Psychosocial Adjustment among Children Living with HIV/AIDS

M. B. Ravikumar and Sampathkumar

Department of Studies in Psychology, University of Mysore, Mysore 570 006, Karnataka, India
E-mail: rkravi777@gmail.com

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ABSTRACT
HIV positive children are discriminated and stigmatised by the society. They are deprived of one or more necessities of life. These children are left helpless, abandoned, neglected by the parents/caregivers due to social, economic and personal reasons like gender, domicile, age, etc. In this context they may develop and face a lot of psychosocial adjustmental problems. Objectives of the present study are formulated as: 1) To study the level of psychosocial adjustment of children living with HIV/AIDS and non-HIV/AIDS; 2) To study the psychosocial adjustment among boys and girls living with HIV/AIDS; 3) To study the psychosocial adjustment among rural and urban children living with HIV/AIDS. For this 800 children were selected as participants; among them 400 were living with HIV/AIDS and 400 were non-HIV/AIDS. The selected children were measured on adjustment inventory. The findings indicated that the children living with HIV/AIDS were having higher social, emotional and educational adjustment problems than children living with non-HIV/AIDS. Further, girls and rural children living with HIV/AIDS were having statistically higher social and emotional adjustment problems than boys and urban children.

INTRODUCTION
Acquired Immune Deficiency Syndrome (AIDS) is a viral disease that renders the body’s immune system unable to resist the invasion by micro-organisms that cause serious infections leading to death. AIDS is a killer, different to cancer or heart disease because it permeates societal stigma, it is lethal, it has contagion risk, and -in some cases- one imprudent act is enough for individuals to become infected.

Human Immunodeficiency Virus /Acquired Immune Deficiency Syndrome (HIV/AIDS) researchers are projecting an estimated 65 million deaths from AIDS by the year 2020, more than triple the number who died in the first 20 years of the epidemic unless major efforts are put towards primary prevention or major developments in treatment take place (Altman 2002). Despite the large number of people who have already died of AIDS, the epidemic is actually still in its early stage and is now being transmitted to every part of the world. According to National Aids Control Organization (NACO) report 2010, India has 2.27 million HIV-infected persons, the third highest in the world after South Africa and Nigeria. The HIV prevalence rate in the country is 0.29 percent and most infections occur through heterosexual and infected mother to child route of transmission. However, in the north-eastern region, injecting drug use is the major cause for the epidemic spread. According to Karnataka State Aids Prevention Society (KSAPS) Consolidated ART report, March 2012, the scenario of Karnataka state is 0.206 million adult and 0.030 million children registered as HIV positive. AIDS is the final stage of infection with the retrovirus. HIV virus gradually impairs the immune system which is crucial for the suppression of infections, viruses and bacteria. As the immune system weakens, HIV infected people become infected with opportunistic infections. AIDS is a chronic disease and without treatment infected persons will eventually die. Yet an outright cure remains elusive, leaving people with the challenges of living with a chronic medical condition.

According to Tate et al. (2003), the new advances for treatment of HIV Infection using Highly Active Antiretroviral Therapy (HAART) have dramatically improved disease prognosis. In children Antiretroviral therapy (ART) preserves or restores immune function; provides sustained suppression of the viral load promotes or restores normal growth and development, improves the quality of life, prevents complicating infections and cancers, and prolongs the child’s life. Therefore, HIV-positive children can live a longer life because of medical and social advances, but treatment programs have not been able to eradicate the virus and cure the disease. As a result, they are living longer with a chronic condition that continuously presents physical, psychological and social challenges. Like all patients with chronic medical disorders, HIV-infected children also are at increased risk
for specific psychiatric and psychosocial problems.

Children are affected in different ways by the HIV/AIDS pandemic. Many children are infected with HIV, and all children in regions with high HIV prevalence are likely to be affected by the ensuing deterioration of services, the weakening of social institutes and high levels of stress. Another category of children affected by HIV/AIDS 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 continue to look after them; children living with very old and frail caregivers (Richter et al. 2004). So 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 (Atwinea et al. 2005).

