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A Study of Psychosocial Adjustment in Children with HIV

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Abstract: Due to early detection and advancements in treatment of HIV, paediatric HIV is now considered as chronic illness. In chronic illness, psychological adjustment of the patient and their family members to the illness is an important aspect. Hence considering the vulnerability of children infected by HIV, we planned a study assessing adjustment problems in children with HIV. The present study is aimed to evaluate the psychosocial adjustment in children with HIV & AIDS and also to compare adjustment problems among children infected with HIV staying with family members and away from family members and children without HIV staying at orphanage homes. A total sample of 90 with the age group 8-14 years of both sexes with three groups of 30 each of HIV children staying with family members, HIV children staying at homes away from family and non HIV children staying at homes away from family was taken for the study. They were administered semi structured intake proforma followed by Children's Self Concept Scale (CSCS) and Pre Adolescent adjustment scale (PAAS). There was no statistically significant difference between mean score of PAAS-TOTAL across the three groups. This indicates children in all three groups were well adjusted. On the sub items of PAAS, there was no significant statistical difference between mean scores of Home, School, Peers and Teacher items among three groups. Mean score of PAAS-General item was 0.80 in HIV with family group, 2.37 in HIV away family group and 3.50 in Non HIV away family group which was statistically significant with p value <0.001. HIV children were well adjusted and have good overall self concept. The general adjustment of HIV children staying with family was significantly lower compared to HIV children staying at homes and Non HIV children staying at homes.

Keywords: HIV, Psychosocial Adjustment, adjustment problems, children's self concept.

INTRODUCTION

The National AIDS Control Organization estimates around 21.17 lakhs people in India are living with HIV giving a national adult prevalence of 0.26% (0.22% -0.32%)[1]. Of these, an estimated 40.5% were females and 6.54% were children below 15 years. In spite of declining trend in HIV prevalence, over the years the percentage of HIV infected women in total estimated number of People Living With HIV (PLHIV) has increased from 29% in 1990s to 40% in 2015. This indicates the increasing feminization of HIV/AIDS in India. This alarming trend is being observed closely as more HIV positive mothers will unknowingly pass the virus on to their children. India has an estimated 1, 34,000 children infected with HIV in country below age of 15 yrs. According to recent finding by NACO, 21,000 children infected every year through Parent-to-child-transmission (PTCT)[1]. Significant advances in the treatment of HIV have lead to dramatic improvements in health outcomes for children born with HIV [2, 3]. Given these advances in treatment and survival, pediatric HIV is now viewed as chronic illness [4]. Because children are now living longer with HIV, the next challenge is to optimize the health of these children.

Children are affected in different ways by the HIV/AIDS pandemic. Children affected by HIV/AIDS mostly are children who lose a parent or parent-substitute; children who live in a household in which one or more people are ill, dying or deceased; children whose caregivers are too ill to look after them; children living with very old and frail caregivers [5]. In addition to dealing with HIV/AIDS, due to the severity of the epidemic, many children face recurrent losses among family members and guardians, as well as the loss of

familiar surroundings and schooling. Thus, the psychological impact may also be recurrent [6]. HIV related stigma and discrimination remain the greatest obstacles to people living with HIV infection. Stigma and discrimination increase people's vulnerability, social isolation, deprive them of their basic human rights, care and support, and worsen the impact of infection. Stigma and discrimination also intensify violations of the rights of AIDS children in particular their access to education, social services and community and family support [7]. The death of a parent during childhood has a profound and lifelong impact on child's psychosocial wellbeing. Cross-cultural research on natural grieving process suggests that most humans need to recognize their grief and be able to express it directly in order to resolve their loss[8,9]. Children in particular are at increased risk for unresolved or complicated bereavement due to their developmental vulnerability like intellectual immaturity and emotional dependency. Children orphaned by HIV/AIDS face additional psychological and social challenges including stigmatization, the impending or actual death of surviving parent, disruptions in subsequent care and financial hardships; these challenges further impede grieving process placing these children at heightened risk of prolonged mental & behavioral problems[10,11]. Loss and bereavement combined with poverty are major risk factors for poor psychosocial adjustment among children. However, limited attention has been paid to psychosocial and developmental needs of children orphaned by HIV/AIDS, particularly in resource poor countries [6,10].

