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Original Article

Emotional and behavioral disturbances in school going HIV positive children attending HIV clinic

Lt Col Deepak Joshi^{a,*}, Maj Mithilesh K. Tiwari^b,
Col Venkatnarayan Kannan^c, Gp Capt S.S. Dalal^d, Surg Cmde S.S. Mathai, VSM^e

^a Associate Professor, Department of Pediatrics, Armed Forces Medical College, Pune 411040, India

^b Graded Specialist (Pediatrics), 160 Military Hospital, C/o 99 APO, India

^c Senior Advisor (Pediatrics), Command Hospital (Southern Command), Pune 411040, India

^d Professor, Department of Pediatrics, Armed Forces Medical College, Pune 411040, India

^e Professor and Head, Department of Pediatrics, Armed Forces Medical College, Pune 411040, India

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ABSTRACT

Background: To study the emotional and behavioral disturbances (EBD) in school going HIV positive children attending HIV center in a tertiary care hospital.

Method: This cross-sectional study was conducted on 258 HIV infected children between 6 and 16 years of age, 200 were on Anti-retroviral therapy (ART) and 58 were not on ART. They were evaluated for EBD by using Pictorial Pediatric Symptom Checklist (PPSC) screening tool. A cut-off score of 28 was taken as significant for detecting early EBD.

Results: The prevalence of EBD in our study is 11.2%. Demographic and disease related profile were assessed for correlation with EBD. Type of family ($p = 0.023$), school attendance ($p = 0.034$), school performance ($p = 0.045$), and CD4 count ($p = 0.015$) were detected to have significant association with early manifestation of EBD in the study group.

Conclusions: HIV positive children who have low CD4 count, poor school attendance, and performance are at a higher risk of being detected with EBD. Screening with PPSC to identify EBD in HIV positive children attending HIV clinic in a hospital setting could help in early diagnosis and management.

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Introduction

The total number of people living with HIV in India is estimated at 21.17 lakhs. Children (<15 years) account for 6.54%. Till September 2015, 77,729 children living with HIV/

AIDS (CLHIV) were in active HIV care at various ART centers of which 49,909 CLHIV are receiving free Anti-retroviral therapy (ART).¹

A major factor that distinguishes HIV/AIDS from another chronic or terminal illness is the stigma. Too often many HIV infected children, and their families live in shame associated

* Corresponding author. Tel.: +91 8007141933.

E-mail address: deepakjoshi6562@yahoo.co.in (D. Joshi).

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with HIV/AIDS. The diagnosis is hidden from relatives and disease not discussed. It continuously poses physical, psychological, and social challenges apart from the inherent problems of the disease per se and these children are at increased risk for emotional and behavioral disturbances (EBD).^{2–4} Emotional and behavioral problems in CLHIV predominantly manifest as attention deficit, hyperactivity, depression, anxiety, adjustment disorder, and violent behavior.^{3–5}

With the improving availability of triple ART, disease prognosis has dramatically improved and these children are surviving into adolescence and adulthood. However, they are at particular risk for psychological disturbance due to both the direct effects of HIV infection on brain and indirect effects related to coping with the range of medical, psychological, and social stresses associated with HIV thus calling for the development of psychological support and treatment services.^{5–7}

The available studies have used behavior checklist indices which require specific training in psychology.^{6,7} Primary care providers and pediatricians do not receive adequate training to assess psychosocial problems. This along with their focus on the primary disease and its overt complications, lack of time to address psychological needs and reluctance to label children with a psychological diagnosis, impact early recognition of EBD.⁸ Behavior screening tools such as Pictorial Pediatric Symptom Checklist (PPSC), is a validated tool in children with chronic disease. It can easily be administered by any health care professional caring for these children.^{8,9} The tool has also been validated in children with HIV infection.^{10–12}

Studies regarding the prevalence of EBD among CLHIV in India are limited.⁵ This study was conducted to ascertain prevalence of EBD by using PPSC in school going HIV positive children attending follow up clinic of a large pediatric ART center and determining its correlation with various factors.

Material and methods

Study population

This was a cross-sectional analytical study conducted at the HIV center of a tertiary care hospital from January 2014 to June 2015. After receiving ethical clearance from the Institutional Ethical Committee, 258 children between 6 and 16 years of age, who were known cases of HIV/AIDS, status known for at least 6 months and attending the HIV clinic were included in the study. Children with any physical, mental handicap or CNS disorders were excluded from the study. Informed consent was taken from the care taker before including subjects in the study.

Assuming a general prevalence of psychiatric problems in India (6–15%),¹³ a higher anticipated prevalence in HIV children was arbitrarily taken to be 50%. Considering α error of 5% with 95% level of confidence; a minimum sample size of 197 was required for the study from the defined study population.