Children suffer tremendously when their parents are tested as positive, and the needs of children with infected parents are often neglected. According to Wood et al. (2006), AIDS-related bereavement is likely to be particularly complicated and difficult to accommodate. Grief may precede the actual death in the form of anticipatory loss and AIDS-related death may be more stigmatized. Children often witness debilitating illness and may experience compromised parenting. In many societies there is no tradition of talking to children as equals and on an intimate basis, and caregivers often report seeing the suffering of children, seeing and hearing everything but never addressed directly. Many families don’t want to look after AIDS children because of the stigma associated with AIDS deaths in many communities (UNAIDS 2004). AIDS-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 familial support (Kang et al. 2005).

Theoretical developmental models concerning the psychosocial consequences of HIV/AIDS as a chronic disease are not yet available in India, given that antiretroviral therapy is relatively new. Despite all the published pediatric findings concerning children’s understanding of illness and pain and the effects of hospitalisation, the ideal of a developmental psychology of illness is now here in sight. Additionally, these pediatric findings may be culturally biased because of the dominance of western research populations.

Various studies (Tate et al. 2003; Wachsler-Felder and Golden 2002) have linked HIV/AIDS with a number of psychosocial problems, depression being the most common. A number of cross-sectional studies have found that chronically ill children are at increased risk of psychosocial problems. Huurre and Aro (2002) say that, these children have been reported to have lower self-esteem, poor body-image, more problems in psychological well-being and adjustment than those without chronic conditions.

Previous researches on impact of HIV/AIDS have focused generally on adults. Richter (2004) argued that, particularly where children are concerned, HIV/AIDS needs to be treated as a broad developmental concern rather than as a narrow health or even public health issue. However, the majority of the studies performed on children have been conducted by researchers working for the medical discipline. These researchers consist mainly of the immunological, medical, and neurological consequences of the disease and tends to neglect the psychosocial effects (Wachsler-Felder and Golden 2002). Therefore, the present study is emphasizing a psychosocial point of view.

Adjustment

The term adjustment is often used as a synonym for accommodation and adaptation. Strictly speaking, the term denotes the results of equilibrium, which may be affect by either of these processes (Monroe 1990). It is used to emphasize the individual’s struggle to along or survive in his or her social and physical environment. 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 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 (Anonymous 1968).

In adjustment, the two crucial factors are the individual and the environment. In a study of the individual, the considerations are the heredity and biological factors, the psychological factors, and the quality of socialization given to him or her, whereas the environment includes all the social factors. To study school adjustment among gender-atypical students, the researchers draw on the literature on school bias against gender-atypical behaviors. This point out that school emphasizes traditional gender expectations and that student’s ability to perform these roles influences their social status at school. Consequently, students who exhibit gender-atypical behaviors face rejection and harassment by peers and sometimes by teachers, as documented in qualitative studies (Eder et al. 1995; Payne 2007; Risman and Seale 2009; Smith 1998). Several studies have been reported in the area of social, educational, health and emotional adjustment of school students of both sexes. Some studies try to relate adjustment with variables like intelligence, achievement, age, sex, socio-economic status, needs, anxiety, and security. Student’s reaction to frustration has also been studied. A few studies focused on the nature, causes, and extent of indiscipline among students. The relation between indiscipline and variables like achievement, participation in co-curricular activities etc., were also examined.

Several factors are thought to influence the psychosocial adjustment of children with HIV infection, including (a) the presence of HIV in the central nervous system during fetal development and throughout childhood; (b) co-occurring medical conditions and complications of HIV disease, including body image issues; (c) teratogenic effects of drug and alcohol during the prenatal period; (d) cognitive and neurological deficits; (e) other psychosocial factors (maternal illness, multiple separations, transitions, and losses); (f) whether the child knows his or her HIV status; and (g) environmental factors (Brown et al. 2000; Gaughan et al. 2004; Havens et al. 1994; Lwin and Melvin 2001; Mellins et al. 2003). Environmental factors affecting families living with HIV include poverty, violence, racism, overcrowding, and single-parent households (Armistead and Forehand 1995). Such factors would likely increase the risk of psychological problems.

