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Full Length Research Paper

HIV disclosure in children in Port Harcourt: Mothers' perceptions

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With Antiretroviral treatment and care, the population of children with HIV infection who grow into adolescence and adulthood will increase. The consequences of not disclosing the diagnosis to them becomes worrisome. This study tries to explore the mothers' opinion on disclosure of their child's positive HIV status to them, and also find out reasons if any, for not disclosing this status to them. Mothers of HIV infected children attending the infectious disease clinic at the University of Port Harcourt Teaching Hospital were interviewed. Of the 223 mothers interviewed, 189(84.7%) would disclose the HIV status to their children and 96 (50.3%) would disclose at age 15–18 years. Reasons for not disclosing before this age were belief that the child would not understand 97(51.3%) and the child's inability to keep his status a secret 42(22.2%). The male gender of the child, maternal HIV sero-negativity status, and primary level of education significantly affected willingness to disclose (p=0001, 0.0000 and 0.005 respectively). 101(45.2%) would not disclose to family members including the siblings. Mothers with HIV infected children are unwilling to disclose the diagnosis to them, until the late adolescent period for fear of stigmatization, as well as inability to cope with the diagnosis and keep it secret.

Keywords: HIV Disclosure, children, mothers' opinion

INTRODUCTION

Many children with HIV/AIDS are surviving to adolescence and some to adulthood. Consequently the disclosure of a diagnosis of HIV infection / AIDS to a child is becoming an increasingly common issue. Disclosing the diagnosis of HIV or AIDS to a child is a controversial and emotionally charged issue among both the health care communities and parents and caregivers of these children (Wiener et al., 2007).

Some parents are reluctant to inform children about their HIV infection status because the majority of HIV-infected children acquired the virus from their mothers and the ensuing parental guilt about transmission distinguishes this disease from other life-threatening pediatric illnesses (Havens et al., 2005). Thus, not only are parents' decisions to disclose affected by their fears about the emotional consequences of disclosure for the child, but also their fears about the child's anger towards the parent, and the potential social consequences associated with the child sharing the diagnosis with others (e.g. ostracism, negative reactions from family, friends and school, lack of community support) (Wiener et al, 2007). Children with a variety of chronic diseases, including those with cancer, have exhibited better coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness (Lipson, 1994; Grubman, 1995). Data from several centers indicate that between 25% and 90% of school-age children with HIV infection/AIDS have not been told they are infected (Walsh and Bibace, 1991; Vreeman et al., 2008; Woodard and Pamies, 1992). There is controversy about the age of disclosure, with some people advocating for disclosure as early as the age of five to seven years, assuming that the older adolescents may not be able to deal with it (Tindyebwa et al., 2006). The American Academy of Pediatrics (American Academy of Pediatrics, 1999) strongly encourages disclosure of HIV infection status to school-age children. Disclosure should optimally be conducted in a controlled situation with parent(s) and

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The public health risks of non-disclosure, including non-adherence to medications that may result in drug resistant strains of HIV combined with risky sexual behavior that may result in transmission of the virus (including such drug-resistant strains), add a sense of urgency to the issue of disclosing the HIV diagnosis to youth living with perinatal HIV infection (Frederick et al, 2000). There is therefore urgent need to encourage parents to disclose their child's HIV status early and to other siblings who are likely to empathize with him and help him in coping. Understanding mothers' barriers and perceptions regarding disclosure are important to improve Pediatric HIV disclosure. To date little attention has been focused on the issue of disclosure as a critical first step to successful family treatment in Nigeria. No study has been done on HIV disclosure in children in University of Port Harcourt Teaching Hospital. This study aims to explore mothers' opinion on disclosing their child's HIV status to him/her.

METHODS

This was a prospective study of consecutive mothers of HIV positive children who brought their children to the Infectious Disease Clinic at the University of Port Harcourt Teaching Hospital (UPTH), Port Harcourt from Jan 1st to June 30th 2008. The recruited mothers constituted 95% of the total number of patients' mothers receiving treatment for HIV in the Unit at the time of the study. The mothers were interviewed using a structured investigator administered questionnaire with closed ended questions. Ethical clearance for the study was obtained from the UPTH Ethics Committee and written informed consent was obtained from the mothers.

Information sought for included the child and mothers' age, parental HIV Status, likely mode of transmission to child, parent's occupation and educational level, age at which mothers would like to disclose a child's HIV status to him/her, and who should disclose, reasons for not disclosing to child and other family members. Majority of the affected children's parents were also receiving care at the adult Infectious Disease clinic of the UPTH. Thus, the parents HIV status was obtained during the interview by requesting for and sighting the HIV result of both mother and father (where father had been tested).