Adjustment is a process by which a living organism maintains a balance between its needs and the circumstances that influence the satisfaction of these needs. Adjustment is a harmonious relationship with the environment involving the ability to satisfy most of one's needs and most of the demands, both physical and social that are put upon one [27]. Adjustment is a state in which the needs of the individual on one hand and the claims of the environment on the other are fully satisfied (Anonymous). According to Pareek *et al*. [12] adjustment is defined as "an individual's orientation towards parents, peers, school and self in terms of the satisfaction derived from interactional relationships with these significant others and self". In chronic illness, psychological adjustment of the patient and their family members to the illness is an important aspect. These adjustments and the problems arising there in are important determinants of the physical nature of the disease as well. This may include the experience and expression of physical illness as well as important management factors such as adherence to medication and recommended life style changes. Children with chronic physical disorders have been found to have higher incidence of psychosocial adaption problems than do children in the general population Rutter *et al*. [13], Singhi *et al*. [14]. Increased adaptation problems in children with chronic illness have been attributed to occur due to adverse developmental impact of having a chronic illness, psychosocial stress on the family, and repeated encounters with medical personnel Perrin *et al*. [15], Wallender *et al*. [1]. There is, however, wide variability observed in the adaptation in children with chronic physical conditions thereby suggesting the need to identify accurately those children who are functioning in the maladjustment range. According to Drotar and Bush[17] systematic documentation of the psychosocial adjustment difficulties experienced by children with chronic physical disorders is of immense importance if programs to meet their needs for mental health services are to be developed.

Review of previous literature showed that studies done by Brown *et al*. [18], Donenberg & Pao, [19]; Gaughan *et al*. [20]; Lwin & Melvin [21; Mellins *et al*. [22] found that several factors influencing psychosocial adjustment of children with HIV infection were presence of HIV in CNS during fetal development and childhood, co-occurring medical conditions and complications of HIV including body image issues, teratogenic effects of drug and alcohol during prenatal period, cognitive and neurological deficits, other psychosocial factors like maternal illness, multiple separations, transitions and losses, whether child knows his or her HIV status and environmental factors. Environmental factors affecting psychosocial adjustment include poverty, violence, racism, overcrowding & single parenthood households [23]. A study by Brown, Lourie, Pao, [24] also found similar finding that children adversely impacted by non-HIV factors such as poverty, inadequate medical services and lack of social support. Bachanas *et al*. [25] study found higher rates of psychological adjustment problems in healthy children compared to children with HIV disease (25%). Previous work has suggested that children with HIV may be at higher risk of social and psychological problems but the available data have been limited particularly in Indian context. Hence, considering the vulnerability of the children infected by HIV the present study is aimed at studying psychosocial adjustment in children with HIV.

Aim and objectives

The present study aimed at systematically evaluating the psychosocial adjustment problems of children with HIV & AIDS. The secondary objectives are to compare adjustment problems among children infected with HIV staying with family members and away from family members and children without HIV staying at orphanage homes and examining the relationship between socio demographic variables and adjustment problems.

MATERIALS AND METHODS

The present study was a comparative cross sectional study conducted at the Pediatric ART Centre, Niloufer Hospital, and a tertiary pediatric hospital at

Hyderabad. Following approval by institutional ethical committee and concerned authorities for conducting study at Pediatric ART centre, a total sample of 90 with three groups of 30 each of HIV children staying with family members, HIV children staying at homes away from family and non HIV children staying at homes away from family was taken for the study. After taking written informed consent from parents or caretakers, children fulfilling inclusion criteria of age group of 8-14 years of both sexes with HIV diagnosis based on NACO / WHO guidelines were taken into the study. Children with Mental retardation, Cerebral palsy, Epilepsy, history of any complicated head injury, acute illness at time of study and other major physical illness (congenital heart disease, congenital anomalies etc) were excluded. Details about socio demographic data were collected with a semi structured intake proforma. Subsequently they were administered Children's Self Concept Scale to evaluate self concept and Pre Adolescent Adjustment Scale PAAS for evaluating adjustment problems. The data thus collected was subjected to statistical analysis using Chi-Square test and ANOVA by statistical software SPSS version 17. The significant findings obtained while comparing the three groups were discussed.

