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*Research Article*

## **Disclosure of Paediatric HIV Status to Infected Children and Significant Others: Impact and Psychosocial outcomes**

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### **ABSTRACT**

There is limited data on disclosure of Paediatric HIV to significant others in the social network of children which may impact on their care. This study determined the prevalence of disclosure of Paediatric HIV to infected children and others as well as their impact on the children. It took place at the Paediatric Infectious Disease Clinic of the University College Hospital, Ibadan. Caregivers of HIV positive school aged children were interviewed using a semi-structured questionnaire and the Parent version of the Strength and Difficulties Questionnaire. Data was analysed using IBM SPSS Statistics version 20.0. A total of 200 children were studied with a male: female ratio of 1.3:1 and ages ranging from 6-17 years. Disclosure of HIV status had been done to 54 (27%) of the 200 children. Disclosure was not associated with a significant difference in psychological functioning or adherence to ART. Disclosure had been made to extended family members in 128 (64%) of the 200 patients, to the children's siblings in 33 (21.4 %) of the 154 who had siblings, to the family spiritual leaders in 28 (14%) of the 200 families and to the children's teachers in 3 (1.5%) of 197 cases in school. In response to disclosure, all the siblings, teachers and spiritual leaders encouraged the families and expressed willingness to support but this was so for only 108 (84.4%) of the 128 extended family members. Major forms of support given were financial, medication reminder, emotional support and prayers. Negative outcomes included stigmatization and HIV related parental separation. There is need for health workers to promote disclosure to significant others and provide support for families who get abandoned by relations following disclosure.

**Keywords:** *Disclosure; HIV; Significant others; children; psychosocial; impact*

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### **INTRODUCTION**

In 2017, about 180,000 children were newly infected with the Human immunodeficiency virus (HIV), bringing the total number of children under age 15 years living with HIV to 1.8 million with nearly 90 per cent of these children living in sub-Saharan Africa (UNICEF, 2018). In order to facilitate improved outcomes in these children, it is important for them to be aware of their diagnosis as disclosure of diagnosis may improve adherence to treatment, retention in care and psychological adjustment ( Battles 2002; Bikaako-Kajura et al., 2006; Haberer et al., 2011, Arrivé et al., 2012).

In spite of the benefits of disclosure, a recent review on disclosure of HIV status to children found that lower proportions of children in low and middle income countries (LMIC) knew their status compared to those in high-income countries: median prevalence of disclosure in lower and middle income countries was 20% in contrast to 43% in high income countries (Pinzon-Iregui, et al., 2013 ). A major reason

for delayed disclosure by parents is perceived emotional immaturity and fear of negative psychological impact on the child (Tadesse et al., 2015, Gyamfi et al., 2017). In spite of this fear, there is little data on the psychological impact of disclosure on infected children in Africa.

A systematic review on the impact of disclosure on adherence showed conflicting results with some showing no association, some others showing a negative impact of disclosure on adherence, and yet others showing positive benefits of disclosure for adherence habits (Nichols et al., 2017). Disclosure of paediatric HIV status to others, may impact Paediatric ART adherence, children's well-being, and their social relationships. Beneficial impacts include improved ART adherence and better engagement of a helping social network (Vreeman et al., 2010). Potential adverse consequences include negative social effects such as discrimination against their families (Vreeman et al., 2010). However, the impacts of disclosure of children's HIV status to others in developing countries have not been well studied. The

objectives of this study were therefore to determine the prevalence of disclosure of Paediatric HIV to infected children and its impact on ART adherence and psychological functioning in the children. Other objectives were to determine the prevalence and pattern of disclosure to significant others as well as its impact on the child's wellbeing.

## **MATERIALS AND METHODS**

**Study design and location:** The design of the study was cross-sectional and it was carried out at the Paediatric Infectious Diseases clinic of the University College Hospital, Ibadan, a federal tertiary hospital in Oyo State, south west Nigeria. The clinic provides HIV care to children in Ibadan and serves as referral center for patients from neighboring cities.

**Study population:** The target population was the primary caregivers of school age children living with HIV infection. These are the persons that are primarily responsible for the care of the children. Inclusion criteria were children aged 6 to 17 years, who had been enrolled in the HIV care programme of the hospital for at least 6 months.

