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# Attitude towards illness and behavioral problems among HIV/AIDS orphaned children and other chronically ill children – A comparative study

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## Abstract

**Objective:** To find out the attitude towards illness and behavioral problems among orphaned children suffering from HIV/AIDS and other chronically ill children – A comparative study.

**Materials and Methods:** The current study is on 110 orphans suffering from HIV in the age group of 8-15 years was conducted at various centers in and around Hyderabad, Telangana. The control group taken was 110 other chronically ill children such as tuberculosis and thalassemia. It followed various tools such as Socio-demographic data sheet developed for the purpose of the study. The scales used were Childhood Attitude Towards Illness Scale (CATIS) and Strength and Difficulties Questionnaire (SDQ).

**Results:** HIV affected children were older than children in control group and this difference was statistically significant ($p<0.01$). HIV affected orphans have more negative attitude towards illness, emotional problems, peer problems, and conduct problems than other chronically ill children. The study also found that overall girls have more negative attitude towards illnesses than boys and boys showed more behavioral problems than girls.

**Conclusion:** HIV affected orphans have more negative attitude towards illness, internalizing problems (emotional and peer problems) but no significant difference in externalizing problem (conduct and hyperactivity).

**Keywords:** HIV Orphans, Psycho-social profile of HIV-AIDS children, Childhood Attitude Towards Illness Scale (CATIS), Strength and Difficulties Questionnaire (SDQ)

## Introduction

The World Health Organization (WHO) estimated that world-wide 36.7 million people and 2.6 million children have AIDS (WHO, 2015).[1] India is one of the largest and most populated countries in the world. It is estimated that around 2-3 million adults and 105,000 children are living in India with HIV/AIDS. In addition to infecting the cells of the immune system, HIV also appears to infect cells of the central nervous system directly (Janssen, 1989).[2] The children with HIV/AIDS are vulnerable to become orphans when their parents die or are abandoned. The odds against AIDS affected orphaned children are staggering. (UNAIDS, 2012).[3] Stigmatized and discriminated, though no fault of theirs, they are psychologically distressed and they do not have access to basic education and basic health care. The first priority, as articulated in the policy is to prevent HIV infection, in order to "ensure an AIDS-free generation". (Bikaako et al., 2006).[4] The study explores the attitude towards illness and the magnitude of the behavioral problems among HIV-AIDS affected orphan children as compared to children with other chronic illness, with a view to counsel them appropriately and minimize adverse impact of HIV and improve their quality of life.

Mwamwenda T.S., (2013)[5] conducted a study on HIV/AIDS knowledge of high school adolescents in Kenya and found that there was a clear evidence that the majority of participants were very knowledgeable about HIV/AIDS, which was similar to what other researchers have reported from time to time.

Larsson S. & Sara Bolding (2010)[6] conducted a study of self-perceived attitudes regarding HIV/AIDS in Cambodia and found that there are several negative attitudes connected with people living with HIV in Cambodia. The main reason for negative attitude seems to be fear of contagion which in practice for example in shown by the informants being pushed out from the social activities in the community.

Col. Gupta R., et al., (2015)[7] studied, a study of psychological impact of diagnosis of HIV in Children and Adolescents in Indian population, have found that knowing about the disease, have significant psychological impact in form of frequent sicknesses, anger, isolation, fearfulness, loss of confidence and suicidal tendencies.

Lata S. and Shikha Verma (2013)[8] have studies mental health of HIV/AIDS orphans in UP, Indian and found that dealt of parents introduces a major change in the life of a child.

Bant DD, et al., (2013)[9] conducted health and psychosocial profile among HIV affected children – a case control study of using Child Behavioral Check List (CBCL) and found that children affected by HIV/AIDS suffer from psycho-social problems without much psychological impairment.

Ravikumar M.B., (2012)[10] studies on psychosocial adjustment among children living with HIV/AIDS in Karnataka and found that rural children living with HIV/AIDS having more emotional

adjustment problems than urban children. Girls living with HIV/AIDS have more educational adjustment problems than boys.

Kumar SG P., et al., (2001),[11] have studied the depression among AIDS affected orphaned children and found that it was higher among children orphaned by AIDS (COA) than children orphaned by other reason (COO) in southern Indian.

Many Studies compared the behavioral problems among HIV infected orphan children with other orphan children. But no studies addressing the self-attitude towards and illness of HIV affected orphaned children and behavioral problems and comparing them with other chronically ill children. Hence this study was taken up.