Measures

Semi structured Intake proforma

An intake proforma specially prepared for the study intended to capture socio-demographic data of the family including age, sex, education, social background, occupation of the parents and socioeconomic status.

Children's Self Concept Scale [26]

The self-concept of the child was measured by the Piers Harris Children's Self Concept Scale (CSCS)– Hindi adaptation. The CSCS consists of 80 first person declarative statements to which the child responds with "yes" or "no". Responses are coded in a manner that a higher score indicates a more positive self concept. The total score and the six sub scale scores (behavior, intellectual and school status, physical appearance, anxiety, popularity, and happiness-satisfaction) were used as dependent measures. The CSCS is a widely used scale and test- retest reliability is 0.88 and the concurrent and factorial validity has also been established.

II. Pre Adolescent Adjustment Scale – PAAS [12]

The PAAS is a 40 item self report scale with a "Yes"/"No" format that describes adjustment as an individual's orientation towards parents, peers, school and self in terms of the satisfaction derived from interactional relationships with these significant others and self [12]. This scale yields separate scores in five areas viz. Home (9 items): School (8items): Peers (8 items): Teachers (8 items) and General (7 items) along with an overall score for total adjustment. The range of scores of total PAAS from minimum of -46 to maximum of +34. There is no time limit but 15-20 minutes is usually required for completion. The scale was developed by Thurston's method of Equal Appearing Intervals using 190 judges. It has been validated with teacher's ratings of adjustment and 3 month test-retest reliability was adequate. The scale values are positive as well as negative for different items. Score for each sub-scale was obtained by adding scale values of the items checked. High positive scores indicate high adjustment in that area, while high negative scores indicate high maladjustment. Scores near zero indicate mild adjustment or maladjustment depending on the direction of the score. The total adjustment score is obtained by adding scores on all the subscales. This scale has been selected since it has been validated on a sample of Indian adolescents. It assesses adjustment in different relevant domains. Test-retest reliability values for different areas, are, however, moderate and range from 0.28 to 0.54.

DATA ANALYSIS

The data was collected and subjected to statistical analysis using means and standard deviation for continuous variables and frequencies and percentages for discrete data. For comparison of frequencies, Chi square Test was used. For continuous variables comparison between three groups, one way ANOVA (analysis of Variance) was used and Post hoc analysis by LSD (Least Square Difference) method was employed to compare the means of individual groups. Null hypothesis is rejected when $p < 0.05$.

RESULTS

Socio demographic distribution across three groups is depicted in table I. All three groups were equally matched with relation to age distribution. Mean age of all three groups was 11 yrs. HIV with family group had 17 boys and 13 girls, HIV away family group had 16 boys and 14 girls and Non HIV away family group had 15 boys and 15 girls. All three groups were equally matched with respect to sex distribution. In HIV with family group, 53.3% belong to urban background and 46.7% belong to rural background, in HIV away family group 43.3% belong to urban background and 56.7% belong to rural background and in Non HIV away family group 50% belong to urban background and 50% belong to rural background. All three groups were comparable in relation to social background. Most of children were pursuing primary education, 73.3% in HIV with family group, 60% in HIV away family group and 70% in Non HIV away family group. Majority of the children in all three groups were school going. Two children (6.7%) in HIV with family group and one child (3.3%) in HIV away family group were not going to the school and staying at home because of severity of illness.

