fifty-five (45.1%) of the parents/caregivers who are yet to disclose chose 15 years and above as appropriate age for disclosure while the remaining 67 (54.9%) opted for between 10 and 14 years of age as appropriate age of disclosure.

DISCUSSION

Challenges of HIV diagnosis disclosure of children remain in Nigeria, despite evidences of its medical and social benefits. Disclosure rates continue to be low especially in resource-poor settings. The observed

Table 4. Caregivers' variables and disclosure of HIV status to infected children.

Variable	HIV status disclosed	HIV status not disclosed	Total (%)	p value	
Sex	Male	7	19	26 (21.3)	0.94*
	female	13	83	96 (78.7)	
	Total	20	102	122 (100)	
Age (years)	20-29	0	10	10 (8.2)	0.004
	30-39	5	55	60 (49.2)	
	40-49	7	25	32 (26.2)	
	50-59	5	10	15 (12.3)	
	60+	3	2	5 (4.1)	
	Total	20	102	122 (100)	
Education (highest)	I	6	59	65 (53.3)	0.001
	II	0	3	3 (2.5)	
	III	4	27	31 (25.4)	
	IV	6	11	17 (13.9)	
	V	4	2	6 (4.9)	
	Total	20	102	122 (100)	
Employment	I	3	26	29(23.8)	0.298
	II	0	1	1(0.8)	
	III	0	12	12 (9.8)	
	IV	11	44	55 (45.1)	
	V	6	19	25 (20.5)	
	Total	20	102	122 (100)	
Marital status	Married	9	55	64 (52.5)	0.942
	Single	2	8	10 (8.2)	
	Co-habiting	1	9	10 (8.2)	
	Separated	1	3	4 (3.3)	
	Divorced	1	1	2 (1.6)	
	Widow/widower	6	26	32 (26.2)	
	Total	20	102	122 (100)	
Relationship to child	Biological mother	10	68	78 (64.0)	0.053
	Biological father	5	16	21 (17.2)	
	Grand parents	4	3	7 (5.7)	
	Other relatives	1	15	16 (13.1)	
	Total	20	102	122 (100)	

*P – Fisher's exact test was used.

disclosure rate of 16.4% is comparable to the 13.5% reported in South West Nigeria six years earlier (Brown et al., 2011) and 14% from New Delhi, India (Arun et al., 2009) but higher than 9% from South Africa (Moodley et al., 2006). The later study however, was conducted in children less than 6 years of age. Conversely, studies from other resource-poor settings have reported higher disclosure rates of 22.3% (Mumburi et al., 2014), 30.1% (Oberdorfer et al., 2006), 33.3% (Tadesse et al., 2015), and 37.8% (Menon et al., 2007), Tanzania, Thailand,

Ethiopia and Zambia, respectively. Disclosure in the Thailand study was however, not full and the Zambian study involved only adolescents aged 11 to 15 years. These rates are lower than 42% from United States of America (Cohen et al., 1997), a resource-rich setting. Our very low rate highlights the difficulties in initiating disclosure by caregivers considering all the psychosocial issues associated with the disease.

Almost twice as many females knew their status compared to the male children in our study. This could be

as a result of some adolescent females who had sexual transmission and were disclosed to by healthcare professionals during the course of their care. This finding has not been reported elsewhere.

The mean age of disclosure of 13.3±2.4 years is higher than that from most studies (Brown et al., 2011; Moodley et al., 2006; Mumburi et al., 2014; Oberdorfer et al., 2006; Tadesse et al., 2015; Atwiine et al., 2015), but comparable to 13 years of age reported in Uganda (Mutumba et al., 2015). The Ugandan study, however, involved adolescents only, compared to other studies which included younger children. Children older than 10 years were more likely to be disclosed to than younger ones. Our relatively higher mean age of disclosure compared to the 8.7 years average reported in the other Nigerian study by Brown et al. (2011) can be explained by the inclusion of younger children, 0 to 14 years while our study's age range was 6 to 17 years.

Children that had both parents alive were more likely to be disclosed to. This contrasts findings of others (Ledlie, 1999; Oberdorfer et al., 2006; Kallam et al., 2011) who reported that children who knew their diagnosis were living with caregivers who were not related to them.

In addition to age, a higher level of schooling of the children was also a determinant of HIV disclosure. This observation was also reported by Myer et al. (2006), Kallam et al. (2011), Bhattacharya et al. (2010) and Vaz et al. (2011). This improved disclosure rate with the children's higher level of schooling shows caregivers' perception of developmental maturity of the children with more educational exposure.

The present study showed that high socio-economic status of the children corresponded with high disclosure rate as noted by Weiner et al. (1996), but contrasts the findings of Oberdorfer et al. (2006) who reported that children whose caregivers had financial problems knew their HIV diagnosis more than those who did not have.

In our study, parental/caregivers' age and level of education were significantly associated with disclosure. People aged between 30 and 49 years were more likely to disclose the children's serostatus to them. Also, disclosure rate was higher among the more educated. This observation compares favourably with other studies (Bhattacharya et al., 2010; Biadgilign et al., 2011) who found parental/caregivers' high level of education to positively affect disclosure. Oberdorfer et al. (2006), however, reported that caregiver or family characteristics did not significantly affect disclosure.

There was no association between the likelihood of disclosure to caregivers' gender, marital status or employment status. These factors have not been considered in other studies.

Fear of child being sad or depressed was the commonest response for non-disclosure, as reported by Oberdorfer et al. (2006). Other studies also noted this as a common reason (Brown et al., 2011, Moodley et al., 2006; Kallam et al., 2011; Bhattacharya et al., 2010; Vaz

et al., 2011; Biadgilign et al., 2011). Repeated counselling of caregivers on the benefits of disclosure will allay their fears and possibly improve disclosure rate. The next reason was fear of blaming parents resulting in parental feelings of guilt and shame. There could also be risk of abandonment and negative reactions from other members of the family as well as the children exhibiting negative reactions towards their parents. This fear of negative effect of disclosure among family members was also noted by Demmer (2011).

A third of the caregivers did not give reasons for non-disclosure probably due to the difficulties of discussing the subject. Psychosocial issues surrounding HIV/AIDS also deserve the concerted effort made towards medical treatment of the disease. These issues are becoming more significant with increasing survival of affected individuals.

Caregivers of status naive children accepted that disclosure was beneficial. Half of them chose 10 to 14 years as appropriate age for disclosure while the remainder chose 15 years and older. Similar ages were reported by Arun et al. (2009) and Brown et al. (2011). The American Academy of Paediatrics [AAP] (1999), encourages disclosure of HIV infection status to school-aged children for maximum benefits. In our country, national guidelines should be developed with appropriate processes indicating when, where, who and how disclosure should take place. The time is ripe for this to form an important aspect of our national Paediatric HIV Care Programme.

Conclusion

The disclosure rate of HIV diagnosis to children in our setting is very low, even among adolescents. It is significantly influenced by gender, age, level of schooling, orphan status and socio-economic status. A well-structured national protocol and guidelines for Paediatric HIV disclosure should be developed and made available for on-going communication among children, caregivers and health providers so as to make the process of disclosure easier and more acceptable.

LIMITATION

The use of parents/caregivers as second parties to source for information concerning the children was a limitation of this study.

Conflict of Interests

The authors have not declared any conflict of interests.

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