Every individual from the time he or she steps out of the family and goes to school makes a long series of adjustments between the whole unique personality and the environment. The ardent desire of each boy and girl to become an individual person having a healthy physique, an adequate adjustment, a growing intellectual ability, a greater degree of emotional poise and increased participation in social groups, such characteristics enhance one’s personality. Children living with HIV/AIDS are considered as a highly deprived class of society. These children are left helpless, abandoned, neglected by the parents/ caregivers due to social, economic and personal reasons like gender, domicile, age, etc. They are deprived of one or more necessities of life. Early separation from parents, deprivation of parental care, love, affection, warmth, security, acceptance and discipline during childhood disrupts their normal socio-emotional development resulting in adjustment problems. So it becomes necessary to know whether positive children who are devoid of family life with the emotional warmth grow up normally. How well they are able to cope with themselves and adjust to the demands of the environment/society around them. The present study attempts to know the level of educational and emotional adjustment problems of children living with HIV/AIDS. As a result the study can suggest the need for appropriate counselling and guidance, and care and support to overcome their adjustment problems. Thus the following objectives were formulated.

**Objectives**

1. To study the level of psychosocial adjustment of children living with HIV/AIDS and Non-HIV/AIDS Children.
2. To study the psychosocial adjustment problems of boys and girls living with HIV/AIDS.
3. To study the psychosocial adjustment problems of rural and urban children living with HIV/AIDS.

**Hypotheses**

\( H_1 \): Children with HIV/AIDS have significantly higher Social, Emotional, Educational, and over all adjustment problems than non-HIV/AIDS.
**H**: Girls with HIV/AIDS have significantly higher Social, Emotional, Educational, and overall adjustment problems than boys with HIV/AIDS.

**H**: Rural children with HIV/AIDS have significantly higher Social, Emotional, Educational, and overall adjustment problems than urban children with HIV/AIDS.

**MATERIAL AND METHODS**

**Participants**

The participant group consists of total 800 children, among them 400 were infected with HIV/AIDS and 400 were non-HIV/AIDS (Table 1). Participants were selected from Paediatric ART Centre, Indira Gandhi Institute of Child Health (IGICH), Bangalore and children living with non-HIV/AIDS were selected from schools nearby areas. The participants’ age ranged from 9 to 14 years and the mean age was 11.5 years. The study was conducted during the year 2010-11. The purposive sampling method was used.

**Table 1: The distribution of the participants is presented here according to their gender and domicile**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Children with HIV/AIDS</th>
<th>Non-HIV/AIDS children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boys</td>
<td>Girls</td>
</tr>
<tr>
<td>Rural</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Urban</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Total</td>
<td>200</td>
<td>200</td>
</tr>
</tbody>
</table>

**Measures**

1. **Personal Information Schedule.**

2. **Adjustment Inventory** developed by Sinha and Singh (1993) was used to study adjustment. It consists of 60 items which measure adjustment in three different areas namely social adjustment, emotional adjustment and educational adjustment with 20 items each. The test-retest reliability is 0.93 and the split-half reliability is 0.95 these values found to be highly and satisfactory. The higher score indicates the higher adjustment problems.

**Procedure**

The participants were given appropriate instructions and administered the Adjustment Inventory in the group of 10 members. They were also asked to give their socio-demographic details in the prescribed proforma. They had to indicate their responses in the answer sheets given to them. Whenever they had doubt in understanding items, the test administrator clarified their doubts in their local language. The participants responded to the inventory on an average of 45-60 minutes approximately. Then the data was scored and statistically analysed by using descriptive, t-test and ANOVA techniques.

**RESULTS AND DISCUSSION**

Table 2 shows mean SD and F values for psychosocial adjustment domain of children with HIV/AIDS and non-HIV/AIDS. Social adjustment of children with HIV/AIDS (Mean=12.24; SD=1.83) and non-HIV/AIDS (Mean=5.64; SD=2.09) (t=47.47; p<.000) indicating highly significant difference. Children with HIV/AIDS were statistically higher than non-HIV/AIDS children in social adjustment. Therefore, formulated **H**, that is, children with HIV/AIDS having more social adjustment problems than non-HIV/AIDS, was accepted.

Emotional adjustment of children with HIV/AIDS (Mean=14.39; SD=1.80) and non-HIV/AIDS (Mean=5.59; SD=2.64) (t=55.00; p<.000) indicating highly significant difference. Chil-
dren with HIV/AIDS were statistically higher than non-HIV/AIDS in emotional adjustment. Therefore, formulated H₁₂ that is, children with HIV/AIDS having more emotional adjustment problems than non-HIV/AIDS, was accepted.

Educational adjustment of children with HIV/AIDS (Mean=14.39; SD=1.80) and non-HIV/AIDS (Mean=5.59; SD=2.06) (t=63.27; p<.000) indicating highly significant difference. Children with HIV/AIDS were statistically higher than non-HIV/AIDS in educational adjustment. Therefore, formulated H₁₃ that is, children with HIV/AIDS having more educational adjustment problems than non-HIV/AIDS, was accepted.