**Data collection:** Caregivers of HIV positive children aged six years or more were invited to participate in the study, which took place between June and November 2016. Data collection was through the use of 2 questionnaires that were administered to the parents or caregivers by the investigator and three other workers who were trained on its administration. The first questionnaire was a semi-structured questionnaire, administered to consecutive consenting caregivers in the absence of the children to ensure confidentiality and avoidance of unplanned disclosure. It was designed to capture socio-demographic data and explore the prevalence and pattern of disclosure to the children and significant others. Data obtained included socio-demographic variables, mode of acquisition of HIV infection by the child, whether or not disclosure had taken place, age at disclosure and impact on adherence to antiretroviral therapy (ART). Other data obtained included disclosure to significant others such as extended family members, siblings of patients, school teachers and family spiritual leaders as well as the responses and social impacts of these disclosures.

Disclosure to children in this study referred to telling the child specifically that he/she had AIDS or a viral infection called HIV. Socio-economic class stratification was based on the method by Oyediji (Oyediji, 1985). Adherence was assessed by asking the caregivers about the number of missed doses of antiretroviral drugs in the preceding period of one month. The adherence rate was then computed. The perceived immediate psychological response of the children to disclosure was also documented. This questionnaire was shared with a mental health expert for input and then translated from English to Yoruba, which is the predominant local language and subsequently translated back to English by another person to ensure it retained the original meaning. Questions that lost their original meaning during the translation process were re-translated to ensure they retained their original meaning. The questionnaire was then pre-tested

on 10 respondents and adjusted as needed before actual commencement of enrolment.

The second questionnaire was the Strength and Difficulties Questionnaire (SDQ)-Parent report measures for children and adolescents aged 04-10 and 11-17 years (Goodman, 1997). The English version of the SDQ was used to assess the psychosocial impact of disclosure on the child. The SDQ was designed, as both a clinical and an epidemiological research tool, to investigate children and adolescent's attention or concentration, peer relations, prosocial behaviours, emotional symptoms and conduct or behavioural disorders (Goodman, 1997, Dickey, 2004, Akpa *et al.*, 2015). It has been used to assess children's psychosocial outcomes in several countries including Nigeria (Doku, 2009; Giannakopoulos *et al.*, 2009, Akpa *et al.*, 2015).

The SDQ consists of 25 items to assess a range of 'strengths' and 'difficulties' as behavioural markers of potential mental health problems in children and adolescents. The items contribute to five subscales/domains of five items each with a minimum domain score of 0 (lowest score) to 10 (highest score): conduct problems, hyperactivity/inattention, emotional symptoms, peer problems, and prosocial behaviour (Goodman, 1997). The Total Difficulties score is generated by summing the scores from all the scales except the Prosocial scale. A higher total difficulty score indicates a greater likelihood of significant problems. The scores from each subscale as well as the total difficulties score were classified into normal (Emotional: 0-3, Conduct: 0-2, Hyperactivity: 0-5, Peer problems: 0-2, Prosocial: 6-10 and Total difficulty: 0-13), borderline (Emotional: 4, Conduct: 3, Hyperactivity: 6, Peer problems: 3, Prosocial: 5 and Total difficulty: 14-16) and abnormal (Emotional: 5-10, Conduct: 4-10, Hyperactivity: 7-10, Peer problems: 4-10, Prosocial: 0-4 and Total difficulty: 17-40). An abnormal score on the total difficulties scale can be used to identify likely cases with psychosocial affectation.

Consecutive mothers or caregivers of HIV infected children who met the inclusion criteria were invited to participate and those who gave informed consent were interviewed.

**Ethical consideration:** Ethical approval for the study was obtained from the Ethics committee of the University of Ibadan and University College Hospital, Ibadan (Approval number: UI/EC/15/0281).

**Data Analysis:** The information obtained from the questionnaire was entered into a spreadsheet and analysis was done using IBM SPSS Statistics version 20.0 software. Summary statistics was computed for continuous variables and means compared using t-test or Analysis of variance (ANOVA) as applicable. Categorical variables were described in frequencies and proportions. Associations were tested using chi square test or Fisher exact test as applicable

## **RESULTS**

A total of 200 children were studied with a male: female ratio of 1.3:1. Their ages ranged from 6-17 years with a mean (Standard deviation=SD) of 10.2(2.7) years. HIV infection was acquired through mother-to-child transmission in 198(99.0%) and through transfusion with infected blood in

2(1.0%) of the children. Out of the 200 children studied, 198 (99.0%) had HIV positive mothers, 2(1%) had HIV negative mothers, 106 (53.0%) had HIV positive fathers, 89 (44.5%) had HIV negative fathers and 5 (2.5%) had fathers with unknown HIV status.

