

ORIGINAL ARTICLE

PREVALENCE OF DISCLOSURE OF HIV POSITIVE STATUS AND ITS PREDICTORS AMONG CHILDREN AND ADOLESCENTS WITH HIV INFECTION ATTENDING THE PAEDIATRIC INFECTIOUS DISEASE CLINIC AT TIKUR ANBESSA SPECIALIZED TEACHING HOSPITAL, ADDIS ABABA, ETHIOPIA

Tigist Argaw, M.D, Etsegenet Gedlu, M.D*

ABSTRACT

Background: *With the advent of antiretroviral therapy(ART), there has been a significant reduction in morbidity and mortality of HIV-infected children and many of the children are surviving through childhood and into adolescence. Despite emerging evidence of the benefits of disclosure, when and how to disclose the diagnosis of HIV to children remains a clinical dilemma.*

Objective: *We investigated the prevalence and factors associated with disclosure of HIV positive status to children and effects of disclosure among children with HIV infection.*

Methods: *A cross-sectional study was conducted among 233 HIV positive children aged 6-18 years from May- July 2013. Data on Socio-demography, disclosure status, age at disclosure and caregivers profile were collected by direct interviewing of caregivers and children. Medical diagnosis, WHO clinical staging, treatment compliance and CD4+ count was obtained from medical records directly. Data was analysed using SPSS version 17.0 software. Descriptive statistics such as frequency, mean, median, standard deviation and range were used to summarize the results. Significance tests and odds ratio were calculated using logistic regression models to examine the predictors and effects of HIV disclosure.*

Results: *The prevalence of disclosure was 32%. The most common reason for non-disclosure was that the child was not mature enough to understand and/or cope with their diagnosis (64.4%). Almost all caregivers agreed that HIV positive status should be disclosed to the children in the future. More than half (52.3%)preferred disclosure to be done by health-care providers only. Age of child >10 years at disclosure, the level of education of the child, longer duration on HIV medication were significantly associated with disclosure. ($P \leq 0.05$). Fewer admission rate and administration of own medication among the disclosed group was identified as significant positive effect of disclosure.*

*Corresponding author, Addis Ababa University, Department of Pediatrics and Child Health
Email: gedlue@gmail.com

Conclusion: *Prevalence of disclosure is very low accounting only in one third of children on follow up clinic and among them only one third of the disclosure was initiated by health workers. Caregivers from non-disclosed group prefer the disclosure to be by health professional only. It is recommended to address the barrier of disclosure in the perspective of health workers and a longitudinal study to be conducted to see health impact of disclosure is recommended.*

Keywords: HIV status disclosure; children; Ethiopia

INTRODUCTION

Introduction of Highly Active Anti-Retroviral Treatment (HAART) and increased accessibility significantly reduced morbidity and mortality of HIV-infected children. More and more children are surviving through childhood and entering to adolescence and young adulthood. ⁽¹⁾

With increased survival, one of the greatest challenges that parents and caregivers face is disclosing HIV infection to the infected children. ⁽²⁾ Many caregivers are reluctant to disclose for fear of stigma and isolation, parental sense of guilt, and fear that the child is too young to cope with stress associated with the illness or fearing that children would not keep the diagnosis to themselves. ^(3,4,5)

Although several studies both in resource rich and low income countries have documented the benefits of disclosure of the HIV status to infected children; health workers especially in low income settings are not comfortable to disclose the positive HIV status to child/adolescent themselves. They think that it is more sensitive and complicated than adult disclosure because many of the-

se settings currently lack standardized, culturally appropriate guidelines and resources for undertaking disclosure. ^(6,7,8,9)

The available evidences regarding disclosure of HIV status of children support a process-oriented approach; which has to be initiated early in patients' childhood and continue throughout adolescent. It is recommended for health care providers to discuss a disclosure plan with caretakers from the outset so that caregivers can prepare themselves for the task of disclosure ahead of time. This gives them confidence to discuss the disease with their children as they mature cognitively, emotionally and sexually. ^(9 10 11)

The aim of this study was to estimate the proportion of disclosure of HIV positive status, to identify predictors of disclosure and to identify effects of disclosure in selected health parameters in children and adolescents attending the paediatric infectious disease clinic of Tikur Anbessa specialized Teaching Hospital in Addis Ababa, Ethiopia.