The mode of transmission was presumed vertical if the mother was HIV positive and there was no history of risk exposure. The non-vertical modes of transmission were presumed if the mother was HIV negative and the child had any of the high risk exposure such as blood transfusion, sexual intercourse, use of sharp objects including intramuscular injections in a patent medicine shop, circumcision by traditional birth attendant and shaving instruments.

Data was analyzed using Epi Info version 6.0. Differences in qualitative data were compared using the Chi square test. Fisher exact test was also used. P value ≤ 0.05 was considered to be statistically significant.

RESULTS

A total number of 223 mothers with age range from 17 to 52 years participated in the study. The age distribution of the mothers, their educational levels, mothers and fathers HIV status, and presumed mode of transmission for the children are presented in Table 1. Of these 223 mothers, 75(33.6%) were aged 31-35 years, most of the mothers 108(48.4%) had secondary education. Two hundred and two (90.6%) of the mothers were HIV positive and the probable mode of transmission for the majority 202 (90.6%) of the children was through mother to child transmission (MTCT). The gender of their children was 120 (53.8%) males, and 103 (46.2%) females, giving a male to female ratio of 1.2:1. Ninety-five (42.6%) were <18months and 128 (57.4%) were ≥ 18 months of age.

Only 179 fathers have been tested out of which 87(48.6%) were positive and 92 (51.4%) were sero-negative. Of the sero-negative fathers, 71 were sero-discordant in which the fathers were negative and the mothers' positive giving a sero-discordant rate of 39.6%. Of the sero-concordant couples 87 fathers/mother pairs were positive and 21 father/mother pair were negative.

Most mothers189 (84.7%) would want to disclose the HIV status to their children and 34 (15.3%) would not. Among the sero-concordant, 97(89.8%) would disclose and 11(10.2%) would not. In discordant couples 55 (77.5%) would disclose while 16 (22.5%) would not disclose. These differences in the willingness to disclose HIV status to children between the sero-concordant and discordant couples was statistically significant (χ^2 =5.1, df=1, p= 0.023) . The male gender of the babies significantly affected willingness of the mothers to disclose, among the 120 mothers with male children 114(95 %) would disclose while 6(5%) would not, but among the 103 with female children 75 (72.8%) would disclose and 28 (27.2%) would not. The difference between those with male children and those with female children who would disclose was statistically significant (χ^2 = 21.11, df=1, p = 0.01). The willingness to disclose was also significantly affected by the mother's level of education as 43 (97.7%) of the 44 mothers with primary education would disclose compared to 82 (76%) out of 108 mothers with secondary education. (χ^2 =68.42,df 1, p-value = 0.000) . Also 64 (90.1%) out of 71 with tertiary education would disclose. This difference between those with secondary and tertiary education was also statistically significant (χ^2 =74.79,df 1, p=0.000). The willingness to disclose was significantly affected by the mother's HIV status. All the negative mothers would want to disclose while the 34 who would not disclose were all HIV positive. This difference was statistically significant

Table 1: General characteristics of the mothers and infants

Characteristics	Number (223)	Percentage
Maternal age in years		
16-20	21	9.4
21-25	31	13.9
26-30	57	25.6
31-35	75	33.6
>35	39	17.5
Maternal Educational level		
Primary	44	19.8
Secondary	108	48.4
Tertiary	71	31.8
Mothers HIV status		
Positive	202	90.6
Negative	21	9.4
Fathers HIV status		
Positive	87	39
Negative	92	41.3
Not yet tested	44	19.7
Mode of transmission for the children		
Vertical	202	90.6
Blood	15	6.7
Sexual	5	2.2
Others	1	0.5

Table 2: Age of the children at which mothers will like to disclose

Age in years	Number	percentage
<10	21	11.1
11-14	65	34.4
15-18	96	50.3
>18	8	4.2
Total	189	100

(Fisher exact test p = 0.005).

The age at which the majority 96 (50.3%) would want to disclose was 15 – 18 years (Table 2). The most important reasons for not disclosing the condition before this age were belief that the child would not understand 97 (51.3%) and anxiety of the child not being able to keep his/her status a secret 42 (22.2%) (Table 3).