Disclosure of HIV status had been done to 54 (27%) of the 200 children and the age at disclosure varied from 5-16 years with a mean (SD) of 11.3(2.5) years.

### Impact of Disclosure to Child

Out of the 200 patients studied, 199 were on antiretroviral therapy (ART) and assessed for impact of disclosure on adherence. Adherence to antiretroviral therapy was 95% in 49 (92.5%) of the 53 patients to whom HIV disclosure had been done, compared with 138 (94.5%) of the 146 in whom disclosure had not been done (Fisher's exact test  $p=0.736$ ).

Analysis of parental perception of the impact of disclosure revealed that no impact was observed in 46.3%, improved drug adherence in 35.2% and depression shortly after disclosure in 18.5% (table 1). The children with improved adherence became more willing to take their medications. The children who were depressed had a higher mean (SD) age of 12.8(1.9) years while those with no obvious

impact was observed had a lower mean (SD) age of 10.1 (2.3) years (ANOVA,  $F= 6.413$ ,  $p =0.003$ ) as shown in Table 1.

**Table 1:**

Parental perception of impact of disclosure

	Frequency	Percent	Mean Age (SD) in years
No impact	25	46.3	10.1 (2.3)
Improved adherence	19	35.2	11.9(2.4)
Depression	10	18.5	12.8(1.9)
Total	54	100	11.3 (2.5)

SD= Standard deviation

### Psychological Functioning

Analysis of psychological functioning of the children using the strength and difficulties questionnaire revealed that abnormal functioning was present in 2% of the cohort on the hyperactivity scale, 3% on the emotional symptom scale, 1.5% on the Prosocial scale, 2.5% on the conduct problem scale, 14% on the Peer problem scale and 2.5% on the total difficulty scale (table 2). There was no statistically significant difference in the percentage of children with abnormal function between those to whom HIV status disclosure had been made and those to whom it had not been made (Table 2).

**Table 2:**

Relationship between HIV status disclosure and Psychological functioning

Disclosure	Abnormal	Borderline	Normal	Total	p-value
<b>Hyperactivity Scale(HAS)</b>					
Yes	0(0)	1(1.9)	53(98.1)	54(100)	0.65
No	4(2.7)	2(1.4)	140(95.9)	146(100)	
Total	4(2)	3(1.5)	193(96.5)	200(100)	
<b>Emotion Symptom Scale(ESS)</b>					
Yes	4(7.4)	1(1.9)	49(90.7)	54(100)	0.07
No	2(1.4)	6(4.1)	138(94.5)	146(100)	
Total	6(3.0)	7(3.5)	187(93.5)	200(100)	
<b>Prosocial scale(PSS)</b>					
Yes	1(1.9)	2(3.7)	51(94.4)	54(100)	0.90
No	2(1.4)	0(0)	144(98.6)	146(100)	
Total	3(1.5)	2(1.0)	195(97.5)	200(100)	
<b>Conduct Problem scale(CPS)</b>					
Yes	1(1.9)	2(3.7)	51(94.4)	54(100)	0.341
No	4(2.7)	15(10.3)	127(87.0)	146(100)	
Total	5(2.5)	17(8.5)	178(89.0)	200(100)	
<b>Peer Problem scale(PPS)</b>					
Yes	7(13.0)	19(35.2)	28(51.9)	54(100)	0.82
No	21(14.4)	57(39.0)	68(46.6)	146(100)	
Total	28(14.0)	76(38)	96(48.0)	200(100)	
<b>Total Difficulties scale(TDS)</b>					
Yes	1(1.9)	2(3.7)	51(94.4)	54(100)	0.90
No	4(2.7)	8(5.5)	134(91.8)	146(100)	
Total	5(2.5)	10(5.0)	185(92.5)	200(100)	