SUBJECT AND METHODS

The study was done at paediatric infectious diseases follow up clinic of Tikur Anbessa

Specialized Teaching Hospital. Two hundred thirty-three children between 6-18 years of age and their caretakers were recruited after calculating the sample size by using single population proportion formula. Estimated prevalence of HIV positive status disclosure of 17.4% which was taken from a previous study in Addis Ababa.⁽⁴⁾ 95% confidence interval and a precision margin of 5% (0.05) were used in the equation to determine the number of participants. Caregivers and children who were visiting the clinic from May - July 2013 were selected by consecutive sampling method and interviewed using structured questionnaire. Socio-demographic characteristics, family status, and information related to disclosure were obtained. Interview about knowledge of HIV status was done separately to avoid unintentional disclosure. Information regarding WHO staging, treatment compliance, hospital admission and CD4 count were taken from the hospital medical records.

For the purpose of this study, care givers were defined as biological parent/s or a person who lives with the child, participate in the child daily care and are knowledgeable about the child's health.

Complete disclosure was considered when the child describes his /her disease as HIV. Non-disclosure defined when the care giver said that the child doesn't know his /her HIV infection status and/or if the caretaker was not sure if the child knew his/her status.

Pre-test was done in a similar study population who are not included in the sample. There was no major problem identified with the questionnaire.

Data were analysed using SPSS version 17.0 software. Descriptive statistics such as frequency, mean, median, standard deviation and range were used to summarize the results. Significance tests and odds ratio were calculated using logistic regression models to examine the predictors and effects of HIV disclosure.

Ethical clearance was obtained from Department of Paediatrics and Child Health Research and Publication Committee (DRCP) and from Institutional Scientific Review Board (IRB) of College of Health Sciences. Verbal and written consent of caregivers as well as oral assent from children older than 12 years was obtained. The right of the respondent not to participate or withdraw from the interview was respected

RESULT

The demographic and clinical characteristics of the 233 children and their caregivers enrolled into the study are illustrated in Table 1. Of the 233 children 54.1% of the children were females, and 68.6% (160/233) were attending grade level of five or below. Most care givers (47.6%) earn at least a monthly income of 500ETB. At the time of the study all children except 27 of them were on HAART, and more than half of them had CD4 cell count greater than 500.

Table 1. Socio Demographic Data of Study Population who are on follow up at Infectious Disease Clinic of Tikur Anbessa Specialized Hospital.

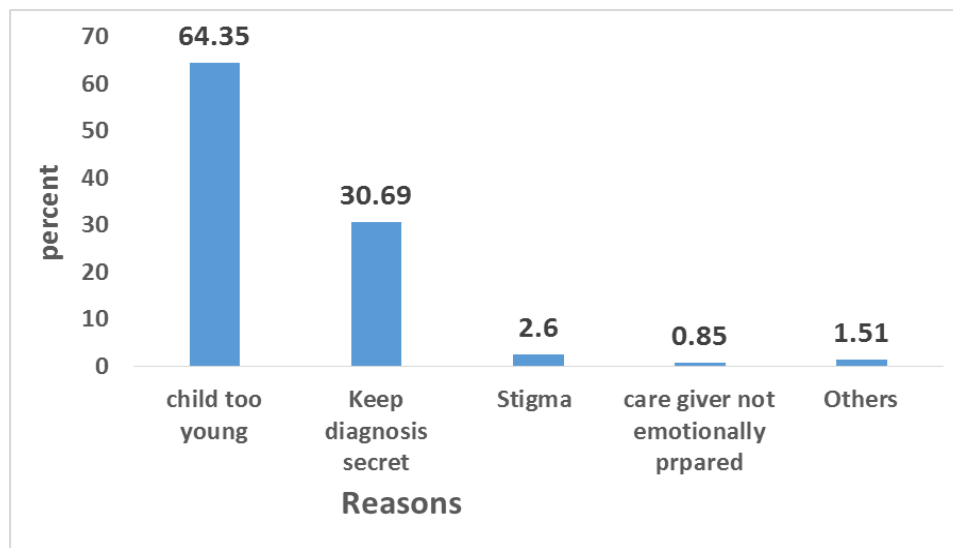
Characteristics	Disclosed (76)	Non- disclosed (157)	Total	%
Gender				
Male	32	75	107	45.9
Female	44	82	126	54.1
Age				
< 10	4	92	96	41.2
>10	72	65	137	58.8
Educational level Child (grade)				
<6	27	133	160	68.7
6-10	47	24	71	30.5
>10	2	0	2	0.85
Caretaker relation to the child				
Biological parents	43	105	148	63.5
Adaptive parents	0	2	2	0.85
Grandparents	5	14	19	8.15
Uncle/Aunt/Elder siblings	19	29	48	20.62
Care provider in Orphanage	6	2	5	2.14
others	3	5	11	4.72
Monthly income				
<500 ETB	43	68	111	47.6
500-1000 ETB	19	46	65	27.9
1000-2000 ETB	8	28	36	15.5
>2000 ETB	6	15	21	9.01
HAART therapy				
Not on HAART	6	21	27	11.6
On HAART	70	136	206	88.4