In HIV with family group, 12 (40%) fathers were illiterates compared to 17(56.7%) in HIV away family group and 9 (30%) illiterates among Non HIV away family group. This was statistically significant

indicating illiteracy was more common in fathers of HIV groups compared to Non HIV group. With regard to education status of mother, 17(56.7%) were illiterates in HIV with family group, 21(70%) were illiterates among HIV away family group and 12(40%) were illiterates among Non HIV away family group. Though it was not statistically significant, illiteracy was more common among mothers of HIV groups compared to Non HIV group. 46.7% of fathers in HIV with family group, 76.7% fathers in HIV away family group and 46.7% fathers in Non HIV away family group were unskilled workers. Semiskilled occupation was more in Non HIV away family group compared to other groups. Similarly, 43.3% of mothers in HIV with family group, 56.7% mothers in HIV away family group and only 16.7% mothers in Non HIV away family group were house wives. 76.7% mothers in Non HIV away family group, 43.3% in HIV away family group and 50% in HIV with family group were unskilled workers. This distribution was statistically significant. 46.7% of children with HIV with family group belong to lower socio economic status, 30% belong to lower middle class, and 20% belong to upper lower class. 96.7% in both HIV away family group and in Non HIV away family group belong to lower socio economic status. This difference reached high statistical significance ($p<0.001$).

Comparison of children self-concept (CSCS) scores across three groups is presented in Table 2. There was no statistically significant difference in overall total self concept scores among three groups. When the mean sub scale scores of CSCS of behavior, intellectual and school status, physical appearance, anxiety, popularity compared across three groups, there was no statistically significant difference. Mean score of happiness and satisfaction was 5.4 in HIV with family group, 5.7 in HIV away family group and 6.1 in Non HIV away family group. This difference was statistically significant with p value of 0.04. It indicates that HIV children with family group were less happy and satisfied compared to other groups. Non HIV children staying away from family group were significantly more happy and satisfied.

One-way ANOVA test was done to find any variance of mean scores of Pre Adolescent Adjustment Scale subscales and total among three groups namely HIV children staying with family, HIV children staying away family, Non HIV children away family which is depicted in table3. There was no statistically significant difference between mean score of PAAS-Total across the three groups. This indicates children in all three groups were well adjusted. On the sub items of PAAS, there was no significant statistical difference between mean scores of Home, School, Peers and Teacher items among three groups. Mean score of PAAS-General item was 0.80 in HIV with family group, 2.37 in HIV away family group and 3.50 in Non HIV away family group which was statistically significant with p value <0.001. The general adjustment of HIV children staying with family was significantly lower compared to HIV children staying at homes and Non HIV children staying at homes.

Table 4 depicts the association between socio demographic variables and total Pre Adolescent Adjustment Scale scores. There was no significant statistical association between socio demographic variables like gender of child, social background of child, education status of child, living status of father, living status of mother, occupation of father and occupation of mother and adjustment. No significant statistical association was found between socioeconomic status and PAAS total scores.