**Table 3:**

Forms of support given by groups to whom disclosure was done

Group disclosed to	Form of support	Frequency	Percent
Extended family members (n=108)	Financial only	44	40.7
	Financial and food	16	14.8
	Financial and prayers	19	17.6
	Bringing child to clinic	16	14.8
	Emotional	13	12.0
Siblings (n=33)	Reminder to take drugs	17	51.5
	Taking the child to the clinic	6	18.2
	Financial	7	21.2
	Emotional	3	9.1
Spiritual leaders (n =28)	Encouragement and prayers	16	57.1
	Prayers and donation of cash and kind (foodstuff)	9	32.1
	Donation of cash and kind alone in	2	7.1
	Caregiving for the child whenever the parent was away from home	1	3.6
	Assistance with class work	1	33.3
Class teacher (n=3)	Emotional	1	33.3
	Financial	1	33.3

**Disclosure of child’s HIV status to significant others**

Disclosure of HIV status had been done to extended family members in 128 (64%) of the 200 patients, to the children’s siblings in 33 (21.4 %) of the 154 who had siblings, to the family spiritual leaders in 28 (14%) of the 200 families and to the children’s teachers in 3 (1.5%) of 197 cases in school. Out of the 130 Christian families in the study, 23 (17.7%) had disclosed to their spiritual leaders compared with 5 (7.1%) out the 70 Muslim families who disclosed to their spiritual leaders (Pearson Chi square, P value =0.040).

Among the 128 children in whom disclosure had been done to family members, it was done to the patients’ maternal relatives in 59 (46.1%) cases, to the paternal relatives in 46 (35.9%) cases and to both maternal and paternal relatives in 23(18.0%) cases. In terms of time interval between diagnosis of HIV infection in the children and disclosure to family members, it was done immediately in 103 (80.5%), weeks after diagnosis in 4 (3.1%), months after diagnosis in 3(2.3%) and years after in 18 (14.1%) cases.

The reason for disclosure to family members was to explain chronic illness, death and use of drugs in 105 (82.0%) cases, the need because of relationship ties in 9 (7.0%) and in order to receive support in 8 (6.3%) cases. No particular reason was given for disclosure in the remaining 6 cases.

**Response and Impact of Disclosure to family members and significant others**

In response to disclosure, all the siblings, teachers and spiritual leaders encouraged the families and expressed willingness to support but this was so for only 108 (84.4%) of the 128 extended family members. Table 3 shows the forms of

support received and indicates that the major form of support given by extended family members was financial, that by siblings was medication reminder, by spiritual leaders was emotional support and prayers.

In 24 (18.8%) of the 128 families to whom disclosure had been made, they avoided play and interaction between their children and the HIV infected child. This includes 15 families that were otherwise supportive to the affected child and family. With regards to the marital status of parents of the 200 children studied, 172 (86%) were married, 1 (0.5%) was not married and 27 (13.5%) were separated, the father having abandoned the child to the care of the mother. Separation was related to disclosure of the child’s HIV diagnosis in 23 (85.2%) of the 27 cases of separation. The 23 cases of HIV related separation represent 11.5% of the study participants. Separation was at the instance of the child’s father in 19 (82.6) %, at the instance of the father’s relatives in 2 (8.7%) and at the instance of the mother in 2 (8.7%) of the 23 children.

There was no statistically significant association between parental separation as a result of the child’s HIV status and religion, father’s HIV status, socio-economic class and disclosure to spiritual leaders.

**Table 4:**

Relationship between socio-demographic factors and parental separation

		Separation related to child’s HIV status			P-value*
		N	Percent	Total	
Socio-economic class	Upper	6	12.2	49	0.802
	Lower	17	11.1	151	
Religion	Christianity	15	11.5	130	1.000
	Islam	8	11.4	70	
Father’s HIV status	Positive	9	8.5	106	0.186
	Negative	14	14.9	94	
Disclosure to spiritual leaders	Yes	4	14.3	28	0.538
	No	19	11.0	172	

\*Fisher’s exact test

**DISCUSSION**

The 27% prevalence of disclosure in our study is similar to 26% reported in Western Kenya but less than the 32.6% reported by Nzota *et al* in Tanzania (Nzota *et al.*, 2015; Vreeman *et al.*, 2014). It is however an improvement on 13.5% reported previously in the same setting and infers an increased awareness by caregivers on the importance of adherence over the years (Brown *et al.*, 2011). However, there is still need for improvement as disclosure rates as high as 65% have been recorded in other African settings without any significant emotional disturbance (Binagwaho *et al.*, 2012).