Disclosure had been made to seventy-six (32.4%) of the children and adolescents. The mean age at disclosure was 10.6years (SD = 2.01). The main reasons for disclosure of HIV positive status given were; the children asking about their illness and medications (37.62%), and health care providers asked them do so (35.64%). Twenty-two (28.9%) of the disclosed children reported that they knew their status before disclosure. Five children from non-disclosed group were able to describe their disease as HIV despite caretakers declared them as non- disclosed. The

main sources of information for inadvertent disclosure were overhearing discussion between health workers and caretakers, reading posters on follow up clinic, and learning about CD4 count at school.

As illustrated in Figure 1, the main reasons for non-disclosure of HIV positive status to children included: child not sufficiently mature to understand and/or cope with their diagnosis (64.3%), failure to keep family secrets outside the home (30.7%) and lack of emotionally readiness of care takers to disclose.

Figure 1: Reason for disclosure by caregivers who are on Follow up at Infectious Disease Clinic of Tikur Anbessa Specialized Hospital



Among the non-disclosed group, 69% (108/157) of the care takers did not disclose the diagnosis despite persistent questioning of the children about their illness and medications. More than two third of the caregivers of the non- disclosed group were planning to disclose the HIV status at the mean

age of 12.56 (SD =2.23). More than half (52.27%) of them wanted the disclosure to be done by health care providers only. Table 2 illustrated predictors of disclosure Age>10 years at disclosure, child's grade≥ 6, (P<0.05) were significantly associated with disclosure.

Table 2. Predictors of HIV status disclosure among children who are on Follow up at Infectious Disease Clinic of Tikur Anbessa Specialized Hospital.

Items	Disclosure (76) (n/%)	Non-disclosure (157) (n/%)	OR(95%CI)
Age(year)			
≤10	31(13.3)	88 (37.8)	0.05 (0.03,0.09)
≥10	45 (19.3)	69 (29.6)	
Education level of child (grade)			
<6	27(11.6)	133(57.1)	0.1(0.06, 0.19)
6-10	47(20.2)	24(10.3)	
>10	2(0.85)	0	
Biological parents			
Yes	43 (18.45)	105(45.06)	0.65(0.37,1.13)
No	33(14.16)	52(22.31)	
Duration of HIV diagnosis(years)			
≤5	19(8.15)	58(24.89)	0.57(0.33,1.15)
6-10	51(21.88)	97(41.63)	
>10	6 (2.57)	2(0.85)	
Duration of clinic attendance (years)			
≤5	22(9.44)	65(27.89)	0.58(0.32,1.04)
>5	54(23.17)	92(39.48)	
Time on HAART (Years)			
≤5	30(12.87)	79(33.9)	0.53(0.3,1.05)
>5	40(17.16)	57(24.46)	

As illustrated on Table 3. A fewer number of hospital admission and administration of own medications were observed as positive effect of disclosure ($P<0.05$). Adherence to treat-

ment, treatment failure, behavioural problems, current WHO Stage of disease, recent CD4 showed no significant difference among the disclosed and non-disclosed group.

Table3. Effects of HIV Infection Disclosure on Selected Health Variables of the study the population who are on follow up at paediatric infectious disease clinic of Tikur Anbessa Specialized Hospital

Items	Disclosed (76) (n/%)	Non -disclosed (157) (n%)	OR (95%CI)
Number of Hospital admission			
≤3	26(11.15)	62(26.6)	0.87(0.45,0.65)
>3	3(1.28)	3 (1.28)	
No Adherence			
Good	65 (27.89)	129(55.36)	0.70(0.21,2.3)
Fair	3(1.28)	5(2.14)	
Poor	2(0.85)	2(0.85)	
Treatment failure			
yes	3 (1.28)	7(3.0)	0.83(0.21,3.25)
No	67 (28.8)	129 (55.4)	
Who administer HARRT			
Child	43 (18.45)	26 (11.15)	6.1(4.34,8.17)
Caregiver	27 (11.6)	101 (43.34)	
Both	0	9 (3.86)	
Behavioural problem			
Yes	17 (7.2)	35(15.02)	1
No	59(25.3)	122(52.36)	
Current WHO stage of disease.			
I	57 (24.46)	111(47.63)	1.2 (0.66,2.32)
II	16 (6.86)	43 (18.45)	
III	1(0.42)	3(1.28)	
IV	2 (0.85)	0	
Recent CD4 count			
<200	1(0.42)	5(2.15)	0.83(0.38,1.16)
200-500	26(11.15)	58(24.9)	
>500	49(21.03)	94(40.3)	