Most mothers 166 (87.8%) would tell the child the truth about how he acquired the infection while 23 (12.2%) would not. All the 23 that would not tell the truth about the likely source of infection were vertical transmission and their reasons were that the child would hate her 8(34.9%), he would be angry 7(30.4%), he would not forgive her 5(21.7%) and 3 (13%) had other reasons. The majority 72 (38.1%) of the respondents felt that both parents should be the ones to disclose the HIV status to the child while only 46 (20.6%) felt that disclosure should be in the presence of both the doctor and parents (Table 4).

Most of these mothers 101 (45.2%) would also not like to disclose to other relations including affected child's siblings.

DISCUSSION

HIV disclosure is more than revealing HIV status. It also entails an ongoing discussion of health and health related issues. This study shows that although most mothers with HIV infected children are willing to disclose the diagnosis to their children, they would do it rather late, during the late adolescent period. By this age, many adolescents would have been involved in risky behaviors and may unwittingly transmit infections to others. This finding is

Table 3: Reasons for not disclosing HIV status before the chosen age.

Reasons	No	Percent
He will not understand	97	51.3
He cannot keep a secret	42	22.2
He will be depressed	30	15.9
He will not cope	20	10.6
Total	189	100

Table 4: Who should disclose HIV status to child

Who should disclose	No	Percentage
Mum and Dad	72	38.1
Mum	50	22.4
Doctor and parents	46	20.6
Dad	30	13.3
Doctor	25	11.2
Total	223	100

similar to studies done in Kenya (Vreeman et al., 2008) and Thailand (Oberdorfer et al., 2006) where most mothers are willing to disclose but at an older age. Although the American Academy of Pediatrics strongly encourages disclosure of HIV infection status to school-age children (American Academy of Pediatrics, 1999), some parents and health care professionals are reluctant to inform children about their HIV infection status. It has also been advocated that disclosure process should start between 5 and 7 years depending on the child's understanding/cognitive development (Tindyebwa et al., 2006; Federal Ministry of Health 2007). Data from several centers indicate that between 25% and 90% of school-age children with HIV infection/AIDS have not been told they are infected (Lipson, 1994; Grubman, 1995; Walsh and Bibace, 1991)

Guidelines exist about the disclosure of a chronic illness to a child. In general, disclosure is geared to a child's level of cognitive development and psychosocial maturity (American Academy of Pediatrics 1999). Disclosure is a continuing process and not a one- time event and is different for each family. Studies have shown that children who know their HIV status have higher self-esteem than infected children who are unaware of their status (Lipson, 1994). Parents who have disclosed the status to their children experience less depression than those who do not (Lipson, 1994).

The female child negatively affected willingness to disclose. This is in contrast to a study done in Kenya where the sex was not associated with disclosure (Wariau et al., 2008). The reason for this association in female children in this study cannot be immediately known. Although this may be seen as protective so that she can marry without discrimination. The HIV status of the mother significantly affected disclosure as seen in this study and others (Wariua et al., 2008; Witte and Lewis, 1997). This is not surprising because they may feel that disclosing HIV status to the child may mean exposing her own status. The reasons often given by parents of HIV-infected children for not disclosing HIV status early include fear of inadvertent disclosure by the child. Also sero-discordancy in the parents negatively affected disclosure because the positive mother may want to keep her status secret even from her spouse. Disclosure of status by the child may lead to stigmatization, discrimination, or ostracism toward the child and other family members. Families are also concerned about the difficulty children have keeping a "secret" and limiting the disclosure to selected persons. These reasons are similar to those given by most mothers in this study for not disclosing early such as the feeling that the child will not be able to understand and cope with the diagnosis. They also fear that the child may be unable to keep the diagnosis a secret if told earlier and as such expose him/herself to stigmatization. Disclosure should optimally be conducted in a controlled situation with parent(s) and knowledgeable professionals. Some parents may decide to have professionals assume this responsibility. This is in contrast to the finding in this study where mothers would prefer to be the source of such disclosure to their children. The danger here is that the correct information may not be given in an attempt by the mother to protect herself from guilt feelings. The mothers in this study would also not disclose the HIV status to other siblings. This may be a disadvantage for the patients because other siblings may not empathize since they do not know

the kind of illness the affected sibling may have; they may not observe universal precaution thereby risking infecting themselves.

CONCLUSION

The study concludes that though most mothers with HIV infected children are willing to disclose the diagnosis to their children, they would do it rather late-- during the late adolescent period because they feel the child will be better able to understand and cope with the diagnosis then. They also fear that the child may be unable to keep the diagnosis a secret if told earlier and as such expose him/herself to stigmatization.

Furthermore, while parents may be making requests for nondisclosure based on what they believe is best for their children, physicians also have a responsibility to make an independent assessment of a child's readiness for disclosure.

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