Data from selected subjects was collected, on a predefined proforma. PPSC was used for assessment of behavioral and emotional disorders. All parents or primary caregivers were asked to complete a PPSC, a set of 35 questions with answers rated as “never,” “sometimes,” “often” with corresponding scores 0, 1, and 2, respectively. These questions were

explained to the responders in the language they understood and their responses noted. The total score was calculated by adding together the score for each of the 35 questions. A cut-off score of 28 or higher was taken to indicate EBD.⁸ Children detected to have EBD were referred to psychiatrist for further evaluation.

The primary objective of this study was to detect prevalence of EBD in school going HIV positive children attending HIV clinic in correlation to duration of the disease, age, sex, and family income of the patient.

It was planned to assess parameters associated with early detection of EBD as secondary outcome, therefore, subgroup analysis was done to correlate other parameters like disclosure of HIV status, stage of disease (HIV), CD4 count, school attendance (regular >60%, irregular <60% in last 6 months) and academic performance (based on school records – average 50–74%, above average >75%, and below average <50%), HIV status of father and mother and type of family.

Statistical analysis

Statistical analysis was done by using Statistical Package for Social Sciences Version 19.0. Qualitative data was expressed by using frequency and percentage (%), and quantitative data was expressed by using descriptive statistics such as mean and SD. Our data showed that 400 children meeting the inclusion criteria were registered at our HIV clinic.

Chi-square test or Fisher's exact test were used to find various associations among cases. For all tests, a p -value of ≤ 0.05 was considered statistically significant.

Results

Demographic and clinical profile of the study subjects is shown in Table 1. Majority of the subjects were in the age group of 11–15 years (56%), living in nuclear family (73%), attending regular school, with World Health Organization (WHO) Clinical Stage I HIV disease and 72% were on ART. As per the protocol of the clinic, children less than 8 years were excluded from disclosure of HIV and among the subjects >8 years of age ($n = 219$), only 38% of children were aware of their HIV status at the time of interview (Table 1).

Prevalence of EBD in our study group was 11.2%. Among them, prevalence of EBD in children on ART was 12% and not on ART was 8.6%.

Among the various parameters, type of family ($p = 0.023$), school attendance ($p = 0.034$), school performance ($p = 0.045$), and CD4 count ($p = 0.015$) were detected to have significant association with early manifestation of EBD in the study group. Other parameters like disclosure of HIV status, stage of disease, and status of parents did not have significant association with early manifestation of EBD (Table 2).

Discussion

Pediatric HIV/AIDS is now emerging as a chronic disease with new set of challenges in its management. Optimal healthcare delivery in children means not just general physical wellbeing,

Table 1 – Demographic profile of study group.

	Number of children	Percentage (%)
Age group (years)		
≤10	77	29.8
11–15	146	56.6
>15	35	13.6
Gender		
Male	146	56.6
Female	112	43.4
Family income (rupees per month)		
≤5000	139	53.9
5001–10,000	72	27.9
10,001–20,000	25	9.7
>20,000	2	0.8
Orphan ^a	20	7.8
Level of education		
Pre-primary	2	0.8
Primary	147	57
Secondary	93	36
Higher secondary	16	6.2
Type of family		
Joint	46	17.8
Nuclear	188	72.9
Orphan	24	9.3
CD4 count (cells/mm ³)		
<200	9	3.5
200–349	18	7
350–500	42	16.3
>500	189	73.2
Stage of disease		
Stage I	216	83.7
Stage II	26	10.1
Stage III	16	6.2
School attendance		
Regular	246	95.3
Irregular	12	4.7
School performance		
Below average	12	4.7
Average	234	90.7
Above average	12	4.7
Disclosure status ^b		
Aware of illness	83	37.9
Not aware of illness	136	62.1
Receipt of ART		
On ART	200	72.5
Not on ART	58	22.5

^a Under NGO care.^b Children <8 years of age excluded from disclosure of HIV.

but also the emotional, social wellbeing and a good overall quality of life. In chronic and serious infection like HIV and with stigma attached to the disease, it is generally expected that the quality of life will be detrimentally affected,^{14–16} but surprisingly studies in HIV infected children usually showed relatively preserved quality of life.^{17,18} The prevalence of EBD in our study was 11.2%. Grover et al. reported a prevalence of 80.7% in their study group against a background prevalence of 18.2% in general population.¹⁶ High prevalence of EBD in their study was attributed to disturbed family environment of the child.¹¹ Denise et al., in their study on long-term outcome

among HIV infected children reported an incidence of 6.17 psychiatric cases per 1000 person-years. This was significantly higher than the incidence of 1.70 cases per 1000 person-years in the general pediatric population. It was also seen that the knowledge of HIV seropositivity status was significantly associated with an increased risk of psychiatric hospitalization.¹⁹

In contrast, a study done at Atlanta reported an EBD prevalence of 25%, where an increased access to multidisciplinary services was thought to contribute to low prevalence.²⁰ In a recent multicenter prospective study done by Gadow et al. in 2010, participants were recruited from 29 Pediatric AIDS Clinical Trial Group in the United States and Puerto Rico, 27% children in the age group 6–17 years were reported to have psychiatric problems.²¹ A higher prevalence of psychological morbidity of 40–46% has been reported in a study by Mendoza et al. in HIV infected children not on ART in the age group 2–8 years. This study attributed low socioeconomic status, caregiver education, medical status, and child neglect as the likely causes for the high prevalence of behavioral problems in these children.²²