## Materials and Method

The current study used a on 110 HIV orphans in the age group of 8-15 years was conducted at various centers in and around Hyderabad, Telangana. The control group taken was 110 other chronically ill children such as tuberculosis and thalassemia. It followed various tools such as Socio-demographic data sheet developed for the purpose of the study. The interview was preceded by an informed consent, obtained from the participants or their attendants. The data were compiled and analyzed using SPSS version 16 software. Student's t-test, ANOVA and Man-Whitney U-test were employed to determine the significance level between the groups.

**Tools Used:**

1. **Socio-demographic data sheet developed for the purpose of the study:** This was developed by the investigator to record the demographics details of subjects and education level, data of admission to center, clinical data such as age of diagnosis and status of parents being alive or not.
2. **Childhood Attitude Towards Illness Scale (CATIS):** CATIS has been developed by Austin in 1993, to provide systemic assessment of how favorably or unfavorably children feel about having a chronic physical condition. Most research on adaptation of childhood chronic illness has focused on parents' perceptions and feelings about their children's illness but has failed to include perceptions from the children. Yet children who have negative feelings were most likely to engage in maladaptive coping behaviors and subsequently have a more negative adaptation to the condition than children who have positive feelings about having a chronic illness. Children's feelings were thought to be especially important when the condition has an attached stigma, such as epilepsy, asthma, tuberculosis, thalassemia etc.,

The scale in the form of administration may be seen on the following page. The chronic condition is placed in the blank area (Ex: Tuberculosis, Thalassemia). Ratings are on 5-point scales. Items 3, 6, 8, 10, 12 are forward scored and items 1, 2, 4, 5, 7, 9, 11 and 13 are reverse scored. The total score is averaged (Total/13) to get the final score. The obtained final score range could be between 1 and 5. A more positive score reflects a more positive attitude toward the condition (Austin, Smith, Risinger, & McNelis, 1994)[12] (Ex: "I am OK with illness / I can manage the illness and live with it". A lesser score reflects a more negative attitude toward the condition (Ex: "I am not OK with illness / I cannot manage the illness and live with it." Age range for the use of CATIS is 8 – 17 years.

Reliability and Validity: Heimlich and colleagues (2000)[13] studied the validity of CATIS with 197 adolescents with epilepsy, aged 11-17 years, excluding those with other medical or psychiatric illness or inability to read at the fifth-grade level. Internal consistency reliability was 0.89 and test-retest reliability was 0.77. Adolescents with the most severe epilepsy had more negative attitudes toward their illness than did those with moderate or mild epilepsy, which is supportive of the validity of the scale.

CATIS is a self-report scale to be used in the clinical setting to assess children's attitudes about having a chronic condition, and as starting point for discussion of their feelings. It could also be used to evaluate whether educational programs designed to help groups of children cope with chronic conditions change these feelings (Austin & Huberty, 1993).[14] These studies represent initial work in development of the scale. CATIS was originally developed for use in research; with further development, it appears to have potential for use in the clinical setting (Austin & Huberty, 1993).[14]

3. **Strength and Difficulties Questionnaire (SDQ):** SDQ was developed by Goodman in 1997 at Institute of Psychiatry, Kings College, University of London. It is a brief behavioral screening questionnaire for 4 - 17 years old children and youth. Self-reporting SDQ version for the children and adolescent is used in this study. It exists in several versions to meet the needs of researchers, clinicians and educationalists.

All versions of the SDQ ask about 25 attributes, some positive and others negative. These 25-items are divided between 5 scales (i.e., 5 x 5 = 25)

a. Domain 1 - Emotional Symptoms (5 items): Items 3, 8, 13, 16 and 24 belongs to this domain.
b. Domain 2 – Peer Problem (5 items): Items 6, 11(R), 14(R), 19 and 23 belongs to this domain.
c. Domain 3 - Hyperactivity Scale (5 items): Items 2, 10, 15, 21(R) and 25(R) belongs to this domain.
d. Domain 4 - Conduct Problems (5 items): Items 5, 7(R), 12, 18 and 22 belongs to this domain.

e. Domain 5 - Pro-social Behavior (5 items): Items 1, 4, 9, 17 and 20 belongs to this domain.
f. SDQ Internalizing Problems: Domains 1 and 2 (Emotional and Peer problems) collectively are called as internalizing problems.
g. SDQ Externalizing Problems: Domains 3 and 4 (Hyperactivity and Conduct problems) collected are called as externalizing problems.
h. Total SDQ Score: All domains (Emotional, Peer, Hyperactivity and Conduct problems) collective are called as total behavioral problems.

Scores: Total Items = 25 = 5-scales x 5-items; Questions with forward scoring (1, 2, 3, 4, 5, 6, 8, 9, 10, 12, 13, 15, 16, 17, 18, 19, 20, 22, 23, 24) can be scored as 0, 1, 2 indicates 'Not True', 'Somewhat True', 'Certainly True' and questions with reverse scoring (7, 11, 14, 21) can be scored as 2, 1, 0 which indicates 'Certainly True', 'Somewhat True' and 'Not True'.

