

Original Research Article

Pattern of disease disclosure to patients in pediatric HIV clinic in a tertiary care center in Kerala

Priya S., Lathika Nayar*, Purushothaman K. K.

Department of Pediatrics, Govt. Medical College Thrissur, Kerala, India

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*Correspondence:

Dr. Lathika Nayar,

E-mail: drlathikanayar@gmail.com

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ABSTRACT

Background: The pattern and rates of disclosure of HIV status to infected children may differ within a country, and among the states, based on the socioeconomic, cultural, and even health status. Understanding this pattern is important in the formulating guidelines of disclosure on their HIV diagnosis to children infected by HIV, and to design strategies for improvement of adherence. This study was proposed to study the pattern of disclosure of HIV status in children aged 6 to 17 years.

Methods: This cross sectional study was conducted for a year (2016-2017) at a Pediatric HIV clinic in Thrissur, Kerala. Participants for this study were 58 HIV-infected children in the age group of 6-17 years who were on ART, and their parents/caregivers.

Results: Among the 58 participants, only 25 (43.1%) were aware of their HIV status, either fully (17; 68%) or partially (8; 32%). Healthcare providers were more likely to disclose the status to the affected child. Majority of the participants (84%) had better compliance to therapy after disclosure and most of the children in the non-institutional group were more supportive towards their parents (50%) after disclosure. The factors that were associated with disclosure in the non-institutional group were age of the child and duration of therapy.

Conclusions: Children infected with HIV showed better adherence after complete disclosure. Rate of disclosure can be improved by reviewing the disclosure hurdles in our state so that intervention programs can be planned for improving the rate of disclosure.

Keywords: Disease status, Pediatric HIV, Disclosure, Caregiver

INTRODUCTION

With increased access to anti-retroviral therapy (ART), many children infected with human immunodeficiency virus (HIV) have improved prognoses and survival.¹ More HIV-infected children are now entering adolescence and adulthood, bringing in new challenges to the healthcare system of developing countries like India. Adherence to medication, life-skills training, long-term disease management are just a few of these. One of the most important and critical clinical issue is the disclosure of HIV status to these children.² Studies show that timely and proper disclosure of their HIV status to children

offers many psychological benefits and positive effects on the management of the disease.^{3,4}

Though there are guidelines on disclosure, the decision to disclose as well as the method is often subjective. Rates of disclosure vary in different countries and proportion of disclosed children range from 0 to 69.2%.⁵ Most of the studies on pattern, rates and effects of disclosure are from developed countries and resource-rich settings. There is paucity of data on patterns of disclosure from India, where 39% of the people living with HIV are children under the age of 15 years.⁶ The rates of disclosure as per the few studies available ranges from 14% to 57.8%.⁷⁻⁹ In

a developing country like India, where parents are still uncomfortable talking about sexuality, marriage and sex, the pattern of disclosure is totally different from developed countries.¹⁰ The pattern and rates of disclosure may differ within a country, and among the states, based on the socioeconomic, cultural, and even health status. Understanding this pattern is important in the formulating guidelines of disclosure on their HIV diagnosis to children infected by HIV, and to design strategies for improvement of compliance to treatment. This study was proposed to study the pattern of disclosure of HIV status in children aged 6 to 17 years.

METHODS

This cross sectional study was conducted for a year (2016-2017) at a pediatric HIV Clinic, in Thrissur, Kerala. Participants for this study were 58 HIV-infected children in the age group of 6-17 years who were on ART, and their parents/caregivers. Only those who provided a written informed consent/assent were included in the study. Only those caregivers who were above 18 years and had firsthand information about the child were included. Children with neuro-developmental disability and those without a consistent caregiver were excluded from the study.

A structured, pretested questionnaire was used to collect information on demographic details, disclosure status, and the caregiver's perception about the disclosure of status to the child. Care was taken to have adequate privacy and confidentiality during the interview. Children were categorized into institutionalized and non-institutionalized based on whether they were cared for at home or an institution like orphanage. Descriptive statistical analysis was done using epi info version 7. The quantitative variables were expressed using mean±standard deviation. The qualitative variables were expressed in percentage.