Disclosure has been shown to improve adherence to antiretroviral drugs in children (Ugwu & Eneh, 2013). In our study, caregivers voluntarily expressed improved adherence in about a third of the children following disclosure in keeping with findings in Uganda (Bikaako-Kajura *et al.*, 2006).

However, disclosure was not associated with a statistically significant difference in adherence in the entire study population. It is possible that children to whom disclosure had not been done achieved adherence through force, coercion or other efforts by the caregivers as alluded to by Bikaako-kajura *et al* (2006). However self-motivated adherence which is seen in disclosed children is better in the long run as the children grow up to be independent of their caregivers. The routine adherence counselling that takes place at the monthly drug pick up appointments for each child in our clinic might have also contributed to the absence of a negative impact of non-disclosure on adherence as well as the high 95% disclosure score which was recorded in over 90% of the patients.

About one-fifth of the children were depressed immediately after disclosure according to parental perception. This was associated with older age of the children and reasonably due to better understanding of the lifelong course of HIV infection by older children. This calls for some professional psychological support during the process of disclosure especially for this subset of children. However, using the Strengths and Difficulties Questionnaire, the study revealed no significant difference in psychological functioning of children irrespective of their disclosure status. This is in keeping with findings by other workers in Africa (Adefalu *et al.*, 2016; Kalembo *et al.*, 2019). This is a reassuring piece of information for parents since a barrier to disclosure expressed by caregivers in previous studies is fear of psychological harm to the children (Gyamfi *et al.*, 2017).

This study has not only shown the pattern of disclosure of family members but also to significant others like religious leaders, school teachers and siblings of the infected children. The major reason for disclosure to family members was to explain chronic illness, death and use of drugs. Disclosure to the child's school teacher and family spiritual leaders were low but worse with the school teachers. Christians were also more likely to disclose to their spiritual leaders than Muslims. Nevertheless, the yield was a supportive response from the teachers and religious spiritual leaders irrespective of religious inclination. The 64% disclosure rate to extended family members implies that disclosure had not been done in over a third of families. This may constitute a psychological burden of secrecy for affected families, requiring counselling and psychological support.

Disclosure of diagnosis by adult HIV patients have been known to engender support such as improved care and material support (Atuyambe., 2014). Our study similarly revealed financial and material support granted to children by various groups of individuals to whom disclosure had been made. In the cultural context of some African settings, caring for children, including sustaining ART adherence, usually involves the support of a network of family and community members (Vreeman *et al.*, 2009). Caregivers in the present study described a wide range of support received from the different persons disclosed to support in cash and kind and assistance in taking the child to the clinic, caring for the child at home whenever the parent was away from home and emotional support. All these forms of support are better appreciated when one considers the fact that the need for regular clinic visits for the child and provision of home care for the children when ill creates a burden of absenteeism from

work on the parents; these are taken care of by supporters to whom disclosure have been made. In our study, siblings assisted with taking HIV infected children to the clinic and also reminded them to take their medications, which facilitated adherence. Similarly, caregivers in Kenya have reported that family members to whom disclosure has been made assist with administration of medications to the children (Vreeman *et al.*, 2010). Our study has shown several forms of social support derivable through disclosure to others and the need to explore and harness them in the care of children infected with HIV.

On the negative side, in almost a fifth of the cases of disclosure to extended family members, the latter prevented their children from playing with the HIV infected children. This form of stigmatization has been described by other workers and calls for better public enlightenment and support for affected families during the disclosure process (Vreeman *et al.*, 2010). Disclosure to family members also resulted in parental separation and paternal abandonment of the HIV infected child with the mother in 11.5% of the study participants. Although there was no association between the father's HIV status and the parental separation, it was mostly at the instance of the father. Social support and family counselling is therefore required in the process of disclosure especially for women who seem to be at the receiving end.

This study has thrown some light on disclosure of Paediatric HIV status to others, a subject that had hitherto been largely neglected. The supportive response by most of the people to whom disclosure was made and the forms of support received is an encouragement to promote this form of disclosure. The instances of family conflict, child abandonment and stigmatization that result call for support from the health institutions and state social welfare departments. More studies are required to better define the pattern and outcomes of disclosure of paediatric HIV status to others.

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