- For each of 5-scales score range = Range of score (0-10) for all items
- Total Difficulties Score = (0-40) i.e., Emotional + Conduct + Hyperactivity + Peer Problems
- Internalizing Problems = (0-20) i.e., Emotional + Peer Problems
- Externalizing Problems = (0-20) i.e., Conduct + Hyperactivity
- Pro-Social Score = (0-10)

Interpretation of the (SDQ-Self Reporting) Score is done as:

| Domain | Normal | Borderline | Abnormal |
|---|---|---|---|
| Internalizing Problems | | | |
| - Conduct | 0-3 | 4 | 5-10 |
| - Hyperactivity | 0-5 | 6 | 7-10 |
| Externalizing Problems | | | |
| - Emotional | 0-5 | 6 | 7-10 |
| - Peer Problems | 0-3 | 4-5 | 6-10 |
| - Pro-Social | 6-10 | 5 | 0-4 |
| Total Difficulties | 0-15 | 16-19 | 20-40 |

**Clinical Assessment:** Many child and adolescent mental health clinics now use the SDQ as part of the initial assessment, getting parents, teachers and young people age range between (4 to 17 years). The findings can then influence how the assessment is carried out and which professionals are involved in the assessment. For example, if a child has been referred with marked conduct problems, an assessment that focused too narrowly on these behaviors and related family issues might overlook associated hyperactivity. Advance knowledge that the child has been given high SDQ hyperactivity ratings by parents and teachers can help ensure that the assessment enquires in detail about hyperactivity; it may also be important to obtain a psychiatric or pediatric opinion early on in the assessment process with a view to establishing suitability for medication.

**Reliability and Validity:** The SDQ self-report version was studied by Goodman in 1998. The SDQ self-report was administered to two samples of 11-16 years olds drawn from the community (n-83) and a mental health clinic (n=116). The questionnaire discriminated satisfactorily between the two samples. The clinical cases were over six times more likely to have a score at or above the normal range (90th percentile). The inter-rater correlations between the SDQ self, parent and teach reports compared favorable with average cross-informant correlations in previous studies on a range of measures (Ex: Achenbach et al. 1987).[15] Study conducted on SDQ in Finland. Internal consistency reliability of self-report SDQ total scores and sub-scores analyzed with Cronbach's coefficient alpha and was found to be (Total = 0.71, Hyperactivity = 0.66, Emotional Symptoms = 0.69, Conduct Problems = 0.57, Peer Problems = x0.63, Pro-social Scale = 0.69 and Mean of Sub-Scores = 0.65).

## Results

Table 1 shows that the mean age of HIV children and other chronically ill children are (12.56) and (11.18) respectively which indicate that HIV affected children were older than children in control group, significant ($p<0.01$). The Standard Deviation for both males and females are 50% each.

**Table 1: Socio-demographic correlates of the study population. Numbers are either mean (SD) or frequency (%)**

| Variables | HIV Children (N=110) | | Control Group (N=110) | |
|---|---|---|---|---|
| | Mean | SD | Mean | SD |
| **Age** | 12.56 | 2.17 | 11.18 | 2.41 |
| | No. | % | No. | % |
| **Sex** | | | | |
| - Male | 55 | 50% | 55 | 50% |
| - Female | 55 | 50% | 55 | 50% |
| **Education** | | | | |
| - Illiterate | 0 | 0% | 7 | 6.36% |
| - Primary School | 50 | 45.45% | 46 | 41.81% |
| - Middle School | 36 | 32.72% | 33 | 30% |
| - High School | 24 | 21.81% | 24 | 21.81% |
| **Status of Mother** | | | | |
| - Alive | 20 | 18.18% | 108 | 98.81% |
| - Not Alive | 90 | 81.81% | 2 | 1.81% |
| **Status of Father** | | | | |
| - Alive | 18 | 16.36% | 109 | 99.09% |
| - Not Alive | 92 | 83.36% | 1 | 0.90% |

**Table 2A: Mean (SD) score on various study measures with respect to HIV and Control Groups (Mann Whitney U-Test)**

| Measures | HIV Group | Control Group | "U" | "p" |
|---|---|---|---|---|
| **CATIS** | 2.08 (0.32) | 2.25 (0.29) | 4276.50 | 0.01 |
| **SDQ** | | | | |
| Emotional Problem | 8.22 (1.25) | 6.32 (0.88) | 1397.50 | 0.01 |
| Peer Problems Scale | 5.46 (1.29) | 4.95 (1.14) | 4773.50 | 0.005 |
| Conduct Problems Scale | 4.80 (1.80) | 3.89 (1.10) | 4099.00 | 0.01 |
| Internalizing Problem | 13.68 (1.97) | 11.26 (1.38) | 1714.50 | 0.01 |
| Total Behavioral Problems | 24.35 (4.03) | 19.31 (2.65) | 1627.00 | 0.01 |