Overall adjustment of children with HIV/AIDS (Mean=39.48; SD= 4.29) and non-HIV/AIDS (Mean=15.28; SD=5.62) (F=68.37; p<.000) indicating highly significant difference. Children with HIV/AIDS were statistically higher than non-HIV/AIDS in all adjustment. Therefore, formulated H₁₄ that is, children with HIV/AIDS having more overall adjustment problems than non-HIV/AIDS, was accepted.

Table 3 shows mean SD and F values for social adjustment domain of boys/girls and rural/urban children living with HIV/AIDS. Social adjustment of rural children (Mean=12.87; SD=1.92) and urban children (Mean=11.62; SD=1.49) (F=69.05; p<.000) indicating significant difference. Rural children were statistically higher than urban in social adjustment. Therefore, formulated H₁₅ that is, children living with HIV/AIDS having more social adjustment problems than urban children was accepted. The interaction effect between gender and domicile on social adjustment (F=57.47; p<.000) was significant.

Table 4 shows mean, SD and F values for emotional adjustment domain of boys/girls and rural/urban children living with HIV/AIDS. Emotional adjustment of boys (Mean=13.77; SD=1.74) and girls (Mean=15.01; SD=1.65) (F=54.86; p<.000) indicating significant difference. Girls were statistically higher than boys in emotional adjustment. Therefore, formulated H₁₆ that is, girls living with HIV/AIDS having more emotional adjustment problems than boys, was accepted.

Emotional adjustment of rural children (Mean=14.72; SD=1.83) and urban children (Mean=14.07; SD=1.72) (F=15.43; p<.000) indicating highly significant difference. Rural children were statistically higher than urban children in emotional adjustment. Therefore, formulated H₁₇ that is, rural children living with HIV/AIDS having more emotional adjustment problems than urban children, was accepted. The interaction effect between gender and domicile on emotional adjustment (F=2.52; p<.113) was not significant.

Table 5 shows mean, SD and F values for educational adjustment domain of boys/girls and rural/urban children living with HIV/AIDS.
rural/urban children living with HIV/AIDS. Educational adjustment of boys (Mean=12.66; SD= 1.72) and girls (Mean=13.09; SD=1.98) (F=6.34; p<.012) indicating highly significant difference. Girls were statistically higher than boys in educational adjustment. Therefore, formulated H₂, that is, girls living with HIV/AIDS have more educational adjustment problems than boys, was accepted.

Educational adjustment of rural children (Mean=13.45; SD=1.85) and urban children (Mean=12.31; SD=1.71) (F=44.62; p<.000) indicating highly significant difference. Rural children were statistically higher than urban children in educational adjustment. Therefore, formulated H₃, that is, rural children living with HIV/AIDS have more educational adjustment problems than urban children, was accepted. The interaction effect between gender and domicile on educational adjustment (F=32.97; p<.000) was found to be highly significant.

Table 5: Mean, SD and F values for educational adjustment domain of boys/girls and rural/urban children living with HIV/AIDS

<table>
<thead>
<tr>
<th>Variables</th>
<th>Source of variations</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Boys</td>
<td>200</td>
<td>12.66</td>
<td>1.72</td>
<td>6.34</td>
<td>.012</td>
</tr>
<tr>
<td></td>
<td>Girls</td>
<td>200</td>
<td>13.09</td>
<td>1.98</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domicile</td>
<td>Rural</td>
<td>200</td>
<td>13.45</td>
<td>1.85</td>
<td>44.62</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Urban</td>
<td>200</td>
<td>12.31</td>
<td>1.71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interaction</td>
<td>Gender*Domicile</td>
<td>400</td>
<td>12.88</td>
<td>1.87</td>
<td>32.97</td>
<td>.000</td>
</tr>
</tbody>
</table>

The overall result indicates that children living with HIV/AIDS have higher social, educational and emotional adjustment problems than Non-HIV/AIDS. Girls and rural children have higher social, educational and emotional adjustment problems than boys and urban children living with HIV/AIDS.