Table-1: Socio demographic distribution of study groups

Variable	HIV With Family N (%)	HIV Away Family N (%)	Non HIV Away Family N (%)	Chi-Square	p Value
Age Of Child	Mean (SD) 11.03(2.04)	Mean (SD) 11.57(1.79)	Mean (SD) 11.30(2.00)	F value 0.56	0.57
Sex	N (%)	N (%)	N (%)		
Male	17(56.7%)	16(53.3%)	15(50%)		
Female	13(43.3%)	14(46.7%)	15(50%)	0.268	0.88
Social Background					
Urban	16(53.3%)	13(43.3%)	15(50%)		
Rural	14(46.7%)	17(56.7%)	15(50%)	0.623	0.73
Education Of Child					
Primary	22(73.3%)	18(60%)	21(70%)		
Secondary	8(26.7%)	11(36.7%)	9(30%)	2.926	0.57
Illiterate	0(.0%)	1 (3.3%)	0(.0%)		
Current Occupation Status Of Child					
School Going	28(93.3%)	29(96.7%)	30(100%)		
Staying At Home	2(6.7%)	1 (3.3%)	0(.0%)	2.069	0.36
Education Status Of Father					
Illiterate	12(40%)	17(56.7%)	9(30%)		
Literate	18(60%)	13(43.3%)	21(70%)	15.78	0.015*
Education Status Of Mother					
Illiterate	17(56.7%)	21(70%)	12(40%)		
Literate	13(43.3%)	9(30%)	18(60%)	8.64	0.07
Occupation Of Father					
Unemployed	1 (3.3%)	0(.0%)	1 (3.3%)		
Unskilled	14(46.7%)	23(76.7%)	14(46.7%)		
Semiskilled	9 (30%)	7(23.3%)	13(43.3%)	13.11	0.04*
Skilled	6(20%)	0(.0%)	2 (6.7%)		
Occupation Of Mother					
House Wife	13(43.3%)	17(56.7%)	5(16.7%)		
Unskilled	15(50%)	13(43.3%)	23(76.7%)	11.69	0.02*
Semiskilled	2 (6.7%)	0(.0%)	2 (6.7%)		
Socioeconomic Status					
Upper Middle	1 (3.3%)	0(.0%)	0(.0%)		
Lower Middle	9(30%)	0(.0%)	0(.0%)		
Upper Lower	6(20%)	1 (3.3%)	1 (3.3%)	32.50	<0.001*
Lower	14(46.7%)	29(96.7%)	29(96.7%)		

Table-2: Children self-concept scale (cscs) scores across three groups

Self Concept Variable	HIV With Family Mean (S.D.)	HIV Away Family Mean (S.D.)	Non HIV Away Family Mean (S.D.)	ANOVA F Value	P Value
Behavioral adjustment	11.7	11.9	11.4	1.66	0.52
Intellectual and school status	12.0	11.8	11.3	1.97	0.12
Physical appearance & attributes	9.0	8.8	8.9	0.88	0.94
Freedom from Anxiety	10.1	9.5	9.9	1.56	0.16
Popularity	9.3	9.5	9.7	0.78	0.98
Happiness & Satisfaction	5.4	5.7	6.1	3.23	0.04*
Total	56.5	57.2	57.3	0.79	0.99

*P < 0.05 significant

Table-3: Pre-adolescent adjustment scale (paas) scores across three groups

Variable	HIV With Family Mean (S.D.)	HIV Away Family Mean (S.D.)	Non HIV Away Family Mean (S.D.)	ANOVA F Value	P Value
Paas – Home	2.37(2.21)	2.13(2.11)	1.77(1.76)	0.66	0.52
Paas – School	1.30(2.48)	2.07(2.32)	1.77(1.52)	0.97	0.38
Paas – Peers	2.30(2.20)	2.97(1.99)	3.40(1.04)	2.80	0.07
Paas – Teacher	1.20(2.11)	1.93(1.95)	1.40(1.43)	1.26	0.29
Paas – General	0.80(2.24)	2.37(2.14)	3.50(1.53)	13.90	<0.001*
Paas – Total Score	7.97(9.94)	11.47(9.69)	12.37(4.98)	2.23	0.11

*P < 0.05 significant

Table-4 : Assosiation between sociodemographic profile and adjustment

	Sex	N	Mean	S.D.	F value	P value
PAAS total score	Male	48	10.71	8.61	0.02	0.90
	Female	42	10.48	8.77		
	Total	90	10.60	8.64		
	Education status					
PAAS total score	Primary	61	10.13	9.79	0.28	0.76
	Secondary	28	11.61	5.60		
	Illiterate	1	11.00			
	Total	90	10.60	8.64		
	Geographical background					
PAAS total score	Urban	44	9.30	9.47	1.99	0.16
	Rural	46	11.85	7.65		
	Total	90	10.60	8.64		
	Socioeconomic status					
PAAS total score	Lower middle	9	10.00	8.37	0.41	0.66
	Upper lower	8	8.63	9.02		
	Lower	72	11.24	8.25		
	Total	89	10.88	8.27		