**Table 2B: Mean (SD) score on various study measures with respect to HIV and Control Groups (Independent t-test)**

| Measures | HIV Group | Control Group | "t" | "p" |
|---|---|---|---|---|
| **SDQ** | | | | |
| Hyperactivity Scale | 8.22 (1.25) | 6.32 (0.88) | 12.93 | 0.01 |
| Pro-Social Scale | 4.94 (1.29) | 5.57 (1.04) | -4.01 | 0.01 |
| Externalizing Scale | 9.74 (1.72) | 9.46 (1.51) | 1.24 | 0.21 |

**Table 3: Mean (SD) of Group and Gender**

| Measures | HIV Group | Control Group |
|---|---|---|
| **CATIS** | | |
| - Male | 2.23 (0.25) | 2.32 (0.28) |
| - Female | 1.92 (0.31) | 2.18 (0.28) |
| **SDQ** | | |
| - Male | 27.00 (3.10) | 20.24 (2.86) |
| - Female | 21.69 (2.97) | 18.38 (2.05) |

Table 2A shows that the children in HIV group had more negative attitude towards illness as compared to the children in control group (other chronically ill children) as measured by CATIS. Table 2A also shows that the children in HIV group had more internalizing problems as compared to the children in control group as measured by sub-scales of SDQ. Table 2B, shows that the children in HIV group and children in control group was found to have no significant difference in externalizing problem as measured by sub-scales of SDQ. There was no group effect or sex effect on CATIS measure. However, a significant interaction between group and sex with respect to CATIS was observed. There was no group effect or sex effect on SDQ measures. However, there was a significant interaction was seen SDQ as shown in Table 3.

## Discussion

The present study showed that HIV-infected children have negative attitude towards illness (ref Table-2A) by CATIS with p = 0.01. Children who have negative feelings were most likely to engage in maladaptive coping behaviors and subsequently have a more negative adaptation to the condition that the children who have positive feelings about having a chronic illness. A lesser score in CATIS reflects a more negative attitude towards the condition (Ex: "I am not OK with illness). It was in conformation with the study conducted by Tanushree Banerjee et al (2007)[16] and Sarah Larsson & Sara Bolding (2010).[6] They found that HIV infected orphan children were vulnerable group in terms of emotional problems. This may be because children whose parents were living with HIV often experience many negative changes in their lives and can start to suffer neglect, including emotional neglect, long before they are orphaned. Eventually, they suffer the death of their parent(s) and the emotional trauma results. The present study also showed the HIV infected children have peer problem and conduct problem (refer Table -2A). It was in conformation with the study conducted by Cluver Lucie et al., (2009)[17] and Doku PN et al., (2009).[18] They found that AIDS affected orphan children had more peer problems and conduct problem along with other psychological problems. Doku PN et al. (2009)[18] found that HIV/AIDS infected children are at heightened risk for psychological disorders, exhibited signs of conduct, peer and emotional problems. Stigma is a powerful tool of social control which is often used to marginalize, isolate and make others coil up. HIV/AIDS affected orphaned children may form their own self-schemata based on their daily stigmatized social interactions which then influence multiple aspects of their lives and results in problems like loneliness. Children living with HIV infection were found to have more conduct problem than other chronically ill children. The behavior could be due to children raised without parental supervision.

The present study also showed that overall girls have more negative attitude towards illnesses than boys and boys showed more behavioral problems than girls (refer Table 3). However, the author of this study did not found any relevant studies to support or contradict it. Implications of these findings may include the need for all health care providers to recognize the traumatic nature of such personal knowledge among AIDS

affected orphans and to provide targeted services, such as developmentally appropriate psychological counseling and interventions (Rothemram-Borus, Murphy, Miller & Drainmin, 1997)[19] to these vulnerable children to rehabilitations centers, at schools and in communities.

## Conclusion

There is a significant psychological impact in form of more negative attitude towards the illness and behavioral problems among HIV-AIDS affected orphan children when compared to other chronically ill children. Girls have more negative attitude towards illness and boys have more behavioral problems. We need to provide appropriate counseling, education and creative ways to decrease the psychological problems to HIV-AIDS children. Psycho-social support for children who are parentally bereaved by AIDS is required. The findings of this and other studies suggest that there is a need for effective interventions to reach a larger proportion of HIV infected orphaned children. Communities must help the HIV infected orphaned children to accept and provide them with necessary services.

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