According to Taha (2000), HIV-related adjusted recurrent problems of fever, chronic diarrhea, vomiting, ear infections, skin conditions, oral thrush, and cough were significantly higher among HIV-infected children compared with HIV-uninfected children. HIV infected children on clinical examination, otitis media, dermatitis, oral candidiasis, signs of active chest problems, lymphadenopathy, and developmental delay, and cough could be attributed to malaria, malnutrition, and respiratory tract infections, respectively were significantly more frequent in them compared to HIV-uninfected children. All these frequent physical sufferings along with the suffering of the family members, and their HIV status will have adverse influence on the psychosocial well being of a child and will translate into increased adjustment problems in children.

Table 6: Mean, SD and F values for overall adjustment domain of children living with HIV/AIDS

<table>
<thead>
<tr>
<th>Variables</th>
<th>Source of variations</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Boys</td>
<td>200</td>
<td>38.01</td>
<td>3.49</td>
<td>67.72</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Girls</td>
<td>200</td>
<td>40.94</td>
<td>4.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domicile</td>
<td>Rural</td>
<td>200</td>
<td>40.96</td>
<td>4.62</td>
<td>70.05</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Urban</td>
<td>200</td>
<td>37.99</td>
<td>3.33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interaction</td>
<td>Gender*Domicile</td>
<td>400</td>
<td>39.47</td>
<td>4.29</td>
<td>46.96</td>
<td>.000</td>
</tr>
</tbody>
</table>
dren living with HIV/AIDS as compared to those non-HIV/AIDS.

Bomba et al. (2010) indicate that the HIV/ AIDS on ART subjects significantly reduced physical (p=0.043) and psychosocial health (p=0.021) functioning, particularly at school (p=0.000), compared with healthy subjects. Beekman and Ter Beest Jozets’ (2007) findings say that the HIV/AIDS on ART children have higher rates of depression/anxiety withdrawal and social problems on all four measurements. Puthanakit et al. (2010) report in their study that the school-aged HIV/AIDS on ART children have lower cognitive function than HIV-affected and normal children. Bachanas (2001) says that approximately 25% of children with AIDS disease have significant emotional or behavioral problems. Van Gelder and Kman (2007) in their findings indicate that the HIV/AIDS on ART children experience approximately the same amount of psychosocial problems as the control group, in spite of the large difference in traumatic experiences or environments they live in. All these findings support the findings of the present study.

Kasinath (1990), Pradhan (1993), Raju (2007) report that the emotional adjustment dimension indicated that boys as compared to girls have not expressed any fear to go out alone in night, see a dead body or control their anger whenever things are not happening according to their wish. As rightly pointed out by Mohanraj and Latha (2005), adjustment is influenced by degree of support, help and commitment in the family (cohesion), extent to which set rules are followed in the family (control), the amount of anger and aggression in the family (conflict), the degree of interest in political, social, school and cultural activities (intellectual-cultural orientation) and the extent to which family members are assertive, self sufficient and make their own decisions (independence). If children are accepted and cared in the family, then they show better adjustment because of parental support for social interaction. This may influence social, emotional, educational and overall adjustment of children.

The present study suggests the need for intervention targeting towards girls and rural children living with HIV/AIDS to restore their optimum level of functioning and preventing them from maladjustment. Under the circumstances where the family atmosphere is unhealthy, institutional care is the best available alternative for these children. However a stable, reliable and understanding relationship does not depend primarily on words but on consistent response to a child’s feelings which gradually develops foundations of trust, confidence, and sense of security. This provides strong base from which they develop self-identity, self-respect, and a sense of confidence at work. These tasks must be partly accomplished before the child adjusts his/her behaviours reasonably to the day’s events in the institution and before they are ready to explore opportunities to learn. Therefore, Government and Non Government Organizations, Educational Institutions, social scientists like psychologists, educationists, sociologists, etc. should focus their attention to educational, and emotional adjustment problems of children living with HIV/AIDS. They should either by providing special training to in teachers or through guidance and counselling services. Future studies should seek to evaluate the efficacy of these interventions, for example, support groups, individual and family therapy and case management, for children and families as they struggle to cope with this devastating disease.

From the above study, it has been evaluated that the children living with HIV/AIDS have more social, emotional, educational and over all adjustment problems than non-HIV/AIDS. Further within the HIV/AIDS group the girls living with HIV/AIDS have more social, emotional, and educational and over all adjustment problems than boys. Rural children living with HIV/AIDS have more social, emotional, educational and over all adjustment problems than urban children.

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