DISCUSSION

Contrary to expectation, no significant differences in the overall adjustment were found among HIV children with family, HIV children away family and Non HIV children away family. Even, there was no statistically significant difference in overall total self concept scores among three groups. These results suggest that children with HIV have good overall self concept and were not experiencing any adjustment difficulties at home, school or with their teachers and peers. These findings are also consistent with previous research by Bachanas *et al*. [25] wherein children with HIV have been found to have lesser adjustment problems compared to normal children. It is possible that children with HIV are more prone to developing behavioural and emotional problems which do not necessarily affect the way they adjust with others and the way they perceive themselves. The sample for the current study has also been taken from tertiary centre where in the HIV children were under regular follow ups and constant monitoring. Probably, the use of Antiretroviral Therapy is likely to be helpful in promoting better overall adjustment in HIV children. Further research should identify the potentially modifiable correlates of the psychological and social functioning of children with HIV.

Demographic and illness related variables were generally not found to be significantly correlated with psychosocial adaptation measures. The general adjustment of HIV children staying with family members was significantly lower when compared to HIV children staying at homes and normal children staying at homes. It indicates low self confidence and low positive sense of oneself in HIV children staying with family due to constant exposure to family psychopathology. On par with normal children, HIV children reported good overall self concept and in domains of self concept of behavior, intellectual and school status, physical appearance, anxiety, popularity. The HIV children staying with family members reported that they were less happy and satisfied than the HIV children staying away from family at homes and normal children staying at homes. As indicated by previous studies by Armistead & Forehand [23]; Brown *et al*. [24]; Mellins *et al*, [22] etc, several psychosocial factors like maternal illness, multiple family losses, poverty, overcrowding and single parenthood affects the psychosocial adjustment of HIV children. All these factors were more observed by HIV children staying with their family members compared to HIV children staying away from family at homes as well as at homes children will be given unconditional support by their caretakers.

Orphans' perceptions of emotional connection, behavioural regulation and psychological autonomy in their relationship with their carer and experiences of connection and regulation in the peer and neighbourhood contexts were all significantly independently associated with healthier outcomes in at least one of the four domains of adjustment assessed. These results suggest that psychosocial interventions for orphans can focus on strengthening resources already available in families and communities. However, programmes should not be restricted to "AIDS orphans" but should address the needs of all orphans and vulnerable children in communities affected by HIV/AIDS. Careful attention should also be paid to child and family functioning in particular, the role of parenting stress both before and after diagnosis of HIV in order to design an effective and workable treatment plan. The findings underscore the urgency and importance of culturally and developmentally appropriate intervention efforts targeting psychosocial problems among children affected by AIDS and call for more exploration of risk and resilience factors, both individual and contextual, affecting the wellbeing of these children. In summary, while the overall findings might suggest that there are lower than expected rates of emotional distress among this population, the fact that a proportion of these families do experience significant distress cannot be ignored. HIV is truly a family illness. Screening, ongoing support, and family-friendly, culturally sensitive mental health services should be an integral part of whole childcare for families living with HIV.

There were few limitations which need to be taken into consideration. The current study was conducted at a tertiary pediatric ART center and hence may not represent general population of children with HIV in the society. Care taker educational status and their psychopathologies were not taken into account. The study sample taken mostly represented lower socio economic group attending Government hospital hence there is no knowledge about other socio economic groups. There was no blinding in this study.

Future directions

Our findings highlight the need to evaluate the adaptation of children with HIV. By recognizing that children with HIV are at a risk for developing adjustment problems, health care providers can through routine systematic screening assessment identify children at risk. It is concluded that there is a need for planning for the mental health needs of children with HIV as part of their overall medical management. While early diagnosis and treatment of mental health problems related to HIV are necessary, the focus should be more towards prevention of mental health problems in families affected by HIV.

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