Our study was done on a population of children in the age group (6–16 years) which was similar to Bachnans et al.²⁰ Thirty percent of children in our study were of younger age group (<10 years). Around 62% of CLHIV, more than 8 years age, were not aware of their disease status and 83% of total subjects were in WHO Stage I, hence less symptomatic. Most of the children in our study were in the early stages of disease; were being followed up at a large HIV clinic as a closed group along with a psychological counselor. This represents the ideal method of institutional follow up of HIV positive cases. Hence, it is plausible that the psychological problems that evolve during the course of the disease were tackled in the OPD itself. Therefore, a one point assessment of EBD in CLHIV has yielded a low prevalence in comparison to other studies.^{16–18} Although the PPSC has been validated both for internalizing and externalizing symptoms of EBD in a child,^{23,24} CLHIV face more of internalizing symptoms and PPSC scores more of externalizing symptoms (like fidgety, trouble with teacher, distracted easily). This also could have contributed to the low EBD scores as compared to literature.^{19–21}

Disease severity in terms of low CD4 count has a significant association with early detection of EBD.^{4,14,25–27} The median CD4 count in our study was 715 cells/mm³; children with low CD4 count <500 cells/mm³ are more likely to develop EBD as compared to children with CD4 count >500 cells/mm³ ($p = 0.015$).

Our study also found that HIV positive children who were living with their parents ($p = 0.023$), attending school regularly with more than 60% school attendance per month ($p = 0.034$) and had average (more than 50% marks) or above average school performance (more than 75% marks) were significantly less likely to develop EBD ($p = 0.045$).

Disclosure status has not been assessed adequately in various studies.^{15,20,21} In a study by Arun et al. only 14% children were aware of their HIV status while 43/50 (86%) were unaware.²⁸ In this study 38% of the study population were aware of illness at the time of interview but no significant association between disclosure status and EBD was established. The effects of disclosure is complexly interrelated to

Table 2 – Association of parameters for early detection of EBD in the study group.

	EBD		Total	p-Value
	Present	Absent		
Type of family				
Joint	5	41	46	0.023
Nuclear	17	171	188	
Orphan	7	17	24	
Total	29	229	258	
School attendance				
Regular	25	221	246	0.034
Irregular	4	8	12	
Total	29	229	258	
School performance				
Below average	4	8	12	0.045
Average	25	209	234	
Above average	0	12	12	
Total	29	229	258	
CD4 count (cells/mm ³)				
<200	0	9	9	0.015
201–349	6	12	18	
350–500	4	38	42	
>500	19	170	189	
Total	29	229	258	
Disclosure status				
Aware of illness	12	71	83	0.564
Not aware of illness	13	123	136	
Total	25	194	219	
Stage of disease				
I	26	190	216	0.338
II	3	23	26	
III	0	16	16	
Total	29	229	258	
Parent (father) status				
Abandoned	1	6	7	0.330
Expired	18	131	149	
Not on ART	0	6	6	
On ART	7	79	86	
Unknown	3	7	10	
Total	29	229	258	
Parent (mother) status				
Expired	12	69	81	0.556
Not on ART	1	9	10	
On ART	16	149	165	
Unknown	0	2	2	
Total	29	229	258	

the age of the child, their understanding about the disease, type of family (joint/nuclear family or orphan) and the parental status (single parent/orphan).^{22,29,30} The final acceptance of disease and its reaction also depends on the available peer group and the basic personality trait of the child.

The tool used in our study was a validated tool, which has been tested specifically to assess psychosocial problems in children with chronic illnesses and is simple to administer by any medical or non-medical professional.^{10–12,23,24}

Our study has assessed multiple parameters correlation with EBD in HIV infected children which have not been assessed before. The absence of correlate between duration of the disease to EBD seems intriguing. The probable reason is that the study was not specifically powered to look at

this, as a primary outcome. Previous studies have not looked at this outcome. We also found that presence of ART did not show any significant association of these parameters to EBD.

The major drawback in assessing any psychological disease in a child is the presence of multiple confounding variables.^{4,13} These confounders can only be assessed if the study is done as a long-term follow up with psychologists doing assessment at community level. This study was not designed to assess the effect of individual disease characteristics such as disease stage, viral load and presence of ART on emotional and behavior disturbance of HIV children. Further studies should be planned on a long-term follow up basis, incorporating other factors as well.

Conclusion

HIV positive children attending the HIV clinic, who have low CD4 count, have a poor school attendance and scholastic performance, are at a higher risk of developing EBD. Based on our result of 11.2% prevalence of EBD in school going CLHIV, we recommend that it must be routinely assessed for as a part of holistic treatment of HIV positive children.

Conflicts of interest

The authors have none to declare.

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