RESULTS

Fifty eight children and their caregivers in the Pediatric HIV Clinic participated in the study, of which 40 resided in homes and 18 in institutions. The two groups were dealt separately due to the differences in caregiver characteristics and environment which influenced disclosure to a large extent. The mean age of children in the two groups – institutionalized and non-institutionalized was around 12 years. Majority of the children in non-institutionalized group (83.33%) were on ART, while 65% of those in institutionalized group was on anti-retroviral therapy. Demographic details and rate of disclosure in the two groups is given in Table 1.

Disclosure data

Among the 58 participants, only 25 (43.1%) were aware of their HIV status, either fully (17; 68%) or partially (8;

32%). Healthcare provider were more likely to disclose the status to the affected child (Table: 2).

Table 1: Demographic details and rate of disclosure among children in the institutionalized and non-institutionalized groups.

	Non-institutional (n=40)	Institutional (n=18)
Gender		
Boys	20	9
Girls	20	9
Age (mean)	12.51	12
Mean age at diagnosis (mean ±SD)	4.93±4.067	3±11
On ART n (%)	27 (65)	15 (83.33)

ART – antiretroviral therapy.

Table 2: Disclosure data in the two groups of participants.

	Non-institutional (n=18)	Institutional (n=7)
Rate of disclosure		
Disclosed	18 (45%)	7 (39%)
Non-disclosed	22 (15%)	11 (61%)
Pattern of disclosure type		
Complete	11 (61.11%)	6 (85.7%)
Partial	7 (38.89%)	1 (14.29%)
Person who disclosed		
Healthcare provider	9 (50%)	7 (100%)
Primary care giver	9 (50%)	0
Age of disclosure (years)		
6-10	5	1
11-14	12	5
15-17	1	1

In most patients, disclosure was done in the age group of 11-14 years and in a gradual manner (Table 3). When compared to non-institutionalized children, the pattern of disclosure was more planned in institutionalized children (71.42%) as it was done by the health care provider with proper counselling when compared to the more direct talk in non-institutionalized children. The mode of disclosure was gradual in both the cases. All the children in institutions had a counselling session for disclosure, while in non-institutionalized group it was more direct (66.67%). Majority of the participants (84%) had better compliance to therapy after disclosure and most of the children in the non-institutional group were more supportive towards their parents (50%).

Caregivers Immediate reaction to disclosure was sadness which was replaced by a more responsible and supportive attitude.

Table 3: Pattern of disclosure in the two groups of participants.

Planned vs unplanned		
	N (%)	N (%)
Planned	7 (38.89)	5 (71.42)
Unplanned	11 (61.11)	2 (28.57)
Trigger for disclosure in unplanned		
Child asking questions	4	
Death of parent	1	
HIV related program in media	6	
Mode of disclosure		
One time event	7 (38.89)	0
Gradual	11 (61.11)	7 (100)
Method of disclosure		
Direct	12 (66.67)	0
Using drawings and stories	1 (5.56)	0
Counselling	5 (27.78)	7 (100)
Change in compliance		
Better	14 (77.78)	7 (100)
No change	4 (22.22)	0
Change in child's behavior post disclosure		
Sadness	5 (27.78)	2 (28.57)
Anger at parents	1 (5.55)	0
Relief	3 (16.67)	0
Fear about future	1 (5.55)	0
More supportive towards parents	9 (50)	0
No change	4 (22.22)	5 (71.43)

Association between demographic characteristics and disclosure

Chi-square test and Fisher's exact test were used to examine the association between the characteristics of the participants and the status of disclosure (Table 4).

The only characteristics associated significantly with disclosure status was age ($p=0.02$) and duration since HIV diagnosis ($p=0.012$), in non-institutional group. None of the other characteristics like gender, treatment, having an affected sibling, or enrollment to school were significantly associated with the disclosure status in either group. Characteristics of the care giver like age, gender, marital status, socio-economic status, employment, or status of infection did not have a statistically significant association with the disclosure status in the non-institutional group (Table 5).

Nondisclosed group

Caregivers of the nondisclosed children also realized the need for disclosure and considered 14-17 years as the appropriate age and stated that the help of treating doctor is essential in the process. Main reasons stated for nondisclosure were concerns about the stress the children would have after disclosure and whether they would reveal the status to outsiders without proper understanding of the condition.

Table 4: Demographic characteristics by disclosure status of the participants.