DISCUSSION

Out of 233 participants, the majority of children were above the age of 10 years, most of them were on HAART and on follow up for more than five years. Unfortunately, only 32.4

% of them knew about their HIV infection status. This low proportion of disclosure was also observed in other studies in sub-Saharan Africa with disclosure ranging from 1.7%-39.6%.^(4,12,13)

In this study caregivers decided to inform their children of their HIV status due to either questions the children had about their illness and medications or following advice of health care providers to disclose. This is in line with studies from other countries.^(3,8,10) Opposing or tiring of secrets, believing in child's right to know their health status, fear the child would get involved in sexual activities without protection and better self-care were additional reasons cited for disclosure in several studies^(3, 5, 14,15)

Concerns about young age and maturity of the child to cope with the stress, to keep the disease as a family secret, and emotional readiness of caretakers were reasons given for non-disclosure and it is similar to other studies from both high and low income countries.^(3-5,10,8, 15)

The mean age at disclosure was 10.6 years and those caretakers who did not disclose the diagnosis prefer disclosure to happen when the child is older (mean 12.6) these findings are lower than what is reported by Bidgilign et.al in which most caregivers prefer to delay disclosure up to the age of 14 and above⁽⁴⁾ Recent review on disclosure of HIV status to children found higher median age of disclosure in low and middle income countries as compared to high income countries with median age of 9.6 and 8.3 years respectively⁽¹⁶⁾. According to WHO children have to have their HIV infection disclosed at school age. It is suggested that disclosure

can be planned incrementally according to their cognitive skills and emotional maturity in preparation for full disclosure.⁽¹⁷⁾

The decision on who should disclose the diagnosis is different among the two groups. Half of the non-disclosed group prefer the disclosure to be done by health professional only, while the majority of the disclosed group did the disclosure by themselves. Decision regarding who should be the primary discloser was found to be variable. Several studies reported the care taker was preferred as primary disclosure^(10,12) while few preferred the health professional.^(2,4) The differences can be explained by several factors including the socio-cultural background of care takers or the level of communication skills of health professional.^(6,10,12)

Delaying disclosure is often associated with unintentional disclosure of child infection status and happens during clinic visits or casual discussions among friends or other family members. In this study one third of the children from the disclosed group knew about their disease before disclosure and five children from non-disclosed describe their illness as HIV. Overhearing discussion between health workers and caretakers, reading posters on follow up clinic, and learning about CD4 count at school were how they knew their illness before disclosure. Although not looked specifically in this study; according to literatures those children who accidentally learn of their diagnosis have a more difficult

time adjusting to the situation and/or develop fear and anxiety; which might result in lack of trust and anger toward caretakers and health care providers^(12,18)

Similar to findings from previous studies (3,10,15,)age >10 years, education of child grade \geq 6, longer durations on HAART were found to be predictors for disclosure.

Fewer numbers of hospital admissions and administration of own medications were benefits observed in the disclosed group. Some health related quality of life parameters such as adherence, treatment failure, and behavioural problems, current severity of the diseases according to WHO Staging and recent CD4 + count showed no significant difference among the two groups. Literatures dealing with health benefits of disclosure showed a mixed result^(11,12,15,16,19)

LIMITATION OF STUDY

The study is cross-sectional and the associations observed may not be causal. As retro-

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spective study may also have subjected to some degree of recall bias

CONCLUSION:

Prevalence of disclosure is low, accounting only in 32% of the children. The main reason for disclosure was children asking questions about their illness and medication. The disclosure was initiated by health workers only in one third of cases. Non-disclosed caregivers delayed disclosure because of concerns about young age, the child's ability to cope with the stress and to keep the disease as a family secret. In this study the barrier of disclosure in perspective of health workers was not addressed and needs to be studied. Health related quality of life and disclosure has to be further investigated. Qualitative and prospective longitudinal studies are recommended.

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