Baseline characteristics of children in the disclosed and non-disclosed group						
Parameter	Non-institutional			P value	Institutional	
	Disclosed (n=18)	Non-disclosed (n=22)			Disclosed (n=7)	Non-disclosed (n=11)
Gender	Male	8	12	0.27	3	6
	Female	10	10		4	5
Age (in years)	< 12	4	13	0.02*	1	7
	> 12	14	9		6	4
Duration (in years)	< 5	1	9	0.012*	NA	NA
	> 5	17	13		NA	NA
On ART	Yes	15	12	0.08	5	10
	No	3	10		2	1
Sibling affected	Yes	2	0		NA	NA
	No	16	22		NA	NA
School enrolled	Yes	18	22		7	7
	No	0	0		0	4

Table 5: Characteristics of the caregiver by disclosure status in the non-institutional group.

Parameter	Disclosed	Non-disclosed	P value
Age (in years)	< 35	4	0.49
	> 35	14	
Gender	Male	2	1
	Female	16	
Marital status	Married	11	0.17
	Widowed	7	

Continued.

Parameter		Disclosed	Non-disclosed	P value
Socio-economic status (Modified Kuppaswamy)¹³	Lower	5	4	
	Upper lower	26	2	
	Lower middle	1	2	
	Upper middle	0	0	
	Upper	0	0	
Caregivers employment	Employed	11	10	0.5
	Unemployed	7	12	
Caregiver infected	Yes	15	18	1
	On ART	15	15	
	Not on ART	0	3	
	No	3	4	

DISCUSSION

The disclosure rate among the study participants was 43.1%, with the rate slightly higher among the non-institutionalized participants (45%) when compared to institutionalized children (39%). This is well within the range of disclosure rates available from other states of India.^{7-9,12} Studies from other countries on disclosure of HIV status to children show that it offers many psychological benefits on treatment and positive impact on clinical course of the disease.^{4,13,14} Despite the evidence on its benefits, the rate of disclosure has not improved in many areas due to varied reasons including stigmatization, parent's guilt, fear of negative impact on disclosure, and fear that child will be unable to keep the diagnosis a secret.¹² This clearly underscores the need to review the disclosure hurdles in our state so as to plan and implement more culturally-sensitive intervention programs to improve the rate.

Our study showed that prior to disclosure, only 50% of the children on ART were actually told that the ART medications they were having was for HIV infection. In spite of this, majority of the disclosures in our study were complete (68%, Table 2), and was done by the healthcare provider (64%). Complete disclosure of disease status is associated with improved adherence to ART as shown in the study by Bikaako-Kajura et al.¹⁵ And this is in lieu with results of our study where 88% of the participants showed better adherence after complete disclosure. In the non-institutional group, both healthcare provider and primary care giver had equal contribution in the disclosure of disease status to the children (Table 2). In the present study there were more non-disclosed participants in the institutional group when compared to the non-institutional group and this difference may be attributed to many factors including 1). Lack of bonding with the caregiver 2). Absence of consistent caregiver 3). Assumption that the child may be knowing as he/she is residing in institution which takes care of people with same illness 4) lack of disclosure skills. These factors may also lead to unnecessary delay in disclosures. This hurdle can be bypassed by training the healthcare providers in disclosure counselling who in turn will advise care givers on disclosure. Counselor-assisted

disclosure can be planned for those care givers who lack disclosure skills.¹⁵

In this study, the factors that were associated with disclosure in the non-institutional group were age of the child and duration of therapy. Association between child's age and longer duration on therapy was reported earlier.^{16,17} Our study did not show any significant association with other factors. None of the caregiver characteristics were significantly associated with the disclosure status in institutionalized or non-institutionalized group. More research based on interviews with children, healthcare providers and caregivers is needed to gather data on the major challenges in facilitating disclosure. Additional quantitative data on disclosure rates and health outcomes, and qualitative data on the disclosure process will help in evaluating the impact of disclosure interventions. This is important for formulating new disclosure programs and policies for better service to these children in Kerala.

CONCLUSION

Children infected with HIV showed better adherence after complete disclosure. Rate of disclosure can be improved by reviewing the disclosure hurdles in our state so that culturally-sensitive intervention programs can be planned for improving the rate of disclosure.

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